

# **Fragile X - A to Z**

**A Guide for Families  
By Families**

Second Edition 2006



# Fragile X - A to Z

## A Guide for Families

This guide is intended to help families cope with the daily challenges of living with a child who has a disability, specifically Fragile X Syndrome. Many of the topics discussed may pertain to parents with children affected by other disabilities and with typically developing children. Most of the anecdotes were posted to the Fragile X Listserv and are reprinted here with permission of the authors.

The names of specific therapies, medications and products are included as resources recommended by individuals, but their inclusion does not constitute an endorsement.

The first edition was produced in 1998 and edited by Wendy Dillworth. The second edition was edited by Mary Beth Langan (mblangan@hotmail.com) and Sally Nantais (sally\_nada@juno.com). Both editions were made possible by the hard work and dedication of the members of the Fragile X Listserv.

The Fragile X listserv is an electronic mail support group open to all and dedicated to discussion of Fragile X syndrome. FRAXA started the listserv in 1995 to serve the entire Fragile X community. We are grateful to Emory University for hosting the listserv.

For information on the listserv, refer to the "Listserv" section under "L" in this guide.



45 Pleasant St.  
Newburyport, MA 01950

Phone: 978-462-1866  
Fax: 978 463-9985  
Email: [info@fraxa.org](mailto:info@fraxa.org)  
Web: [www.fraxa.org](http://www.fraxa.org)

## FRAGILE X – A TO Z

<b>A IS FOR .....</b>	<b>3</b>
APPLIED BEHAVIORAL ANALYSIS (ABA) .....	3
ADD/ADHD .....	5
ADOLESCENCE .....	6
ADOPTION .....	7
ADULTS WITH FRAGILE X .....	8
ADVOCACY .....	9
<i>The power of words</i> .....	9
AMNIOCENTESIS TESTING .....	10
ANXIETY .....	10
<b>B IS FOR .....</b>	<b>13</b>
BEHAVIOR.....	13
BIKE RIDING .....	17
BITING .....	19
<b>C IS FOR .....</b>	<b>20</b>
CALMING TECHNIQUES .....	20
CHEWING .....	21
COMPUTERS & SOFTWARE.....	22
COPING .....	24
<b>D IS FOR .....</b>	<b>25</b>
DAILY LIVING TIPS .....	25
DENTAL WORK .....	29
DIAGNOSIS.....	30
<b>E IS FOR .....</b>	<b>30</b>
EAR INFECTIONS .....	30
EDUCATION.....	32
EXPLAINING YOUR CHILD TO OTHERS.....	37
<b>F IS FOR .....</b>	<b>39</b>
FAMILY ISSUES/FINDING OUT .....	39
FATHER’S MESSAGES.....	42
<i>FX from a father's perspective</i> .....	42
<i>Internal cry of a father</i> .....	42
FLOORTIME THERAPY .....	44
FOOD ISSUES.....	45
FXTAS .....	45
<b>G IS FOR .....</b>	<b>47</b>
GENETICS AND GENETIC TESTING.....	48
GIRLS WITH FRAGILE X .....	50
GOODNESS .....	51
GRIEF AND GUILT .....	52
<i>Grief can be a gift</i> .....	53

<b>H IS FOR ...</b>	<b>54</b>
HANDS IN THE PANTS.....	54
HANDWRITING.....	55
HIGH FUNCTIONING.....	57
HITTING.....	58
HORSEBACK RIDING.....	59
<b>I IS FOR ...</b>	<b>61</b>
IEP (INDIVIDUALIZED EDUCATIONAL PROGRAM).....	61
INCLUSION.....	64
INSPIRATION.....	66
<b>J IS FOR ...</b>	<b>67</b>
JUMPING.....	67
<b>K IS FOR ...</b>	<b>67</b>
KNOWLEDGE (AND INCIDENTAL LEARNING).....	67
<b>L IS FOR ...</b>	<b>68</b>
LIFE.....	68
<i>Welcome To Holland</i> .....	68
<i>Life is different now... not necessarily better or worse</i> .....	69
<i>What is it like to parent a child with Fragile X?</i> .....	70
LIFE PLANNING.....	72
LISTSERV - FRAGILE X.....	73
LISTSERV ETIQUETTE 101.....	74
<b>M IS FOR ...</b>	<b>75</b>
MATH.....	75
MEDICATION (FOR FXERS).....	76
MEDICATION (FOR CARRIERS).....	79
<b>N IS FOR ...</b>	<b>81</b>
NOISE.....	81
<b>O IS FOR ...</b>	<b>83</b>
OBSSESSIONS.....	83
OCCUPATIONAL THERAPY (OT).....	84
<b>P IS FOR ...</b>	<b>85</b>
PICTURE EXCHANGE COMMUNICATION SYSTEM (PECS).....	85
PLANNED FAILURE.....	86
PREIMPLANTATION GENETIC DIAGNOSIS (PGD).....	87
PREMATURE OVARIAN FAILURE (POF).....	90
PUBERTY.....	91
<b>R IS FOR ...</b>	<b>92</b>
READING.....	92
RESOURCES.....	94

Fragile X Organizations and helpful Fragile X links:.....	94
Fragile X Clinics .....	96
Research Organizations .....	101
Miscellaneous Organizations .....	102
<b>S IS FOR ...</b> .....	<b>103</b>
SAFETY .....	103
<i>How do we keep him safe?</i> .....	103
SEIZURES .....	105
SENSORY INTEGRATION (SI) .....	106
SIBLING SUPPORT .....	109
SIGN LANGUAGE.....	110
SLEEP (HOW TO GET MORE OF IT!).....	111
SOCIAL STORIES.....	112
SPEECH, LANGUAGE AND COMMUNICATION.....	113
SPORTS .....	119
STRESS.....	120
<b>T IS FOR ...</b> .....	<b>122</b>
THERAPEUTIC LISTENING.....	122
THERAPEUTIC MATERIALS – RESOURCES .....	122
TOILET TRAINING .....	123
TOYS WITH A TWIST.....	125
TRANSITIONS .....	125
TRANSITION PLANNING.....	127
TRAVEL.....	130
<b>U IS FOR ...</b> .....	<b>135</b>
UNDERSTANDING.....	135
UNIQUE.....	136
<b>V IS FOR ...</b> .....	<b>137</b>
VERBAL PERSEVERATION .....	137
VIDEOS .....	138
<b>W IS FOR ...</b> .....	<b>139</b>
WAITING .....	139
WEBSITES .....	140
WISDOM.....	140
<b>X IS FOR ...</b> .....	<b>142</b>
X CHROMOSOME.....	142
X-RAYS .....	143
<b>Y IS FOR ...</b> .....	<b>143</b>
Y CHROMOSOME.....	143
<b>Z IS FOR ...</b> .....	<b>144</b>
ZANY TALES .....	144

# *A is for ...*



## **Applied Behavioral Analysis (ABA)**

ABA is a combination of behavior management, instruction, generalization and socialization. ABA aims to eliminate negative behaviors and help the child function through consistent positive reinforcement.

Our experience with ABA began in 1999. Our first son Matthew began Early Intervention in the fall of 1998, at age one and a half. Our Early Intervention service provider ran out of money in 1999, so instead of continuing to receive speech therapy in the home, our service coordinator sent us to the Eden Institute in Princeton (<http://www.edenservices.org/index.jsp>) for speech therapy. After a routine assessment, they suggested that speech therapy be used with an ABA approach, breaking each task down into its simplest form. Matthew was asked to point to pictures, choose colors, identify numbers, repeat and imitate sounds, in trials of 10. This seemed excruciating to watch from behind a one-way mirror, but Matthew was quickly transformed.

He went from no speech and a lot of frustration to being able to point, sign and eventually utter sounds and words. He really didn't speak full words and phrases until after his 4<sup>th</sup> birthday. Now he's almost 8 and doesn't ever stop talking, so my feeling is that it worked for him.

I read about ABA prior to receiving the FX diagnosis because a neurologist suggested Autism as Matthew's issue. ABA is not for everyone and not for every FX child. My younger son Benjamin just turned 2 and is starting ABA. His program is more rudimentary than Matthew's was because his behavior is so much more in the way of his learning than Matthew's.

Benjamin is working on (1) sitting in a chair to attend, (2) picking up an object, (3) giving it to the therapist, (4) repeating animal sounds, (5) blowing bubbles, (6) using sign language (more, finished, help, please, me) and (7) alphabet recognition.

Here are some helpful ABA links:

<http://www.abatherapists.com/>

[www.ABAconnections.com](http://www.ABAconnections.com)

[www.abaresources.com](http://www.abaresources.com)

*Paula Fasciano, Marlboro, New Jersey '05*

## **Early Intensive Behavioral Intervention (EIBI) using Applied Behavioral Analysis (ABA)**

Parents and experts refer to EIBI programs by other names such as Applied Behavioral Analysis (ABA), Discrete Trial Training (DTT) or Verbal Behavior (VB). Early Intensive Behavioral Intervention (EIBI) is “a highly structured approach to teaching ... which is carefully designed and follows predictable patterns of instruction. It is based on well-studied principles of human learning and designed to capitalize on the capacity of children to benefit from proven methods of instruction.” (Weiss and Harris, 1998).

For example, an EIBI session will involve the child working with a trained instructor practicing lessons in a highly structured manner. When the child succeeds at a lesson, the instructor immediately provides a reward to reinforce the correct behavior. These lessons are taught at first in small steps. Early lessons may be as simple as instructing the child to ‘Do this’ while the instructor claps her/his hands. Typically, the instructor will assist the child initially (hand-over-hand prompt) to assure the child’s success.

Lessons may range from simple imitations such as the previous example, rudimentary self help skills such as potty use or hair brushing, to complex social interaction settings like group play.

### **Books That Describe EIBI Programs**

Maurice, Catherine, Green, Gina, Luce, Stephen (Eds.), (1996), *Behavioral Intervention for Individuals with Autism, A Manual for Parents and Professionals*, Austin: Pro-Ed.

Leaf, Ron and McEachin, John, Editors, (1999), *A Work In Progress: Behavior Management Strategies and a Curriculum for Intensive Behavioral Treatment for Autism*, New York, DRL Books, Inc.

Harris, Sandra, and Weiss, Mary Jane, (1998), *Right From the Start: Behavioral Intervention for Individuals with Autism, A Guide for Parents and Professionals*, Bethesda: Woodbine House.

Maurice, Catherine, (1993), *Let Me Hear Your Voice*, New York: Knopf Publishing.

Partington, James, Sundberg, Mark, (1998) *Teaching Language to Children with Autism and Other Developmental Disabilities*, California: Behavior Analysts Inc.

Hamilton, Lynne, (2000) *Facing Autism*, Colorado: WaterBrook Press.

### **Internet Resources for Additional Information on ABA**

#### **THE AUTISM SOCIETY OF AMERICA:**

[http://www.autism-society.org/packages/discrete\\_trial.html](http://www.autism-society.org/packages/discrete_trial.html) is the Autism Society of America’s website for information about EIBI.

**FEAT** – Families for Early Autism Treatment. The national organization can be found at <http://www.feat.org>. and it boasts the best collection of links to other sites about autism, EIBI and virtually every subject of importance to a family with a child who has autism. There are also links to local FEAT websites.

#### **Studies on Effectiveness of EIBI**

U.S. Department of Health and Human Services. *Mental Health: A Report of the Surgeon General Executive Summary*, Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health, 1999.

*Lori Peacock, Columbus, Ohio ‘05*

Alex started ABA six months ago in a clinic setting. He was there for six hours a day, five days a week. He learned many new things quickly; brushing teeth, gross motor imitation, puzzles, etc. We were really impressed at how quickly he picked up on things using this method. That clinic was not the best environment for him (for many reasons) but we wanted to keep the ABA piece, so he's in a special purpose (Floortime) school in the morning and we've just started in-home Discrete Trial (DT) using ABA in the afternoon. I love that I have the ability to see how things are done so that I can carry over when the therapist isn't here. It's amazing how much he can accomplish when he's working for something that is motivating to him. They are currently doing an assessment to see where he is with various skills and will build the programs from that. The combination of ABA & Floortime seems to be the best approach for Alex.

*Julie, Maine, 05*

## **ADD/ADHD**

*Most young boys with fragile X have some degree of Attention Deficit Disorder (ADD) or Attention Deficit Hyperactivity Disorder (ADHD). Fortunately, many of them grow out of it as they get older.*

When my son was small, he had severe ADHD. We tried a lot of different meds and most of them just made him more whiny and irritable. At one point, his teacher said they would rather have him "hyper and happy than medicated, crying and miserable!" so we gave up on the Ritalin. Keep in mind, they didn't have Concerta and the other newer medications available when he was little (he's 15-years-old now). We used a weighted vest and a lot of deep pressure hugs. Sensory integration helped a lot and we also tried glasses designed for kids with ADHD. They kind of pull their eyes down for table work. They're called refractive lenses.

*Jackie, Marysville, Ohio '05*

### **Recommended Books:**

*The ADHD Autism Connection* by Dianne M. Kennedy

### **Website Resources:**

[www.addinfonetwork.com](http://www.addinfonetwork.com) - Attention Deficit Information Network, Inc.

[www.chadd.org](http://www.chadd.org) - Children and Adults with ADHD (CHADD)

[www.ldanatl.org](http://www.ldanatl.org) - Learning Disabilities Association (LDA)

[www.add.org](http://www.add.org) - National Attention Deficit Disorder Association (ADDA)

[www.drhallowell.com](http://www.drhallowell.com) - The Hallowell Center was founded by Dr. Edward M. Hallowell and specializes in the treatment of Attention Deficit Disorder (ADD), Worry/Anxiety, and Child Learning Disabilities.

**[EP Magazine's National Resources for Specific Disabilities also lists:](#)**

[www.kennedykrieger.org](http://www.kennedykrieger.org) - Kennedy Krieger Institute

[www.addresources.org](http://www.addresources.org) - ADD Resources



# Adolescence

My son David (16) is as normal as apple pie when it comes to NOTICING girls, he just doesn't know what to do with them, which is just fine with me at this point. He has always been an affectionate guy, and even though he won't make eye contact, he can flirt with the best of them. He also has a "caretaker" attitude toward some girls. There is a girl at our daycare provider who is a year younger and lower functioning than David and he has known her for about 9 years. He is very affectionate with her (perhaps a little more than he should be) and if she is having a rough time, throwing temper tantrums or giving a bus driver trouble, she calms down immediately for him. He now meets her when she gets off the bus (they go to different schools), extending his hand and escorting her into the house. Whenever I see the drivers they tell me what a sweet, gentlemanly young man he is. But I have had to have talks with him about how much affection he can and cannot give at his age, that there are certain things that are not appropriate. I don't know how much he comprehends and he needs an occasional reminder, but all in all is well behaved. It's never too soon to start letting them know what's appropriate and what isn't.

And believe me, one reason David loves his new school so much is that most of his teachers are under 30 and very attractive!

*Debbie '98*

## **Fragile X Teens and their Sexuality**

I'll chime in and share what we went through at our house.

At the age of twelve, Josh's body started to change. He chunked out a little bit and had mood swings. He had more outbursts from hell between the ages of 12-16. He would yell, scream, rage, and threaten to call the police, the FBI, the President and anyone else he thought would listen. He blamed us for everyone dying, the Saddam and Osama stuff-- you got it---our fault too. Whatever popped in his mind was our fault. He was always packing up and leaving and "see ya later buhhhh bye" was the story. We were going nuts. That testosterone stuff was in his veins and he was in high gear. He would eat like a horse, sleep some days and others he was an insomniac! He was a devil child straight from hell--but other times he was this sweet natured boy I knew. :)

We explained sexuality in terms that Josh could understand. He asked a million questions and we gave a million of the same answers over and over. I explained STDs, condoms and why we wait until we get married to have sex. I even used a sock to show Josh the concept of a condom. I found him many times rolling his socks onto his feet! He understood!

We talked about masturbation and that it was okay to have "sexy" feelings but those feelings were private. We didn't announce them because it's inappropriate. Josh has always been a kid who responds to words like "inappropriate," "unacceptable," "delicious," etc. He has a great vocabulary, which does include those four letter naughty words.

During his junior year in high school, he really knew he was different and this sent him into a tailspin. He was depressed and wanted to commit suicide. We went to a clinical social worker who really helped Josh. Josh told him he wanted to be a regular boy. This broke my heart. Josh also told Geoff (the CSW) that he would jump out the window and fly away from the world. I was scared. We have a two-story home so I checked Josh's window. The screen was gone. He had already taken it out and it was lying in the bushes. Nothing usually scares me but this ---well it broke my heart and scared me to death.

I believe that Fragile X kids really struggle through puberty. They can't express all the emotions they go through and they can't understand the hormone overload. I believe that with all children

it's important to watch and really listen. Your children will become these creatures you won't recognize and you surely won't want to claim them as your own!

Be prepared to have an endless supply of patience, hugs, and food readily available in your home. Be prepared to use professional help and don't feel ashamed about using it. Understand that medications may need to be increased. Josh went through four increases in his Zoloft from the age of 12-19.

Josh will be 21 this September and things are great at our house. We all survived Fragile X puberty! Josh is a very typical guy. He thinks all women are hot! He announced that lesbians rock and he liked seeing two girls kiss at school. He told us that he can buy porn (Playboy) but he chooses not to! It's not allowed at my house. I was informed that Joey his older brother had a stash when he lived at home. Josh also wants "Girls Gone Wild" videos--NO, NO AND Nooooooooo!

For those of you dealing with puberty and sexuality I wish you good luck!

*Eileen, Indiana '05*

## **Adoption**

**M**y husband David and I have a FX son Andrew (17) and an adopted daughter Alexandra (2 1/2) from Guatemala. We adopted her when she was only months old. The adoption process was long, tedious and frustrating at times. There were background checks, fingerprinting, interviews by Social Services and endless paperwork that had to be perfect or it was rejected.

We wanted Andrew to be involved in the adoption process as much as possible. We took him to Guatemala twice, once for a visit and the next time to pick her up. He did very well both times. He especially liked getting a passport.

Of course, it was all worth it. Alexandra has been a blessing to our family and has helped Andrew.

Andrew has become more caring. He loves to get Alexandra when she wakes up in the morning and bring her downstairs. He fixes her juice and seems to know just what to do to help calm her when she gets upset. Andrew has never been one to like being hugged and kissed but he will let Alexandra kiss him and hug him (she is a very loving little girl). Recently he has started putting her down for her naps. He takes this job very seriously.

Andrew does have his meltdowns and sometimes it really scares her but we try to take her out of the room until he calms down. I think having a brother with Fragile X will teach Alexandra some valuable lessons in life. I know I have learned a lot from him. We are working on having Andrew read or tell her some stories at nap or bedtime. He can read very simple books but he just cannot bring himself to do it. His Developmental Pediatrician has also noticed that his social skills have improved but we always have room for improvement.

He loves his little sister so much and he is a big help in caring for her. She thinks her big brother is the best.

*Teri Hall, Macon, Georgia '05*

# Adults with Fragile X

I want to offer you encouragement. I have 2 Fragile X guys and they are wonderful. My youngest told our church fellowship that he was a MR child, but they didn't need to worry about him because he has the Lord in his heart (he's 27). My oldest is 38 and he is doing great too. They both have jobs, they live independently from their parents in homes with other MR adults (5 in one home and 4 in the other). They are happy and that's what counts. We are the ones that say they have to achieve to certain levels or status - usually to satisfy our ego. Yes, it would be nice to have grandchildren.. But who knows what they are spared from by not having what the average person has? They have no worries, they are taken care of. There are many good things I could say if I sat here long enough, but I'm sure many have already told you many more. Be encouraged and have hope.

*Erlyne '98*

Jason is 34 years old and is fully affected Fragile X. He was not diagnosed until he was 19 years old when the gene was identified and testing became a little more common. Jason has lived in an apartment since he was 26 years old. This came after he graduated from the LESA Adult program in Howell, Michigan. Jason's apartment rent is subsidized and he is able to live in a very nice one-bedroom apartment on his own. This is possible with daily support supplied by his mother and staff who prompt him to take his medications, take him once a week grocery shopping, once a month to the barber and whatever necessary doctor and dentist appointments.

Jason attends a daily program 3 days per week for 1/2 day. On Thursdays, he volunteers with the "Meals on Wheels" program, which he enjoys very much. This utilizes his positive personality traits of being compassionate, sociable and helpful.

Among Jason's other passions are University of Michigan sports, and all Detroit major league sports, of which he is VERY knowledgeable. He has participated in Special Olympics since childhood and this provides him with additional opportunities for being with friends and feeling successful and learning good sportsmanship. He loves all music and Playstation 2.

Jason has an older brother to whom he is very attached, though unfortunately, his brother lives 150 miles away with his growing family. Jason has a good sense of humor and his family is very proud of his progress

*Evelyn Zarycki, Howell, Michigan '05*

*About a group home situation...*

A group of families purchased the home under a general trust agreement--I believe using government financing etc. They sold condo units (so to speak) in the house (duplex-males on one side, females on the other). The condo association oversees staffing, etc. Each family owns a unit for their child-actually I think the child may own it. This seemed to work well and if a resident did not work out for any reason—the condo unit could be sold to another family. Obviously there were parameters in the trust. It was the first option that struck me as very realistic both financially and with respect to my child's future.

*Kim '98*

# Advocacy

*This article was published on April 14, 2005, in The Grosse Pointe News, Grosse Pointe, Michigan.*

## The power of words

Dear Ms. Okray,

Knowing that I have a brother with Fragile X, hearing the word *retard* really hurts because I hate it when people say that to my brother and hearing people call other people that. Could you try and stop the word from being said? I would feel much better.

Sincerely,  
Natalie

Natalie is a 10-year-old girl who has seen and felt how words can hurt.

She is a student at McKinley Elementary in Wyandotte, Michigan, where Ms. Okray, her principal, and the school staff have instilled in her the importance of words.

McKinley students have a life skills curriculum that has a list of terms infused into the daily life at school and promoted as excellent vocabulary for every facet of life:

caring	integrity
common sense	organization
cooperation	patience
courage	perseverance
curiosity	pride
effort	problem solving
flexibility	resourcefulness
friendship	responsibility
initiative	sense of humor

Natalie knows the word *retard* is not appropriate. She knows it is not a positive term like the vocabulary she is encouraged to use at school and at home. She knew she could trust her principal to help her begin to wipe it out at McKinley.

Ms. Okray brought up Natalie's concern at one of her regular Friday assemblies. Her assemblies are often positive, uplifting times. But her students understand when she has to talk seriously. And she did just that when it came to the Friday she discussed *retard* and other examples of name-calling.

Wouldn't it be nice if the world had a non-negotiable list of words to never use? If it did, we'd put *retard* at the top of the list.

In our house, we are committed to deleting *stupid* from our vocabulary. It'd be better to wipe that out and have more room for positive words, like the list from Natalie's school. Everyone can learn a lot from Natalie, Ms. Okray and the McKinley Elementary staff.

Let's avoid using the "R" word. And let's teach our children and others to do the same.

If for no other reason than simply because it hurts.

Take it from a peaceful but powerful girl who happens to have a brother affected by Fragile X.

Help make her and all of our children feel better about themselves and others by hearing fewer negative words and more positive ones. The power is in your hands and mouths.

*Mary Beth Langan and Theodore G. Couilish, Grosse Pointe, Michigan '05*

# Amniocentesis Testing

*Amniocentesis testing is the most common prenatal test used to screen for genetic birth defects; most medical providers offer this testing to pregnant women who are age 35 or older. The amnio test can detect Fragile X, but only if the lab is specifically looking for it. The routine amnio test does NOT usually include Fragile X testing.*

**W**e found out that Fragile X was in our family when my Dad was diagnosed as a carrier, meaning that, as his daughter, I was too. We started genetic counseling right away. At the time our daughter was almost three and our genetic center highly discourages testing of children who are not showing any signs of a genetic disorder. They believe that it should be up to the child to want those results for themselves, around the age of 18. When we decided that we were going to have a second child, we were certain that we would have an amniocentesis done because they will test on an unborn child (mostly in the case that the parents decide they want to terminate a pregnancy if there is something wrong). This would never be an option for us but we felt it was to our advantage to know the status of our baby so we would be able to recognize signs of challenges that may be helped through early intervention.

We booked our amnio and went to the hospital to have our test done. I had been told that it was no sweat, they do local freezing and you could barely feel it. I soon discovered that for me, this was not the case, it did hurt and at one point I was ready to hit the doctor. About a month later we discovered the results of our test: we were having a son and he was a Fragile X carrier. My Dad is a Fragile X male carrier and has Fragile X-associated tremor/ataxia syndrome (FXTAS). I know that there could be some very real setbacks in his life, and there are probably many that haven't even been discovered yet.

Our son Jackson is now three and doing very well. There has not been a day that goes by that I regret learning his status through our amnio. I'm sure that it has eased my mind a bit, not constantly analyzing him like I sometimes do with our daughter, looking for anything that may indicate that she has a full mutation. We still do not know the status of our daughter; hopefully someday soon we can get her tested. Even though it was very painful and there is a small percent chance of risk in the pregnancy, I am very thankful that we did decide to do the amnio. If we were to have more children, there wouldn't be any hesitation at all for us to do it again.

*Lisa Brotherton, Calgary, Alberta, Canada '05*

## Anxiety

**B**efore receiving the FX diagnosis for our son at age 21 months, I never thought I'd have to worry about anxiety in my child. Although, pre-diagnosis I'd already spent many anxious moments worrying about his anxiety!

Anxiety, hyperactivity, hyperarousal – you read these terms in FX literature, but they seem to blur at times. Especially when thinking of them in terms of a non-verbal, young child. In August 2004, Andrew was 3 when we took him to see FX guru Dr. Elizabeth Berry-Kravis at Rush University in Chicago, Illinois. With her wisdom and assistance, I've come to better understand these terms and how each manifests in individuals with FX.

**Anxiety** – Many types of anxiety occur in FX individuals including separation, panic, social phobia, anxiety related to limitation of obsessive and perseverative behaviors, and aversive anxiety (fear of a traumatic experience). Individuals with FX experience many things as traumatic that would not normally be considered upsetting. FX individuals also have problems with "unlearning" or forgetting an experience perceived as traumatic or fearful, which is why they become extremely anxious and fearful and then tantrum when they arrive at a place or event that resembles something that upset them before. Individuals with FXS perceive many normal daily things as fearful, resulting in anxiety – feeling nervous and “on edge” in many non-threatening situations.

**Hyperactivity** – Boys with FX are very often in constant motion – fidgeting, squirming, wandering, making a variety of little movements with the body. This over activity is accompanied by difficulty sitting to do a task and very easy distraction. The hyperactivity is often worsened when in a situation that makes the child more anxious or excited.

**Hyperarousal** – Hyperarousal is the tendency to over-respond to many types of sensory and environmental stimuli. Sometimes this is a positive response – e.g. excitement, and other times negative, eg. being anxious or upset. Whatever the direction, the response is excessive and can make the FX individual feel very uncomfortable. This is why even when very excited and having fun, the FX child may suddenly crash because he/she just can't handle the excessive stimulation. When hyperaroused, physical signs can be easily observed in many FX individuals – and include flushing, sweating, increased heart rate, speech cluttering (rapid talking with the words slurred together), an increase in fidgety movements, pacing, reduction in eye contact.

All three of these problems are intertwined in FX. They have overlapping symptoms and signs and they often exist to varying degrees at the same time. Often it may be hard to define which problem or combination of problems is driving behavioral dysfunction in FX. In fact, researchers believe these problems may all come from a common defective mechanism in the FX brain, which is the inability to normally inhibit (calm down) brain reactions to things, such as fear, excitement, noise, touches, etc.

When we were discussing Andrew's behaviors, Dr. Berry-Kravis said something that really helped me. She said "virtually all affected by Fragile X Syndrome have both anxiety and hyperactivity, but one runs the show. At a young age, it is sometimes hard to see which runs the show."

She was referring to the common difficulty of deciding whether the ADHD-like (hyperactivity/distractibility) symptoms or the anxiety symptoms are the bigger problem driving behavioral dysfunction in a child with FX. In the end, the decision may be made by “educated guessing” followed by trying medications that target these problems in a specific sequence and finding out which type of medication works best – ADHD-type medications (eg. Ritalin, Adderall) or anxiety medicines (eg. Prozac, Zoloft, Lexapro), or both types of symptoms may need to be treated and a combination may work best.

It's hard with Andrew to see which symptom is “running the show,” so we first tried Clonidine (December 2004). It would've been a dream, if it had worked, because it can target anxiety and hyperactivity. After Clonidine, it was on to Ritalin, which targets hyperactivity, but was also a failed med trial for Andrew. Our third med seems to be doing some good things. Andrew's now on Zoloft, which targets anxiety. His transitions and demeanor seem a bit more calm. The jury is still out, but I'm less anxious about his anxiety, which is a good thing!

*Mary Beth Langan, Grosse Pointe, Michigan,*

*with assistance from Dr. Elizabeth Berry-Kravis, Chicago, Illinois '05*

The thing that is most disabling about Fragile X for my 15-year-old son is the anxiety. It really affects what we do and where we go to a great extent. When he was younger, I was less inclined to try new things for fear of a meltdown. However, as he got older I realized just plowing through something that caused him anxiety was the only way to lessen it. We would go to movies not planning to stay, festivals where we never got through the front gate, malls where we practically ran through the stores, all practice runs for the real life we wanted him to be part of. Some of those things we have actually been able to do on a regular basis, movies for example. Some of them, like the mall, we just decided we would rather have our teeth drilled than try the mall anymore.

*Jackie, Marysville, Ohio '05*

### **Anxiety in FX Girls**

My daughter was born in 1995. At the time we had never heard of the term “Fragile X”. We did not have or know of a family history of any genetically inherited conditions. What we did know was that by the time she was three months old, we had an extremely shy child on our hands.

Bailey was the type of baby who “made strange”. This was what everyone told us. David and I saw something different. We saw a child who was profoundly affected by large places, commotion, noise and strange faces. She could not make eye contact with anyone but my parents, my sister, and David and me. This continued throughout her first year of life, and she didn't outgrow it. In fact, it became progressively harder to take her anywhere. People told us that it was our fault, that we coddled her, that we needed to expose her to more people, more often. Unfortunately, instead of taking cues from our profoundly sensitive child, we caved to the criticisms of our parenting skills and attempted to force her to be social.

The result was a lot of crying and a lot of vomit. She would throw up after sobbing her heart out whenever we took her into a situation that was more than she could bear. One of my biggest regrets as a parent is that I did not listen to my gut instinct that told me not to force her.

When Bailey turned three, we enrolled her in preschool. She didn't speak for the entire eight months she was there. We sent her to Junior Kindergarten where she didn't speak or interact for the first five months. At home she was a bright little chatterbox. At school, a shrinking violet.

Her teachers expressed serious concerns about her social abilities and her deep anxieties. We took her to doctors. No one had an answer for us. She could not stand excessive noise. Eye contact was a form of torture. Only certain people could touch or hug her. Music and singing sent her into fits of tears. But the worst of all was (and still is) the sound of laughter. Bailey reacts to most laughter as though a cruel joke has just been directed at her and all the world is laughing. I have seen her crouch into a ball, sobbing, at the sound of someone's laugh. It was hell for us and, more importantly, for her. The hardest part was having no answers.

As Bailey turned five, we were expecting a baby. I prayed not for a boy or a girl, but for a child who wasn't shy. With the birth of Maya, we got just that. Maya speaks to most anyone and usually doesn't stop talking.

Becoming a big sister started to build Bailey's confidence and, in Grades 1 and 2, she was blessed with two teachers who took her under their wings and created a comfort level that allowed her to begin to express herself to others. During this time, we discovered FX in our family and our girls were both diagnosed with a full mutation. As I started to research FX it

became very clear to me that the source of Bailey's anxiety was the manifestation of FX in her little being.

At the age of ten, Bailey is now very articulate. She is able to explain that laughter makes her feelings hurt deep in her chest. That too many people in a room make her feel overwhelmed. That happiness, sadness, fear and anxiety are very real and very extreme.

It is my belief, that for these girls, their senses are so heightened that everything they experience is much stronger than what we feel. She has a great capacity for love and compassion, but she is easily frightened by the unknown and doesn't work well out of her comfort zone.

The good news is that with age come coping skills. Bailey can now set her own boundaries and knows her limitations. This past January, Bailey and I went to her first concert. It was Hillary Duff, and let me tell you, it was LOUD! She rocked along with all the other ten-year-olds and beamed with a smile I will never forget. I can't forget, my ears are still ringing!

*Lori, Ontario, Canada '05*

## ***B is for ...***



## **Behavior**

In the midst of a behavior crisis, quite by accident, I discovered I had in my possession a gold mine. Before school started, I checked a book out from our local Autism Society's library called: "Solving Behavior Problems in Autism (Visual Strategies Series)" by Linda A. Hodgdon. The book is so good I actually bought a copy. It includes many useful ideas for teaching how to use communication instead of behavior. I've had the school include the section on "Calming Strategies" in my son's Behavioral Intervention Plan.

This book is a must-have resource for parents, or educators, who are struggling with behavior and self-management challenges. The book is the second book in a series; the first book is: "Visual Strategies for Improving Communication: Practical Supports for School & Home" by Linda A. Hodgdon.

It's on my must-read list, once I get past the behavior issues.

*Cheryl, Maine '05*



*In response to a message on the listserv about a Fragile X child being suspended from school:*

Your instincts are correct; the school's approach to handling your son's behavior is truly awful. Anxiety can often cause behavior outbursts, especially if the child cannot express this anxiety. I know when my son is anxious by the increase in verbal outbursts and the best way to alleviate this is try to reduce his anxiety. Medication, specifically Abilify, has greatly reduced behavior issues also but varies in its effectiveness for our kids. I too found that any stimulants, like Ritalin or Adderall, would increase his behavior outbursts. His old school expert psychologist wanted to put him on Valium, which would have made things even worse, so be careful about recommendations from people who are not familiar with the syndrome.

Forcing someone into compliance may cause him to eliminate the behavior but he will likely replace it with another one. Persistence and consistency is very important but not in the manner they are using it. The law is quite clear that a functional behavior assessment is required to understand WHY your son is having outbursts. With the philosophy this school seems to have, it is unlikely they will perform an assessment that is meaningful. I would request, in writing, an independent functional behavior assessment. They must provide you with this unless they want to go to court to prove they can do their own. In addition, you could request counseling for you and your husband to receive some help with implementing true positive behavior support strategies. You should also insist that the school do the same.

Behavior strategies that tend to work well with all kids:

1. Providing choices throughout their day, so they feel they have some sense of control in their lives. For example, the teacher could give him a choice of activities to do rather than forcing one.
2. Increasing the types of activities he prefers, using items and subjects he is especially fond of. My son loves anything to do with space. Give him a report to do on the space shuttle and he's in heaven!
3. Giving short breaks, especially during tough periods. Ideally, he can learn to ask for a break when he feels himself getting tense or anxious. This could be a short walk in the hall, a 5-minute turn on the computer, whatever will make him feel more relaxed.
4. Providing lots of visual supports, such as a picture schedule. Transitioning from one activity to another often causes lots of anxiety. Knowing what will occur in the next 5 or 10 minutes or knowing he will have to stop the present activity can often reduce stress.
5. Providing sensory input: having a small box of sensory items, such as a Koosh ball that he could use during the day that would not interfere with his learning.
6. Using social stories to help him learn what the preferred behavior is.

Also, check out these sites:

Addressing student behavior: <http://www.air.org/cecp/fba/problembehavior/main.htm>

Positive Behavioral Interventions and Supports: <http://www.pbis.org/main.htm>

These are all general ideas; the school needs to learn what, specifically, is setting your son off so they can tailor the strategies for his needs. His behavior is telling them something; they need to learn what it is!

*Orah Raia, New Jersey '05*

*More from Orah: additional helpful resources for Positive Behavior Supports*

**IEP Team's Introduction To Functional Behavioral Assessment And Behavior Intervention Plans** (2nd edition) Provides in-depth information on functional behavioral assessments. <http://www.air.org/cecp/fba/problembehavior/main.htm>

**Kentucky Department of Education Behavior Home Page:**

This site offers school personnel, parents, and other professionals access to information and ongoing consultation and technical assistance concerning the full range of behavior problems and challenges displayed by children and youth in school and community settings. <http://www.state.ky.us/agencies/behave/homepage.html>

**Multimodal Functional Behavioral Assessment**

Provides sample blank and completed forms for functional behavioral assessments and behavior intervention plans. <http://mfba.net/> <<http://mfba.duq.edu/>>

**Positive Behavioral Intervention and Supports**

The Technical Assistance Center on Positive Behavioral Interventions and Supports (PBIS) has been established by the Office of Special Education Programs, US Department of Education to give schools capacity-building information and technical assistance for identifying, adapting, and sustaining effective school-wide disciplinary practices. <http://www.pbis.org/>

**Rehabilitation Research and Training Center on Positive Behavioral Support (RRTC-PBS)**

A national research and training effort to develop and disseminate effective, practical, and empirically validated procedures for improving support for individuals with disabilities and problem behavior. <http://rrtcpbs.fmhi.usf.edu/statement.html>

*Orah Raia, New Jersey '05*

When my son was in first grade, a specialist was brought in to develop and implement a behavior plan. It was disastrous--for him, for the aide and for the classroom teacher. My son is now 18 and has had hundreds of (alright, a new one every year, it just feels like hundreds) behavior plans. We, his parents and older brother, have found that the right medication and acting like border collies works for us. We can lead and loop back next to him; he will eventually follow. It takes a long time. Direct conflict always, always, always ends in misery for all involved.

What works for me now is: I say. "It's time to brush your teeth. Please brush your teeth now." He says everything he can think of, related or unrelated to brushing teeth. I tell him that I can't talk to him about anything until he brushes his teeth. This is the only thing I say to him until he gets bored and brushes his teeth. If I slip up and let him engage me in this "conversation," it could go on for hours.

When it comes to leaving the house (which he hates), I say I am leaving now. You need to come with me. (no, no, no, no, no!). I am going out the front door. I am getting in the car. You need to come with me. Then I go out into the car and wait as long as I need to. Raising my voice is the worst thing I can do. But I'm not super human, and if my patience is shot, and the border collie barks, we start all over, except I've got a very hostile person I'm trying to lead. I always regret raising my voice. Also, at 18, he can drown me out completely.

This is the best I've been able to do after 18 years. And, I've got to say, despite our kids having a developmental disorder, they do continue to develop. James is a whole lot easier to deal with at 18 than he was at 8.

*Mary Lou Supple, Newburyport, Massachusetts '05*

## **Behavior Management: It's a Rule**

Is it difficult for your child to remember the "rules"? There may be a simple solution. Put the "rules" in writing. When your child protests, say, "Sorry, it's a rule", and show him/her the rule.

I have created a list of our most important rules. Using the written rule as an arbiter of "good behavior" removes the test of wills between the child and parent that often accompanies enforcement of rules. For example, if my son doesn't want to buckle up in the van, I tell him he has to, it's the law and rule #25, and then I show him the rule.

I have each rule written on a 2 x 3 card, on a key ring, it's my "key chain" list of rules. My key chain only has words on it, but for my son it doesn't matter that he can't read, just showing him the printed rule helps. I've included our list of rules below.

- #1: Always tell Mom, Dad, and family how much you love them
- #2: When you wake up always go to the bathroom and go potty.
- #3: When you need to ask for something use the word "Please."
- #4: When someone gives you something or does something nice say, "Thank You."
- #5: When someone tells you Thank You say "You're Welcome."
- #6: When someone sneezes say "Bless You."
- #7: When you need help--ask.
- #8: We don't hit. Hands are not for hitting.
- #9: Always use your inside voice when you are indoors.
- #10: Always keep your hands to yourself; some people don't like to be touched.
- #11: Our hands can only go in our pockets, don't put them inside your pants or underwear.
- #12: We don't throw things (unless it is a ball outside).
- #13: We always keep our clothes on, except when we are sleeping or taking a bath.
- #14: It's good to share and take turns.
- #15: It's good to help others.
- #16: If someone is doing something you don't like, ask them to STOP.
- #17: It's okay to take a break.
- #18: Before you go to bed, go potty, wash your hands and brush your teeth.
- #19: If you need a hug--ask.
- #20: We don't bite. Biting is only for eating food.
- #21: We don't kick anything but a ball.
- #22: The only right place to go potty is in the bathroom.
- #23: Smile often. It makes you and others feel good.
- #24: It's okay to cry if you are upset, but don't forget to use words to tell others what's bothering you.
- #25: Always wear your seatbelt when traveling in a car, truck, bus or van.
- #26: Turn off your TV when you are not in your room.
- #27: Always go to the bathroom before leaving for anywhere.
- #28: Ask for snacks or juice.
- #29: No running in the house.
- #30: Try your best to follow all the rules.

When we leave to go anywhere, I no longer have to tell my children to use the bathroom, I just say time for Rule #27 and they're all scampering off to the bathroom. Now, if I can only get my husband to follow Rule #12 I'd be in heaven. One day he broke the rule throwing an exercise ball in the house, knocking over a glass of water. After he left for work my five-year-old couldn't wait to tattle on him!

*Sally Nantais, Wyandotte, Michigan '05*

**M**y son's aggression is almost always fueled by anxiety. When we get into an anxious situation, I am on hyper alert for signs of a meltdown. Once I took him to a scrapbooking party attended by several of the para's in his school. He walked in the door, saw them out of their surroundings, and he turned and smacked the woman who was selling the scrapbook products full across the face! She was very gracious and plowed through her presentation with my son's handprint on her face. Needless to say, I bought a lot of scrapbooking stuff that night! Now I know to prepare him before we go somewhere for all scenarios.

*Jackie, Marysville, Ohio '05*

## **Bike Riding**

**C**eleste's story brought back fond memories of Josh learning to ride his bike! He was also afraid of falling. So I told him I would tape him on the bike! (he liked tape at the time). So, I took scotch tape and rolled a big piece up and put it on his rear, and he sat on the bike... I said *Okay guy, you're safe*, the tape will hold! He rode and did fine! We never used the tape again! If 3M only knew the real uses of the tape!

*Eileen '98*

**W**e had tremendous success with a bike. At 11 David is riding a mountain bike with gears and it can practically bring tears to my eyes. What a sense of accomplishment he shows. We started with a small bike so he was comfortable. Of course it had training wheels. We rode as a family so there was that motivation. Also, I arranged get-togethers with other kids to ride bikes. There is a great new item called an *Alley Cat*. It is designed to fit on the back of an adult bike. It is a wheel with pedals and a handle bar. The child actually pedals and holds on, but the adult does most of the work. It's kind of like a tandem bike.

*Anita '98*

**O**ur son Matthew rode with training wheels with no problem but the transition to a two wheeler was much more difficult. After trying to help him and run along side MANY times we finally left him alone, setting aside a training wheel budget since they kept breaking. We saw him one day on the side of the street on his bike, walking and then RIDING the bike! What did it? Peer pressure and he loves his banana seat that has a bar on the back. Seems to give him a sense of security. He had just turned 8 when he started riding the two wheeler.

*Wendy '98*

**M**y two FX boys began with tricycles riding in front of our house. They later graduated to small 16" bicycles with training wheels. We had a large enclosed patio where we allowed the boys to ride when the weather was cold or rainy.

As small children, I felt it benefited them to get outdoors. Bike riding seemed to relieve stress and made them physically tired, an added benefit since they slept better which gave my wife a break. Biking has made them more independent; they are willing to put out the effort to pedal to the pool, McDonalds, the park, or the supermarket rather than getting in the car. They never ride alone; one adult is always with them. Both boys have learned to follow rules like "drive on the right side of the road," "stop at stop signs," and "look for cars." They also know how to operate a crosswalk signal.

At first, learning to ride was difficult for them and progress was slow, but I enjoyed biking and spending time with my boys. The one thing that was the most important was my willingness to put out the effort. I would take the boys biking at every chance possible rather than viewing it as a chore.

After each boy mastered riding a bike with training wheels in front of the house, I began using bicycles for transportation. We would ride to our local park or to another neighborhood. It was fun for the boys to see other kids and other places.

We went through a pair of 16" wheel bikes with, and then without, training wheels. Each FX child has his own ability level. What worked for me to take the step of removing the training wheels is the boys would "scoot" while sitting on their bike, walking and occasionally lifting their feet to coast. At the time, it seemed like they did this method forever before they learned to balance. I recommend this method - have patience. My youngest boy was not getting the balancing thing, so after about three weeks, we put his training wheels back on for a few months. When we tried it again, he was riding without training wheels in just a few weeks. When you purchase a bike, try to get one with low gearing because it is easier to pedal and actually makes the kids ride faster.

My boys, ages 10 and 12, are currently riding 20" wheel BMX bikes. We recently installed taller handlebars because they outgrew the original ones.

Resources on the web for protective gear:

Reflective Safety Vests: [www.safetyline.com](http://www.safetyline.com). My boys wear their vests when they ride during the day or at night. The sizes are the same as T-shirt sizes. We use the "mesh" vests, one boy has a sleeveless vest and one uses a vest with short sleeves. These vests feature a zippered front on the adult sizes and a Velcro front on the child sizes. In the catalog, the child's vest is on an adult mannequin and looks like a bikini top. My boys wear the smallest adult size.

Spoke Blazers: [www.besafeinc.com/spokeblazers.shtml](http://www.besafeinc.com/spokeblazers.shtml). These look like drinking straws covered with reflective tape. They are small, lightweight and not noticeable in the daytime. This safety device is well worth the price. They install without tools. We have them on all the kids' bikes.

Super Streak Bicycle Lights: [www.outdoorcreationsinc.com/index.cgi?page=lmss](http://www.outdoorcreationsinc.com/index.cgi?page=lmss). I highly recommend these lights. We use them on our kids' bikes. They use two AAA batteries that typically last for 6 months. They provide excellent visibility from the side.

The Rick Shaw: [www.inter.ab.ca/rickshaw/](http://www.inter.ab.ca/rickshaw/). The Rick Shaw originated by a family's desire to aid in the mobility and quality of life of a loved one. In 1993 Jim Anderson and his sister Darla decided to provide their physically challenged brother, Rick, with a bike trailer. Unable to find anything for an adult they decided to make one of their own. After one year of design, construction and testing they had their first adult trailer on the bike path.

*Pat, San Jacinto, California '05*

**W**e put stabilizer bars on our son's new bike and he went riding solo for the first time in his life! The joy in his face was a tear-jerker for me, so much emotion in this wee little yet giant step. The stabilizer bars are worth their weight in gold. We got the best, with the most poundage to allow him to grow with it; they will hold up to 300 pounds. My son is 12 1/2 and weighs 150 pounds.

Our Fatwheels were shipped out to us within a week and fit to the bike we had chosen without a problem. The tires are similar to a regular bike tire, with thick rubber treads and an inner tube.( I

personally think his bike looks 'cool'.) He almost got away from us, LOL, so we are going to add a strap behind the seat, in the event he pedals fast when we are pooped.

For more information on the stabilizer bars and Fatwheels, go to [www.fatwheels.com](http://www.fatwheels.com). I found the best method to contact the company was through their email address.

*Leslie, Orlando, Florida, 05*

## Biting

**O**ur 6-year-old daughter is a biter. She does not bite herself. She does not like chew toys. She bites anyone in close proximity to her on the arms, back, legs, wherever. She bites when she is scared. She bites when she is anxious. She bites when she is excited.

Basically, biting is a big part of how she copes with her daily life. Biting makes her feel safe. Biting makes her feel less anxious. Biting helps her escape and biting feels good.

In order to help our daughter decrease her tendency to bite we have tried many things. What works one day may not work the next, but we have to continue to be consistent with our reaction to her biting even if she isn't.

The most important thing we have learned is to NOT LET her "get that bite in." Take the defensive approach and walk away from the child when you think they are going to bite. If we see our daughter escalating and going into the "bite mode," we distance ourselves from her and try to distract her and get her mind off the biting. For example, she likes to sing and look out the window so we'll go over to the window and just start singing without her. Or perhaps, we will offer her an alternative sensory input like picking her up and swinging her or squishing her between pillows. Telling her we are going to chase her usually works the best for our daughter.

The key is to not let her get the reinforcement of the bite and then get her mind totally off the situation at hand. It's not as easy as it sounds. We do not tell her "no biting." Rather, we say "Oh, I see that you are upset/mad/excited. Do you want to chase/have a pillow fight etc?" If our daughter does bite, we push our arm (if she is biting the arm) toward her and she will release. We have learned through our friends at Developmental FX (Mouse, Tracy and Jen) that we should not pull our arm away but push into the bite. Pushing feels better than pulling anyway.

So, biting is a big issue for us every day. We are always trying to be one step ahead of our daughter in keeping her anxiety down and talking to her all the time about her feelings. Our daughter will not chew on chew toys, etc. She prefers to bite people so the most important thing for us is to not let her get that initial bite. The more she is able to bite the more the biting is being reinforced.

*Deborah Parker, Pennsylvania '05*

**M**y 4-year-old son Michael (soon to be 5 in June) has been a biter since the age of 2. He has bitten numerous kids at his preschool and continually bites his family members including myself, husband and daughter. I find that the times when he bites others are when he is overstimulated (rough play) or when others are in his face. He also likes to bite on his clothing when he is excited. I have found the best thing that works for him is a chewy tube. He is able to get the oral stimulation and feedback that he needs and he does not bite others or his clothes when we give him one. If and when he does bite one of us, I put him in Time Out and tell him "we do not bite"

and that he has to apologize to the person he bites. When he was younger, I don't think it really sunk in, but now, he shows remorse and knows that he has done something wrong. I think with time and using the chewy tube, biting has become much more manageable and hopefully, it will eventually be eliminated.

*Bonnie Lucio, Mandeville, Louisiana '05*

**B**iting and noise are two areas that were significant when Christopher was very young. Biting: Not food, not other people -- just himself, in particular, his index finger! This would occur when he was overstimulated and needed to center himself. It was confusing to me at the beginning: Why would he bite down on his finger and make loud noises (growling) at the same time? In my naive days, I tried Tabasco sauce on his finger! Of course this didn't work, and lucky for Christopher that I discarded that remedy very quickly. As I became a bit more educated about sensory integration, I learned that this biting was Christopher's way of getting in touch with himself and blocking out the stimulants that had overwhelmed him. He is now 17, and has grown out of this, but a big callous on his finger tells the story of what used to be one of his ways to deal with life when it got too much for him.

*Carol Collins, Sandusky, Ohio '05*

*C is for ...*



## Calming Techniques

1. Stretch arms out in front, fist clenched, release. When you release the hands stretch the fingers out
2. Stretch legs only clench the toes.
3. Drop head forward and bring it back up.
4. Twist head from side to side, slowly.

Do each exercise 5 times. Say the word "Relax "slowly in time to the exercise. I don't have the manual any more but this worked. So did the Lamaze Breathing exercises.

*Dani Feierstein, Chesapeake, Virginia '05*

What we have discovered is that David, 12, will use his headphones and CD (or tape, ipod, or mp3) player whenever he needs to calm himself. He turns the volume up very loud, holds the headphones to his head, and nods his head to the music. At first I was very concerned, but a PT friend of mine explained that he needed to do that because he has so much commotion that he hears (similar to ADD kids) that he has to hear just one thing to calm himself. After I gave it some thought, it made sense. His music is very portable, easy to use on the school bus, easy to use anywhere.

*Cindy Saracino, Geneva, New York '05*

## Chewing

My son also loves to chew; it seems to be an uncontrollable need. He has “killed” Stretch Armstrong and many other toys. His PT at school got him what I call a chewy. It’s a piece of blue rubber tubing. It works great! Kyle will put his hands in his mouth a lot. We have tried to rid him of the “habit” since he was 3 years old, but we finally figured out it’s not really a habit--more of a need for the oral stimulation. I think the idea of a “necklace” is a great idea. I know we had to buy a cordless phone because he was starting to chew through the cord and it got pretty WET!

*Gail '98*

When our FX son Dan used to chew holes in his shirt, we tied a "bandana" around his neck and he chewed on that instead. It saved the shirts and we had several to switch around as needed. Also, we could re-roll them so the holes were in different spots.

*Carol Grunwald, Newton, Wisconsin '05*

I’ve come up with a solution that is working for my son (Pat, 12) chewing on his shirt (and I do mean big time chewing--top and bottom and sometime the sleeves). What I am using is a translucent flexible plastic key chain on a chain around his neck. It is flexible-chewable-and he seems happy with it. My husband is going to talk to his plastic supplier and find out what the material is called. We’re going to see if we can get a small sheet of it and cut it to a shape Pat likes - maybe P for Pat. This is working well and even when he takes it off he doesn’t go immediately for the shirt. I can’t tell you how thrilled we are. Has anyone tried hospital tubing? You can get that from plastics suppliers, too. It says it’s tasteless. Might make a good chain.

*Sue '98*

We have bought hospital tubing from a medical supply store (the kind that is wrapped around your arm when blood is drawn) and cut it into pieces about 5-6 inches long. Dave chews on them when he’s nervous or bored, I think. He keeps one in his desk at school. His first grade teacher said he reached for it during standardized testing! Pretty good as a self-calming technique. These have saved a lot of shirts, edges of sleeping bags in front of the TV, toys, etc.!

*Gail '98*



**M**y son chewed constantly on a receiving blanket from when he was an infant...I have tried just about everything to get him to stop, with no luck. One thing that has helped somewhat is the tall water bottles that have the hard plastic straws in them. He drinks a lot and it was good for SI too-the sucking, so it seemed logical to me to try. He chews the devil out of it when he needs to. He has a water bottle at his desk in both classrooms at school and available to him at home too. The problem is not completely gone but this has helped and is more appropriate than chewing on his clothes or a blanket.

*Suzzane '98*

**A** teacher I work with came up with the idea of giving a student with autism a rubbery football mouth-guard, which he will use instead of his hands.

*Sue, OT '98*

**M**y son, Nick, used to chew on his shirts. He also chewed through all of his coats, including winter parkas. Talk about expensive to replace! We started reinforcing the collars with pieces of leather and he chewed through these as well. I really can't say what stopped it, but I believe he chewed because of anxiety; chewing was calming. He is on Zoloft to address his anxiety issues, which helped tremendously. We tried all kinds of tactics, including social pressures. We gave him lots of socially appropriate replacements like gum or straws to chew on and gradually he stopped chewing on his clothes. He still has a tremendous need to chew and he still goes through a lot of gum and straws!

*Nancy, Upstate New York '05*

## **Computers & Software**

**I**f you are attempting to create a little independence for your children when they are using a computer, make copies of your CDs and DVDs. Only let your children use the copies. If your household is like mine, you'll seldom see CDs or DVDs in their protective cases. They'll be walked on, sat on and quite possibly used as Frisbees or flying saucers. Keep your originals in a safe spot and if your children accidentally destroy their CD or DVD you can easily make another copy.

*Sally Nantais, Wyandotte, Michigan '05*

**M**y son was the official computer person in his classroom when they needed someone to download or pull up a web site. He can't write his name but the boy is a whiz on the computer! He learned it by being able to just play on the computer and from his kindergarten teacher who had the patience of Job. I'm always amazed by how much he knows when I sit with him at the computer. Now that he is a teenager he tells me to "Go away, mama!" The other day I got an email from Amazon thanking me for my order. I knew I hadn't ordered anything so I checked it out. Sure enough, someone in my house ordered a Pokemon DVD! Hmmm... What a coincidence, my son just happens to be a huge Pokemon fan! Now, I have to watch him more carefully when he gets on Amazon and eBay!

*Jackie, Marysville, Ohio '05*

We have used the *Living Books*, *Arthur's Teacher Trouble*, *Just Grandma and Me*, etc. Josh loves them all! Less expensive, *Math Workshop* from *Broderbund* is great too. It is for ages 6-10. We also purchased *Kids Pix Studio*, another fun program and very easy to use.

We have purchased *Edmark's Imagination Express*, *Destination Castle*. It is a CD-ROM Win/Mac Program and you create stories. *Edmark* also has *Thinkin' Things 1-3*, for three different age levels. These programs develop problem-solving skills. I have been staying away from the expensive so-called Special Ed Software. Many companies offer neat stuff, it just takes time to find it!

Eileen '98

When it comes to computers, the best advice I can give is to play a little with your child at first. You may need to do a little hand-over-hand and then sit back, let them explore. Computers were at one time a very big part of my life and I used to teach a few business software packages. Most people don't like people sitting behind them always telling them what to do. Our kids are no different. Give them a little space. I was amazed when Natalie had to ask Austin how to find a treasure in one of the "Freddie the Fish" games. His memory worked to his advantage and he was able show her what to do.

As for hardware, we've never had touch screens but we've always had two computers set up, one has a trackball and one has a mouse. All our children quickly became adept at switching between a mouse and trackball. I believe when individuals (adults or children) are just beginning, the trackball is easier to use.

My children have enjoyed some of the same games Eileen mentions (above). We not only have "Just Grandma and Me" but many of the other books by Mercer Mayer in a computer format. The Mercer Mayer programs have just a few options which are easy for kids to navigate when they are just beginning. Mercer Mayer books are marketed by Living Books and typically allow you to switch between English, French, German and Spanish.

Sally Nantais, Wyandotte, Michigan '05

#### **Additional resources:**

[www.aSmarterU.com](http://www.aSmarterU.com) - Kids educational products, Toll Free: 800-315-2612 (available 24 hours). You can shop by age level, grade level or publisher. They have a variety of products, including hardware. They also have free online games and activity sheets available.

[www.childrensoftwareonline.com](http://www.childrensoftwareonline.com) – Children's Software Online, Toll Free: 866-774-8505. Self-paced learning combined with vivid graphics and animation create an exciting learning environment... Easy to navigate website and they also offer Videos and DVDs.

[www.softwareforkids.com](http://www.softwareforkids.com) – Software for Kids, Phone: 650-85-8340, based in San Mateo, California. Children Educational Software Serving Parents, Teachers, Students & Schools. Software for Kids caters to children all ages, from toddlers, preschool, kindergarten, K-5 to middle school.

[www.kidsfreeware.com](http://www.kidsfreeware.com) – Free programs for kids. Some are online and some can be downloaded to your computer.

# Coping

I do a simple breathing meditation in the morning and the evening. Even if you just do it for five minutes it really helps you focus and calm. Here's how it works.

Pick a quiet time and place where you won't be interrupted.

You can sit either on a cushion on the floor or in a chair. Sit comfortably with your hands in your lap, your eyes open and focused on the floor a few feet in front of you. Keep your spine straight.

Take three deep slow breaths in and out to relax.

Set a timer for 5 minutes (so you don't have to keep looking at a clock), and allow yourself to breathe naturally.

On your exhalation count silently '1'

On your inhalation count silently '2'

Continue this up to 10 and then go back to one.

If your thoughts stray, as soon as you are aware that you have lost count go back to '1' on the next exhalation. Don't get upset with yourself if you lose count. It's natural for the mind to wander. The important thing is that you gently bring your concentration back to breathing and counting.

That's the whole meditation.

This has been really helpful for me. It's sort of an exercise for your brain and body. Once I started doing this every morning my mind didn't run away with itself so easily.

This is also helpful in the small hours of the morning when I'm unable to sleep because my mind is on overdrive. I can lay in bed, open my eyes, look at the ceiling, and start counting my breaths. No matter how anxious I am, after counting breaths for a bit I seem to naturally fall asleep. (Part of the trick is learning not to worry about being worried. When I notice that I'm anxious I just make a note of it and turn my attention back to my breath).

*Adam Long, London, UK '05*

The best coping tool ever is a sense of humor! If I could only recount the number of times I started out crying and ended up laughing. Having a sitter or grandpa on speed dial also helps. Sometimes just stepping away for a while is the only thing that helps. You come back refreshed and ready to get on with it. It also helps me to review old articles and books I've read about why our kids act the way they do. When I find myself thinking "why is he doing this?" I get those articles out and they help me see that my son isn't doing anything to torture me, he's doing it because he has Fragile X.

*Jackie, Marysville, Ohio '05*

One thing that really helps me to cope is keeping two journals.

The first journal is all about our journey to a Fragile X diagnosis, about my feelings of loss and sadness regarding all the issues involved with having a child with Fragile X. Whenever I feel overwhelmed by Joey's needs, or impatient by his steady but slow progress, or if I'm just feeling gloomy because Joey is so far behind his cousins, I write down my feelings about what happened. My first journal is a place for me to vent and record my sad feelings so that I don't drive everyone crazy by talking about them all the time.

In my second journal, I record all the happy times we have with Joey. Many people comment on Joey's friendly personality and big smile. I write all of those stories down in my second journal. I record all of the fun times that my parents, sister, husband, I or anyone have with him. For example, Joey's speech therapist says his smile "lights up the world"; when my dad takes Joey to Tim Horton's for a donut he always tells me about how Joey goes around to all the retirees' tables and smiles at them while flapping his arms cheering everyone up. I write down anything new Joey does and I record any progress he is making, no matter how small. I record funny things Joey does. He loves to jump up and down and flap his arms while we open our venetian blinds in the morning. My husband and I call it the "Joey jig."

When I'm feeling down, it helps to read my second journal and focus on all the joys, happiness, love, and laughter Joey has brought to our lives, as well as others'.

*Carrie Stemen Narcelles, Columbus, Ohio '05*

## *D is for ...*



## **Daily Living Tips**

### **Bathing:**

One little thing I do to help the boys be more independent in their day-to-day lives is: I put bottles of water in the door of the refrigerator so that when they want a drink of water they can get it themselves at any time. It works! I also rely heavily on a kitchen timer to help the boys through their day. For example, to let them know when they can be finished with a task, or when they don't have to wait any more. I velcroed photographs of clothes contained in each dresser drawer to the outside of their drawers, so they have a visual cue as to what is in each. Then they are able to pick out their own clothes.

*Cindi '98*

**Bed Wetting:**

**B**ed wetting tip: layer sheet sets (plastic mattress cover, mattress pad, fitted sheet, then a plastic cover--not the zip up kind!-- **repeat**, mattress pad, fitted sheet) for several layers. Then when the bed is wet at 2 a.m. all you have to do is peel off a layer and *voila!* a clean dry bed awaits! Sure, there is a lot of laundry the next day, but you can return to sleep very quickly so you'll have the energy to do the next-day's laundry!

*Claudia Burrows, Indiana '05*

**Hair - Brushing, Cutting and Shampooing:**

**W**e have four sons (one with Fragile X). Each morning they wake up with bird nests for hair. We use a fingernail brush—that we bought just for this purpose—that we have held under warm running water to tame their unruly messes. The brush holds enough water so that we can brush their hair while they watch TV and we don't have to keep running back and forth to the sink. The TV really distracts them, and it's over in about 30 seconds. Of course, they have 'simple boy' haircuts, and straight hair, which helps. This method probably would not work on girl's longer hair or for really curly hair. We have to use a comb if we need to put a part in their hair.

Also for their haircuts, my husband Greg, uses the '*Flowbee.*' It is a small machine, that he bought off an 800# for \$80 about two years ago. It hooks up to a vacuum (we use a shop-vac) that literally sucks up the cut hair so there is no mess to clean up. You can adjust the cutting blades to different lengths, for various styles. We have the boys watch a favorite video while they get their haircuts; we have to turn the volume up, because of the noise of the vacuum. They sit on an old office chair that has been jacked up to my husband's arm level. It sounds complicated, but really isn't once you get the hang of it. It has saved us a lot of time and hassle going to the hairdressers every 6 weeks not to mention all the \$ it has saved. Greg is now cutting the hair of a boy with autism; his mom cannot believe how great this method is.

*Susan and Greg '98*

**H**air brushing and hair cutting are two of Kyle's least favorite activities. We have solved this problem by having his hair cut short on the top and sides and a bit longer in the back, which looks nice on him. He also has the most beautiful blond soft hair and his texture is great, not soft or fine, so brushing is about four swipes. When we first started cutting his hair we would put him in a cardboard box on the kitchen table with a set of keys and he would be happy for a bit and distracted. Later he would only let 'mom' do it and we discovered he loves the clippers so we will let him feel the vibrations of the clipper, do a few cuts etc. I made the mistake of thinking he needed a better haircut and took him to a shop to have them do it. He cried the whole time, his haircut turned out just like when I did it and I had to pay for it!

*Gail '98*

**G**o frequently (in spite of tears) and often. A lollipop does help in this case. Lots of praise when completed. When they are little, have them sit in your lap, when older, stay by their side. The more frequent, the more familiar the routine gets.

*Pattie Devlin, Burlington, New Jersey '05*

**I** started taking my son to one of the salons for kids in our area when he was younger and he still loves to go there at 15! They have a VCR in front of every chair and the kids can pick their own videos. I always laugh because he is so big next to the little kids getting their first haircut and crying. He always tries to calm them down. He still tries to get away with sitting on the merry go round horses to get his haircut, but I give him a threatening look and he grins at me and goes over to a regular barber chair! We always go during the day when they aren't too crowded--never on the weekend!

*Jackie, Marysville, Ohio '05*

### **Nail Cutting:**

**T**ry doing so after a bath or shower as the nails are much softer and easier to cut, particularly if you have to tackle the toe nails. We also give Brent something to chew on when we are cutting his nails.

*Kim '98*

**W**e would clip one hand, letting my son know how many more. Then we handed the clippers to my son so he could "clip" our nails - he would try, it made him feel better and more in control.

*Pattie Devlin, Burlington, New Jersey '05*

**N**ail cutting used to be quite traumatic in our house, filled with tears and screams. He was a light sleeper so cutting at night was not an option. One day I broke the task down to the smallest step. After each bath, I would cut one nail, only one. When he adjusted to one at a time, we moved on to two, before you knew it I was cutting his nails a whole hand or foot at a time.

*Sally Nantais, Wyandotte, Michigan '05*

### **Shoe Tying:**

**I** had worked for many years to try to get Simon to tie his shoes. He hated velcro laces, so we struggled nearly every day. When he was in 2<sup>nd</sup> grade he was among the first special education kids in the county to be included in a regular classroom. His teacher was a 35-year veteran who originally wasn't all that enthusiastic about inclusion. But she and Simon really liked each other. One day, when he (again) asked her to tie his shoes, she told him she was too old to bend over and he needed to tie his shoes himself. And he did! Six years later Simon is in 8<sup>th</sup> grade and he still tries to get others to help him tie his shoes! He can do it, but he just doesn't want to.

*Nancy '98*

**W**e have been using an elastic coiled shoestring called WHY TIE. We buy them at Walmart. They look like a coiled telephone cord and when properly laced make any shoe easy to put on and off. My two FX boys cannot tie shoelaces but the WHY TIE allows them to put their shoes on without help.

*Pat, San Jacinto, California '05*

**Tooth Brushing:**

Try those strips they have out now that you can put on your finger. Put it on your child's finger so they can get familiar with where teeth are in their mouth.

*Pattie Devlin, Burlington, New Jersey '05*

**General:**

My son is older but here are some of the things that helped us early on:

- socks with different colored heels and toes to help him know how to pull them on.
- A sticker system on a clock to tell how much time passed.
- Hanging outfits that matched together in the closet so he could pick out his own.
- PETS! To feed, and to CALM HIM DOWN. Get a kitten so it learns early to be handled. (But John has always done so gently)
- Colors, red and blue, on the bathtub water spigots.
- Vacuum cleaning with the long handle...seems again to calm him down, sure helps me!

*Tonii '98*

**Books:**

For the books you realize are loved, try this suggestion for getting a longer shelf-life. Carefully rip out the pages and laminate each one. Then, choose one of these three methods to finish your longer lasting book: put all the pages into a binder, put them onto a metal ring or two (not within a binder) or have them put into a coil holder.

*Laura Moodie, San Antonio, Texas '05*

**Pants:**

My husband needs to be credited with this clever solution.

My fast growing son recently moved into men's sized pants. While he is capable of using a belt, it takes him a long time. This was a particular concern when going to school - so generally for school we had him wear pants without belts - and even without zippers if possible.

Finding ourselves in this new world -- his size dictated that he now really needs a belt to hold up his pants--we looked through a number of stores hoping to find an easy-to-use belt. Someone recommended an Army/Navy store, but the belt my husband came home with, while the right type, was too wide.

Yesterday my husband went to a Police Uniform Supply store. There he purchased what they call an "Inside Belt." This belt is worn by police officers to keep their pants up, and allows them to wear a gun belt over it. It's leather on the outside - but entirely velcro on the inside - so it's completely adjustable. They even have women's sizes. My husband recommends bringing the kids as they will have a good time looking at all the other neat stuff in the store. The only catch is that they are only black in color. I'm thinking of writing to the manufacturers to see if they would consider making brown.

So there you have it - an inside tip for an "Inside Belt" for those having trouble using buckles.

*Pattie and Matt Devlin, Burlington, New Jersey '05*

# Dental Work

Dental work is often difficult for kids with Fragile X (and many other people). Dentists often recommend sedating kids to get work done and there was discussion of the best medication to use. Several families report success with Sodium Brevitol. This should be discussed with your Dentist.

I would highly recommend a Pediatric Dentist. The office is set up with kids in mind. Our dentist has Game Boys and videos running. The kids wear sunglasses to reduce the glare of the light. Matthew is always given something in his hands to fidget with. At first, they would just brush his teeth, but after several visits Matthew has a full cleaning!

*Wendy '98*

Dentists and Doctors – the “D” words that can create fear in many of our children with Fragile X. Think about it. It's people our children don't know, poking and prodding; it's in a strange place; they all wear white coats or nurse smocks. The lighting is different from home; it smells odd; and if you're at the dentist, there are those awful sounds. A trip to the dentist/doctor can create a lot of anxiety for our children.

What can you do to reduce that anxiety? Take away some of the unknowns. Don't make their first visit to the dentist/doctor be a visit where they actually have work done. Visit the office beforehand. Take pictures and create a social story. If possible, make occasional visits to the dentist/doctor on a regular basis. Get your child more familiar with the building, the environment. You could stop in for 10 or 15 minutes, say hello to the nurses, read a book in the corner, or play with any games in the waiting area. Maybe the nurses/assistants could provide a sucker or sticker when you stop in.

My son is 13 and we do wonderfully at the doctor, the dentist and even the lab when blood work is necessary. It wasn't always like this.

Austin has two younger sisters, and bringing him along for their checkups helped. They didn't cry, except when they had to have shots when they were very young (and Austin would cry along with them--he's very empathetic). He had been doing very well with visits to the doctor until he had to have the blood work for the FX test at age four. It took me more than six months to get him over that. He would walk into the building and start trembling (the lab and the doctor's office are in the same building – convenient for me but for Austin it would be better if they were separate). At one point, I was there for our youngest baby's check up, and Austin was so worked up, he threw up in one of the exam rooms. The staff was great and understanding. They even gave us a smock to wear home and keep, so we started playing doctor with it. Playing doctor/dentist helped immensely. In addition, for a short time I had Austin get shots during separate visits so he didn't associate trips to the doctors with always getting shots.

Look for and use children's videos/books on going to the doctor or dentist. For example, “The Wiggles – Top of the Tots” has excerpts on dentists, doctors and much, much more. Let your child play doctor and role-play going to the doctor in front of your child. During visits, take a favorite toy or stuffed animal with you, and have the doctor check the toy first. The more you prepare, the better.

*Sally Nantais, Wyandotte, Michigan '05*



# Diagnosis

For those of you who are newly diagnosed, there is something I think you might want to consider when you try to explain your child to others: I believe it is important that you say your child has Fragile X syndrome.

You are a key player in increasing awareness, putting a face to this syndrome and educating others. The "What is Fragile X?" business cards (which you can buy from FRAXA or create yourself) are a great tool to assist us in making "Fragile X Syndrome" as well known as autism. For the layperson just telling them that Fragile X is a genetic condition, often with similar characteristics as autism, will be enough.

If you want to go more in depth I highly recommend the booklet "**Families and Fragile X Syndrome**" produced by The National Institute of Child Health and Human Development. It is available online (<http://www.nichd.nih.gov/publications/pubs/FragileX/index.htm>) and in print. The booklet is free and you can order multiple copies by phone 1-800-370-2943 or the website <http://www.nichd.nih.gov/publications/pubs.cfm> (Chose "Fragile X Syndrome" under "Subject" list). I always order in groups of ten, when I have five or less on hand, I reorder. I've passed them out to neighbors, family, school staff and medical professionals.

*Sally Nantais, Wyandotte, Michigan '05*

## *E is for ...*



## Ear Infections

I wish I had known that kiddos with Fragile X often have ear infections when they are very young. I used to tell our doctor that I felt like renting my own space in his office because we were there so often for Christopher's ear infections. I now know that Eustachian tubes in FX kids sometimes collapse and block drainage, (this has to do with connective tissue weakness), which provides a breeding ground for the bacteria that are trapped. Up until age 3, ear infections were very frequent for Christopher. After age 3 - just like magic! - no more ear infections!

*Carol Collins, Ohio '05*

**E**ar infections were a part of Josh's life right from the very start. He would scream endlessly. I took him to our family doctor and it was always the same old story and the same old drug: amoxicillin. This particular med is worthless for children with chronic ear infections. Josh never seemed to get totally well. The late night screaming was horrible for Josh and Mom!

I finally went to an ENT who is wonderful! He listened and we tried Ceclor. This was the magic antibiotic for Josh. He took it and got well after a 21 day period of being on the med. The ENT also gave us a Rx for Tylenol w/ codeine elixir. This is a life saver med that no parent or child should be denied! This knocked out the pain and allowed us all to get much needed sleep.

Josh's ear infections kept returning so the ENT did tubes. Another lifesaver! Josh got tubes and got well! We made sure we plugged his ears in the pool and we had some ear drops also prescribed by the ENT just in case.

Josh went through three sets of tubes over a course of 5 years. Many doctors are concerned about scarring and hearing loss. Josh has great hearing.

I did take Josh to an allergist and we found that his allergies to dust, mold, dogs, trees and dairy contributed to his problems. We made some changes and Josh did even better!

I know that ear infections are a common problem for Fragile X children. This may be due in part to the floppy connective tissue that fails to support the Eustachian tube. When Josh gets a sinus infection I take him to a massage therapist, who does a facial massage. I believe this allows the "gunk" to drain.

I would hope that ENTs and family doctors would take a more serious look at children with chronic ear infections who are developmentally delayed. Could this be a true flag for Fragile X? I think so.

With my non Fragile X daughter we found that doctors have the idea that a 7-10 day course of antibiotics solves the infection. Sometimes it takes a 21 day course along with Prednisone. I prefer to skip the family doctor and go straight to the ENT or allergist.

*Eileen, Indiana '05*

**B**oy, do I know this story. In fact, ear infections were our main concern before we even had a clue about Fragile X. At 10 months they started and we went on the antibiotic merry-go-round for about 5 months. He just got sicker and sicker and sicker until I realized that the antibiotics were causing his immune system to be compromised and we embarked on a full-press effort to treat him with alternative therapies. We did everything.

Too long a story to recount. But the osteopathy eventually cleared his ears of the fluid. That took about 5 months and a very strict diet - no dairy, no wheat, etc. But with his first cold subsequent to the cleaning of his ears, they clogged up again. By this time, his delays were becoming quite apparent, and we felt that we couldn't delay the tubes. We had them put in when Tyler was about 2 ½. We didn't have any trouble with them and I haven't regretted having them. He is now 6 and has been tube-free for about 1 ½ years without problems.

*Sarah '98*

**O**ur son David, now 12, had MANY ear infections. He had his first tubes put in at six months of age yet he continued to have ear infections. After several antibiotics and six more sets of tubes, we found the answer. At the age of nine, we took him to the Doris Rapp Center in Buffalo, New York, for allergy testing. Dr. Rapp had been on several TV shows, demonstrating how food allergies affect children's behavior. What an experience! We discovered that David was allergic to yeast! Every antibiotic he was given increased the yeast in his system (just like we can get yeast infections during a course of antibiotic treatments). Therefore, every time he had an ear infection we were giving him the exact thing that caused him to have an allergic reaction, get stuffy, and have another ear infection. It was a vicious cycle. The best part was that.... IT ALL MADE PERFECT SENSE! Now, if he should get an ear infection we only treat it with drops. If by chance he ever needs an antibiotic, of course we would give it to him. It did take a while to cleanse his system of yeast with a special diet, and daily doses of nystatin. It has worked, though.

*Cindy Saracino, Geneva, New York '05*

**G**uy had multiple ear infections up to the age of two. It affected his hearing, but the use of medication cleared up the problems. During the period that Guy had ear infections he was not only non-verbal but he made almost no noise at all. He began to make jabbering noises and eventually acquired words after the infections cleared up and he received speech and language services. Guy did not have tubes in his ears.

*Jane Chambers, Maryland '05*

## Education

Wow! How do we cover this huge topic? There are many good resources but here are some great ideas....(IEP meetings are covered under "I"):

**I** am including a blank version of the Positive Student Profile for parents to fill out for their own child. I update this every year and I also ask Brian's teachers to update it and I incorporate their info with mine to come up with one new profile every year. It is included in his IEP as part of his educational status.

### Positive Student Profile

This form is to be filled out by the parent to provide a "snapshot" of your child which should be reflected in his/her IEP.

1. Who is \_\_\_\_\_? (Describe your child, including information such as place in family, personality, likes and dislikes)
2. What are \_\_\_\_\_'s strengths? (Highlight all areas in which your child does well, including educational and social environments.)
3. What are \_\_\_\_\_'s successes? (List all successes, no matter how small)
4. What are \_\_\_\_\_'s greatest challenges? (List the areas in which your child has the greatest difficulties.)

5. What supports are needed for \_\_\_\_\_? (List supports that will help your child achieve his/her potential.)
6. What are our dreams for \_\_\_\_\_? (Describe your vision for your child's future, including both short-term and long-term goals.)
7. Other helpful information. (List any pertinent information, including health care needs, that has not been detailed elsewhere on the form.)

Orah '98

**I** know that I have written in the not too distant past about Nick's successes and the struggles we have faced to get there, but I have to share the latest.

I have continually pushed for the schools to work from top to bottom with my sons. They are both fully included with 1:1 paraprofessionals, currently in 6th grade and first grade. In addition to the usual related services, my older son was pulled out for math and reading/language arts. He repeated 2nd grade, and by the end of third grade he was making very slow progress. He had made little progress in reading in 2 years, and we finally hired a tutor. Well, this tutor worked according to the level he was *functioning* at, not the level he was *testing* at. She used high interest series where he got interested in particular characters, and looked forward to reading more about them in the next book. He gained a whole reading grade level in less than six months. But more importantly, he saw the success, and began to like reading instead of fighting it every step of the way. For his reading, the best thing we ever did was hiring the tutor! The next year in school, they started reading high interest novels as a class, and he loved them. We started getting the books on tape from the library so that he could listen and follow along at home as well, repeating and reinforcing what he had read in school. He now regularly gets audio books out from the library, and even requests them as gifts! This is a kid that we had to practically sit on to get him to read or just to listen to a story!

At the end of third grade, his resource teacher was ready to give up on him in Math. He was not progressing, and she felt that he was holding the rest of the group back. I had very little respect for this teacher as she had been working with him in math and reading since first grade, and he had very little to show for it. I always believed that he could do it – we just needed to find the way. He was going to have the same resource teacher the following year and I insisted that I wanted him to stay in the regular class for math, doing the same work as the other kids, but at an easier level. If the class was doing 3-digit addition, he could do 1 or maybe 2 digit math. I could never understand why he could not remember his multiplication facts because he has always had a great memory! I wanted him to have a facts sheet for multiplication, and be expected to do the class work, with the modifications and assistance of the 1:1 aide. Once the pressure of having to memorize the facts was off, he did much better! The resource teacher would never move on until he had mastered a skill, but when I insisted that they move on anyway (with much resistance), he got it! He started doing the math problems without even needing the fact sheet! He might only do short division while the rest of the class was doing long division, but he was progressing and experiencing success!

In sixth grade this year, he is doing the full curriculum for math, with the only modifications being fewer homework problems and extended time for tests. He still is weak with money skills, and he still adds and subtracts using his fingers (and very slowly at that). But he is doing pre-algebra, adding and subtracting, multiplying and dividing fractions, decimals, you name it! He has always needed lots of pushing and incentives to work, but it has been effective. He likes to play games a lot, so we have always played lots of games that require reading and math. He

might keep score with a card game (Skipbo, Uno, Spades -which requires strategy and planning), be the banker in Monopoly or Life, or just read the spaces on the various games. He likes to pay the bill when we are at a restaurant, but first I make him figure out the tip. We never let up on him, and I think he has finally started to appreciate it. He is feeling successful.

The ultimate reward was yesterday we received a letter saying that he is eligible for honors math next year in 7th grade! Of course, this would be insane to put that added pressure on him, but all that matters is that he sees that the school recognizes that he can do it! I wonder if they have ever had a student in honors math with a 1:1 paraprofessional before. Honestly, I think it must be a clerical mistake, but he sure is feeling proud! And so are we!

*Nancy, Upstate New York '05*

**T**he approach that has worked for us is to present ourselves as there to help the school teachers and other professional personnel understand and help Keadon. Do your homework very well. Prepare a summary of things your child responds to well and things that are negative stimuli. Prepare a set of goals that you think are realistic for him. Put together a package of basic material on Fragile X from FRAXA, the National Fragile X Foundation and the listserv that will provide understanding and be a reference resource for them. Offer to volunteer in the classroom if that is reasonable. Our experience is that educators welcome parent involvement that they feel is positively motivated to help them. They become defensive and resistant to demands and criticism. Don't be too hung up as to whether or not you are having formal IEP or teacher conferences at the preschool level as long as you are having good interaction and communication to help guide things in the direction you want.

*Marvin '98*

**J**osh is the first child at the private Catholic school to be involved in inclusion. It has worked great! Not always easy, but well worth the effort. I went into the classroom when Josh was in the 3<sup>rd</sup> grade--he is now a 5<sup>th</sup> grader--and I spoke to the class. I explained to them what Josh needed, why he was different, and asked them to help me help him. It was great! I had parents call me, and ask about him, and tell me they would be glad to help him too. I am a lucky person...I have wonderful people who have really worked as a team to help my son. The secret is teamwork.

*Eileen '98*

**T**he best learning environments have been where there are other children modeling "normal" behavior and my son strives to work harder to improve. In the setting where he was the most advanced, he really stopped trying. So as his advocates, we choose very selectively his learning environments. So how does he learn? At this age (4), by modeling. We had a lot of singing/doing videos. I was ever so surprised to come downstairs one morning and find him cracking eggs into the skillet—singing "fixing breakfast, fixing breakfast!!" Singing was a great way to learn the alphabet. Now, at 8, he is memorizing words and even is participating in spelling tests. Pre-math is just now emerging, and maybe beginning math, although this concept is hardest. I'm not very worried about math, because I think it will come as he learns about math in the everyday world, for example, counting out the silverware for the table, patterns in setting the table, adding up the shopping prices.

*Anonymous '98*

I have ideas that have helped us with communication between home and school. They are: (excerpts from a letter sent to teaching staff)

- *Quantity of communication:* We have a notebook that stays in our children's backpacks for the purpose of writing notes back and forth from home to school. I cannot begin to tell you how much we appreciate this. The notes are not long, no need to be. They give us an insight into what progress is being made and any problems during the day. If daily note writing is not possible, consider writing notes no less than once per week.
- *Quality communication:* Information sharing between the school and parents about the student's disorder and their educational needs is of great importance. From our side of this communication we have shared information with teachers that will help them better understand our children's disorder. All of our children's teachers knew very little, and in some cases knew nothing, about Fragile X Syndrome. We try to carefully choose what items we send to our teachers, knowing how busy they are.
- *Follow the Golden Rule:* Speak to us as you would like us to speak to you if the tables were turned. Mentally prepare yourself by asking "How can I best phrase what I have to say to them?" We have attended several IEPs over the years. These meetings are stressful for us, and I know are stressful for educators as well. We have left some IEPs in tears, while others we have left smiling and happy. What is the difference? It boils down to not WHAT was said but HOW it was said. Let me give you an example: A goal on Chris' IEP may be Chris will identify all colors with a 100% accuracy on three consecutive trials. We will be hurt if you tell us "Chris cannot consistently identify gray. He cannot consistently identify red and he cannot consistently identify blue. We are going to continue this goal into next year's IEP." The term 'cannot' is a negative term that cuts right to the heart. It just reminds us that Chris cannot do many things. We can feel much better about Chris' accomplishments if you were to tell us "Chris does well in identifying colors. His favorite color is green. He can consistently identify all of the colors except gray, red and blue. We are going to continue with this goal into next year's IEP." Both of these examples give us the same information, but the last one softens the blow and helps us to appreciate what Chris can do. This type of communication means all the difference to those of us who are already emotional about our special children.
- *Ask and you shall receive:* I know that we would do anything to help in the education process of our children. I know many other parents of special needs children who would do the same. At some point in your career I'm sure you have said "I sure could use some help with..." or "If only a parent would contact the district about... we could get the equipment we need." We cannot help you unless we know *how* we can help. All you need to do is ask. I realize that not all parents can or will respond to your request, but I bet the majority of us will."

James '98

One of the things we did when our sons transitioned from one school to another was to go to the school and take pictures of things there. We took pictures of the classroom, the teachers, the principal, lunchroom, even the bathrooms. We put them in a scrapbook with titles and read it and talked about it often. It seemed to help our sons feel more comfortable about the move. We would also go the school before school began and walk around the building several times. We'd meet the teachers and get acquainted with the rest of the staff. Finding out about how the teacher schedules the day and sharing this with your son may help also.

Another idea might be to have a small item that your son can keep in his pocket and reach for in times of stress. He doesn't even need to bring it out, but just have it there to touch and focus on. We've used a small piece of *theraputty* for our kids. Others have given their child a ring or smooth stone they can hold when they feel overwhelmed. It sounds crazy, but it can help to have something to 'center' on. The classroom teacher would need to know ahead of time about this.

Anything you can do to make the transition less threatening is terrific. This is also true for the classroom teacher. Being open with the staff and sharing as much as you can about Fragile X and your son's needs are extremely important. I believe in 'most' situations education (of others) removes a lot of fear and makes people more willing to help. My children are all young adults and transitions are still difficult issues for them.

Jeannie '98

**O**ur concern over the functionality of John's education really began three years ago, when it dawned on me that if he couldn't read or write yet, it wasn't likely to happen. I wish we had done the following sooner, and gotten more of a handle on what we, who know him best, felt would benefit him most:

Make a written statement of what is important in your family as goals for your child to achieve. Each of us raises our kids with differing priorities: putting these priorities down on paper gives us a tool to examine how to achieve them. What is appropriate at an elementary age for self-care? What is appropriate at a later age for making change? Asking for help in a restaurant? What is important for you to see your son or daughter capable of doing?

Take a look at past IEPs, and figure out (I usually choose three main things-non-negotiable) what you need to see happen this year. Do this at home, and then try to blend those goals into the context and language of current classes and goals. Stretch the definitions of what is traditional class content. For example, when telling time is the math lesson, buy a \$9.00 watch that TELLS the time when you push a little button. Telling time can be literally that. Our kids do not have to read a clock if they learn other ways to gain information. Have the teacher reinforce the actual time on a clock face against a digital clock (auto kind, that sticks) on a notebook. I also wanted John's math practices to come from the grocery circulars. He doesn't have to read to recognize fruits and meats and other pictures, conveniently located next to their prices. A calculator is an absolute to me. (Not that John uses his).The concept of what to do with the numbers is more important than memorizing them

Social Studies? What better place to incorporate some self-advocacy skills, at any age level! Civics, geography, all can be *ssstreeetched* to include some of your particular concerns. ALL our kids should know how to write their name and some key numbers. Social Security numbers. John struggled for ten years with his address and phone number. Does he get another ten to learn a new one if we move? No, but his Social Security number will always get him home throughout his life or living situations. *Note: With fraud related to identity theft please carefully consider how SSNs are used – '05.*

I think the critical issue for most of us will be this: identifying the differences between what our kids need to learn to do or know to live well, and to recognize what strategies are available to enable them to live well. Can't count? You can still get bus fare from a pocket by having two 3x5 cards stapled together, with holes cut in one for the change to fit against. Why not a key ring for cards with different amounts? One for soda machines, one for change to use the phone, etc. It can fit neatly into a wallet, and doesn't look awkward.

John does not do a lot of these things... Another benefit of having written hopes and expectations is having something to measure progress against. We have had to realize that some of what was important to us isn't to him, and that he cannot always do those things. So we adjust, school has to rewrite the IEP. It is his life, not ours. We have found a measure of success, one day at a time.

*Tonii '98*

When you say 'if he hasn't learned to read or do math yet, it isn't likely to happen' don't be so sure. One thing I've learned is to not put limits on when learning will occur. Our oldest son will be 22 in March. As a small child we read to him constantly and worked with him on his reading skills. He made reasonable progress, but nothing astounding. He has only recently started enjoying getting books from the library to read independently. He is working his way through an enlarged print version of an Agatha Christie murder mystery right now. He struggles with some of the words and generally reads aloud, but has shown a tremendous amount of growth. I never thought he would reach this point and it's exciting that he has developed a skill he can enjoy for life. Both of our boys have had severe delays in math (common in Fragile X). But this year (at 19) Sean has flourished. He is doing 2 and 3 column addition, subtraction and multiplication. He does most of his work on his own, but when things get too difficult he has learned to use a calculator effectively. I guess what I'm trying to say is that it's important to develop the functional areas, but at the same time don't close the doors on the possibility of learning occurring much later than you might have thought.

*Jeannie '98*

## **Explaining Your Child to Others**

This year my husband brought a basketball, a football and a soccer ball to school. He put each of them on out on the desk and asked "Which ball is best?" The children, fourth graders, eventually concluded that no ball was "the best." Each ball is good at different things, each ball is unique, but each ball was still a ball even though they were different. It was a great illustration for the kids and they understood it.

*Shaylan Keirstead, Florida '05*

### **Circle of Friends Activity:**

When trying to highlight the importance of social connections for people with disabilities, I often will have participants in the workshop do this activity:

1. Draw four circles on a page, starting with circle 1, a small circle in the middle of the page, drawing circle 2 around that, circle 3 around that and the biggest circle, number 4, being the outside circle (so it looks somewhat like a bulls-eye).
2. Circle 1, direct everyone to write the names (or initials) of the people who are closest to him or her in their lives.
3. Circle 2, write the names of their good friends.
4. Circle 3, write the names people who are acquaintances, people they might go out for a cup of coffee with, have lunch with once in a while.



5. Circle 4 should consist of only those people you pay to be in your life, such as a doctor, manicurist, etc.

Once everyone is done, I ask them which circle has the most people in it. Most will say, 1, 2 and/or 3. Then I show them a circle I did for my son when he was 7 and in a private, segregated school. Most of the people in his circle were those on the outside. When asked how they would feel if that was what their life looked like, most would be very sad. I explained that for many people with disabilities, that is a very common occurrence. I then show them his circle five years later, after he was included in the public schools and there is a significant change; he has more people on the inner circles. The importance of this is to highlight that we often take friendship for granted in our lives; however, when people with disabilities are segregated their lives will often consist of lots of caretakers and very few real friendships.

*Orah Raia, New Jersey '05*

## **We Are All Different**

The Fragile X Listserv had a very sad, yet common question posted one day. How do you explain to another child who asks why your child is different? My own daughter has asked me the very same question about her brother. This is how I have defined different.

We are all different. Some of us have blue eyes, some of us have brown. Some of us wear glasses, some of us don't. Some of us like math, some of us don't. Some of us like broccoli, some of us don't. Sometimes our parts didn't get put together just right, some people are deaf and can't hear; some people are blind and can't see; some people may have legs and can't walk. Just like things we can physically see there are many things we can't. Our brain tells us how to see, feel, hear, touch, and smell. Important switches in the brain that should be turned on are turned off and some that should be turned off are being overloaded.

More than anything in the world, a blind person may wish to see the sunrise, a deaf person may wish to hear the birds and a crippled person may wish to walk on the beach feeling the sand under their feet. It's important to remember that just because a blind person doesn't see the sunrise it doesn't mean they can't feel or enjoy it. Being blind, deaf, crippled, or having Fragile X Syndrome, Down Syndrome, or Autism is not something we choose, it's just something that happens. When it happens, it makes some people very special because they have many challenges they may have to face just to do some of the ordinary things you and I can do. Austin may see things much differently than you, lights and colors may be much brighter, sounds may be much louder and not as clear. Sometimes their brains are overloaded with everything they hear, see and smell. Little noises you may not hear, like the fridge running or the fan spinning, might be running like a train through their heads.

First and foremost, Austin is a kid just like you. He wants to play, he wants to have friends, he wants to be loved and he wants to be recognized for those things he does well. Austin has Fragile X Syndrome and Autism, which makes some things very difficult for him. There are many things he can't do that you may have been doing for a long time. It doesn't mean he wouldn't like to do them. It just means that some of those switches that are turned on for you are turned off for Austin. Sometimes Austin is very frightened by things that are new; a new place, a new person or a new experience. He has a hard time telling us what's bothering him or what's scaring him. When this happens, his brain might be overloaded and his way to tell us or let it out is to just scream. He can't take any more but needs someone to know that something is bothering him. He doesn't mean to scare you but he is very, very scared and instead of words coming out to tell us why, it comes out in a scream.

All I ask from you is to think about what it would be like if you were like Austin and how would you want people to treat you.

Sadly, I know my message has gotten through when one afternoon I found Natalie sitting on the curb crying. When I asked her why, she told me it was because the other kids wouldn't let Austin play. My heart did break in two but I told her that was why we are here, to help people understand, to teach them compassion and that together we would do it one kid or grownup at a time.

*Sally Nantais, Wyandotte, Michigan '05*

***F is for ...***



## **Family Issues/Finding Out**

**H**i, I'm new to the list, but not new to Fragile X. My 14-year-old son was diagnosed when he was 6. He's mildly to moderately affected. I have a 17-year-old son who we thought was 'normal' but we found out this year that he is a carrier and has some mild characteristics. When Simon was diagnosed, I had never heard of Fragile X. I'm one of three girls; my mother was an only child; her mother was one of 3 girls. One of my grandmother's sisters was an unusual woman. I only met her once, before Simon was born. It was only in retrospect that I realize she had Fragile X. My mother still has a hard time with the family history. She doesn't want her family to be 'blamed'. My older sister has 2 sons, neither of whom has been tested. She doesn't want to pay for the expensive DNA testing. I suspect her younger son, who has some learning disabilities, is affected. I 'diagnose' people in grocery stores, on the street, and everywhere else.

*Nancy '98*

**W**e knew our daughter (now 27) had some sort of learning disability, but couldn't find anyone in the 70's and 80's to take the time to help us figure it out. We are lucky to have had someone with Eric that led us to the FX testing, and we are SO glad we did. There are others on my side of the family (I am a carrier) who display FX signs ranging from mild to an uncle who is mentally retarded. But, my family doesn't want to acknowledge Fragile X -- I find that so sad. I know now FINALLY that I cannot change them. So, I will concentrate on my own children and my future grandchildren. Their lives will be richer for having the knowledge we have found concerning FX, especially on this life-saving listserv!

*Margie '98*

A little over four years ago, I was walking across a prep school campus with my husband David and my stepson Christopher. I recall thinking that perhaps it would be special for Brent, our one-year-old son, to follow Chris' path in this school, rather than the one I had already assumed he would attend. But then the pit came to my stomach, because although at the time no one believed me, I thought there was something very wrong with Brent. A year later, Children's Hospital confirmed my suspicions. He was delayed and needed immediate intervention. I was sure I could cope -- we would get him physical, occupational and speech therapy and fix the problems; get him caught up before kindergarten. And then, several months and many tests later, the words of the neurologist..."I'm sorry Mrs. Yoshida...Brent had Fragile X Syndrome inherited from you, and your daughter Keiko is also at risk." I knew a little about Fragile X because Brent's godmother had sent me an article on it and she had scribbled across the top.... "*Kim, just thank God Brent doesn't have this syndrome.*" I knew my suspicions were right that he was probably mentally retarded. I knew males with Fragile X sometimes had severe behavior issues, and as a result, sometimes ended up in institutions. I knew there was no cure; Brent could not be fixed. Driving home from the doctor's that afternoon, my head was spinning as I kept thinking...this could not really be happening to me. Yes, I knew it happened, but to others, not to me and not to the family we had created.

I didn't crumble, I crashed. As the reality of Brent's diagnosis hit me, a sense of utter hopelessness enveloped my life and I truly became stuck. "Never" and "couldn't" became common vocabulary as I spent an inordinate amount of energy focusing on the many things I assumed Brent and our family unit could not and would not ever do or be. I had already planned my life, and nowhere had this happening even flashed before me for consideration. I often asked "God, why me?" and "why have you given me this child?" And, I didn't hear an answer; I didn't know if there was an answer.

Books and counseling assured me that it was normal and healthy to feel anger, guilt, grief, and frustration. And I did. Guilt - he had inherited it from me. Anger and frustration - with Brent, when I couldn't understand him, with my husband and his ability to accept the situation and not just dwell on the negatives, with friends and family who tried, but couldn't really understand, and with myself, because for the first time in my life, I couldn't just pick up and go forward.

I don't know exactly at what point the scale of my emotions became more balanced or what triggered it. It may have been watching Brent's sister Keiko playing with him, encouraging him to keep trying to draw a simple line, and sharing with him her delight when he did -- not bothered that he was four and should have accomplished this long before. It may have been one day at a drug store when, to my own surprise, I stepped up the counter to assist two people with language and mental disabilities explain to the pharmacist their needs ...instead of assuming my usual reaction: impatiently waiting in line, perturbed at being delayed. It may have been the utter joy I experienced when Brent, nearly five years old, finally mastered the motor planning necessary to plant his sloppy, but first, real kiss on my cheek.

Slowly, very slowly, I began to see Brent as he was, rather than who he was not. I began to see our family use the sensitivities we had developed, rather than dwell on what we could not do. I began to see that the plans I held as to what would make my child happy were, in fact, what would make me happy, not Brent; that he would find his own niche and level of accomplishment. I began to use the words "maybe" and "we hope" rather than "never." And, I began to see that as a family, we were not, as I had thought, deprived but enriched, because we were forced to go beyond our small, seemingly safe, environment.

This is not a "metamorphosis" - which is defined as a complete transformation - it is a "transforming," a continuing process. I can't say I'm glad that my son is retarded - the pain and

sense of loss that David and I hold is real and will never go away. It will always be with us, and in a perhaps, conflicting, positive way, remind us of the expansion Brent has brought into our lives.

I no longer need to ask “Why?” because now I have a sense of why ...why me, why us.

Kim '98

A diagnosis of FX is a hard thing to cope with at any age.... We faced it at 32 months and found it very difficult because our son wasn't really able to do anything by that age. The emphasis in discussions with doctors and therapists was always on what he couldn't do. I found myself lying in bed at night concentrating on all the things he might do and how he might do them. No football, no band, no prom date, no astronaut, no marriage, no grandchildren.

To cut a long story short, our son has demonstrated much more progress in the 3 years since his diagnosis than he ever did in his early years. I put this apparent progress down to several things. Firstly, he is now able to express himself a bit and has revealed to us that there was more going on inside his 32 month old brain than anyone ever thought (Mozart might have seemed like a pretty ordinary kid if he never had a piano to play on :-)).

Secondly, kids with FX don't seem to be good at the abstract thought required to pull bits of info together. They need to see the whole thing working together first. So they can be silently soaking up bits of information (like all kids do) but they might not be able to demonstrate it until they have seen the whole thing working. I think that this is one reason why their pattern of development sometimes seems very stop/start (quite a few posts on this list have referred to a “lull” just before their kids take a “leap”). I guess the most likely time for little kids to be picked up and diagnosed would be in a lull when they appear to be developing very slowly.

Thirdly, we have had professional help and support since diagnosis. It is likely that over the next few years your son will make good progress and will learn to do lots of things. As he does, there will be more positive things for your whole family to focus on and be amazed by. You know your life will not be like everyone else's, but at the moment you probably have no vision of what it will be like, so it is natural to be despondent. When we first found out about our son I was desperate to have someone tell me exactly how his life was going to be (What are we in for?) so that I could prepare to handle it. No one was game to say because of the variability among our kids, among ourselves, among our circumstances, etc. Our family is only a few years further along the track but I thought it might be helpful to start to try painting a bit of a positive picture for you to focus on. This might be a peg to rest your hope on. I'll leave out the negative side. No point looking forward to that. Our kids vary a lot and this is not meant to be a “mine is better than yours” exercise. Some of our kids will not be able to do these things and some will take longer than others and other kids will go much further and faster.

Our son is happy when he is healthy; can talk by adapting/combining rote learned phrases (eg. *May I have some, go to the park, yes please Guy*); rides a horse (at a riding for the disabled group); operates the CD player by himself; makes jokes that genuinely make you laugh (even if neither of you understand them); bakes cakes (and makes a huge mess); is very good at jumping on a trampoline; loves his family. It is almost certain that your son will play football, play in a band, dance at a Prom and fly like an astronaut. It just might be football in the park with Dad, banging on tin can drums in the backyard, dancing by himself, and flying through the air as he bounces on a trampoline. I think the trick is to have very high expectations of your son but be able to celebrate his achievements at whatever level they come. My humble opinion...

Guy '98

# Father's Messages

## **FX from a father's perspective**

When I knew my child was going to be a boy, I felt as macho as any man could. A son means that my name will be carried on. A son means a legacy. It means I can teach him all the good lessons I learned and how to avoid all the mistakes I made. To me, as with many fathers, a son means I can say, "You will go further than me in life- you will be able to do all the things I had only dreamed of! You will play ball for the pros- be a fighter pilot or race motorcycles." To a father, a son is more than just a child. To a father, a son is the culmination of a lifetime of hopes, wishes and dreams that will finally be realized through the life of his child.

Of course this is absolutely irrational, but it's the way it is. I knew when my son was young that there was something not quite right. He couldn't catch a football that well. He was uncoordinated and just a little "different". As he got older, his disability became more obvious. For example, we signed him up for soccer. He was the worst one on the team. The ball would be kicked to him and he would just watch it. My wife thought it was cute. My dream of professional sports died that day.

The pain of dying dreams is not easily soothed nor does it go away all at once. When my son was labeled, "learning disabled", the fighter pilot in me passed away. Every day, in some way or another, I see my son's disability and when I do I see the remnants of dead dreams. Culturally, most women are raised valuing relationships. They play house and other games where competition is not the central theme. To boys on the other hand, everything is a competition of win or lose. Thus, it is easier for most mothers to have the unconditional love that overlooks their son's disability. For many fathers, not only are they coping with the pain of lost dreams, but the embarrassment of knowing their son (who represents themselves) will not be the best. Embarrassment is the right word. Watching my boy be the worst on the soccer team, I was embarrassed to be his dad. Isn't that horrible?! And then I was mad at myself for being embarrassed. This is some of what fathers cope with. Again, I understand it is irrational, but it's the way it is.

To make matters worse, many men do not have the emotional vocabulary to articulate the storm they are in: embarrassment, pain, hopelessness and despair. For men, all these emotions come across as anger. Reading FX books, going to IEPs, reading the listserv and going to Conferences all serve to reinforce the fact that my dreams for my son are dead. Although cognitively I know this is not true, it's what I feel emotionally and it's this pain that causes many men to react to their family in a "fight or flight" mode. None of this discourse is to give liberty to or excuse bad behavior, it is just to try to shed some light on what went on (and still goes on) in an FXS dad.

*Pete Keirstead, Florida, father of two boys with FX '05*

## **Internal cry of a father**

I haven't written in a while since we last received the news back in February that my son Elijah has FX. It took me a while to come to terms with this information as I tried to deal with so many emotions that engulfed my being. I can't say that I have totally dealt with every emotion, but I can say that with every day that elapsed I have hope and I see a difference and a change. I am writing this because I believe it will help me to deal with remaining and current emotions that I

haven't dealt with and I think by writing it down it will strengthen my resolve about my sons condition.

Let me begin by saying that when I see my son Elijah I see a wonderful, funny, enthusiastic, compassionate, bright child--and hope. However, there are days when he is having horrible meltdowns, when he is screaming to high heaven and hitting himself, is resistant to touch, can't be redirected, and decides to urinate on himself that I begin to wonder what type of future he is going to have. I say this because last week when he was on spring break it was the most trying week we had with Elijah.

It was then that I realized that I hadn't dealt with what I call my internal cries.

Sometimes I cry internally when I am on the train and I see a boy around the age of Elijah who is four and he and his father are engaging in simple conversation and having fun talking about anything. I often wonder are we going to have days like this?

I cry internally when I am having a conversation with a parent and they begin by talking about all the great things their kids are accomplishing and the cry comes not because I think their kid is better than mine, but I cry because I see normality. I begin to feel guilty because my soul cries out for it and I wonder am I not grateful for the wonderful son I have? But I quickly come to my senses and ask my self what is actually normal in society today? However, the cry continues when I tell colleagues or friends what Elijah has and I see the look of death on their face as if my son has just died a horrible death. But I soon realize that the look is not of death, but of deep concern and compassion to help in consoling me in the struggle ahead, and that I feel this way because of insecurity on my part.

The cry deepens as I often look at my little girl Sara who is 17 months and is advancing well and have said to myself, "God, why can't Elijah be like her?" Soon my head limps into my hands, and falls into my lap as I realize I have committed the greatest sin comparing siblings, knowing that I marvel at the difference and cherish the complexity of the relationship between Elijah and his sister and I love that my son is greatly different from his sister.

Although there have been many days of internal cries, my days begin to turn to joy when I see my son Elijah smile at me and nudge me to play wheel barrow, try to comb my hair, and repeat the very same directives toward us in his own little funny way that we have given him or when he asks for his favorite food popcorn.

I have hope when I rise from my daily prayers and have communed with the great father in heaven. In those prayers I find hope and dreams beyond what I can imagine. I really find great joy when his teachers from school write home and say that Elijah had a good day today and that he wiped everyone's nose which shows his great compassion toward his classmates, or when his teacher calls home and tells us that Elijah has just said three to four words.

This is when I soon begin to realize that I must abandon some of my past dreams and begin to create new ones. Knowing that all is not lost and we can't write our life script, but we sure can be involved in the movie.

*Tamaro Hudson, Maryland '05*

# Floortime Therapy

We officially did floortime therapy with Andrew from July 2003 to August 2004, although we still often play with him using the theories of floortime. In southeastern Michigan, Dr. Richard Solomon runs the P.L.A.Y. Project. P.L.A.Y. = Play and Language for Autistic Youngsters. P.L.A.Y. therapy is based on Stanley Greenspan's Developmental, Individualized and Relationship-oriented (DIR) model, or more informally floortime therapy, since a basic building block of the therapy is spending time playing down on the floor with your child. It's about you and your child getting engaged with each other and building a better relationship starting from wherever your child is. A simple example: if your child likes to spin wheels on a car, use that activity to build a relationship by taking turns spinning the wheels.

The lessons learned from floortime therapy can help all parents build stronger relationships with their children. A great book to read that discusses floortime therapy is "The Child with Special Needs" by Stanley Greenspan, M.D. and Serena Wieder. For more information, visit [www.playproject.org](http://www.playproject.org).

*Mary Beth Langan, Grosse Pointe, Michigan '05*

We started the P.L.A.Y. Project in the winter of 2005 and did it for about 6 months. Once a month the therapist came to our house and spent three hours with our family. During that time she videotaped us and gave us some pointers on what to do with our children (twin boys with FX). She taped about an hour of us playing. Dr Solomon reviewed the tape and sent it back to us with an audiotape where he told us about the progress and things that we should concentrate more on. We found it very helpful because sometimes we don't know how to approach them. During those six months we noticed huge improvements in the boys' eye contact and social skills. I know FX children learn better in a stricter environment, but we try to add P.L.A.Y. to make it more fun for them. We continue to implement those techniques at home and it works every time. You can check the web site [www.playproject.org](http://www.playproject.org) for the CD-ROM information.

*Elina Gelfand, West Bloomfield, Michigan '05*

## **Additional websites for Floortime Therapy:**

[www.floortime.org](http://www.floortime.org) - Floortime Foundation. To redefine the potential of children with developmental and communication challenges by making DIR/Floortime broadly available.

[www.icdl.com](http://www.icdl.com) - The Interdisciplinary Council on Developmental and Learning Disorders. Its aim is to improve the identification, prevention and treatment of developmental and learning disorders.

# Food Issues

I have the same problem [with over-eating]! I let him 'graze' all day and try to cut down on the portions. His OT recommended looking into stomach problems but the doctor blew it off, told me to try and give him Zantac during the day. He would find the pill and spit it out or throw it up...We have switched to all the 'fat free' foods that we can... He is still a large child...8 years, about 4'9" and weighs about 120 lbs. I have also delayed the times between eating. I would love any advice in this area as well... I do know that some may be sensory related as well as being compulsive behavior. But sometimes it's just not worth the 'tantrum' if he doesn't get the food.

*Suzzane '98*

We also have the issues with the over stuffing the mouth so I can't give any input there. But I can tell you what we have done about leaving the table while still eating his dinner. Keadon used to leave the table during dinner and then come back and take a bite and repeat this over and over no matter how many times I said he had to stay at the table. Well, what we do now is if he leaves the table we put his plate in the sink and that's it--no more dinner. We did this for every meal. He cried and tantrumed but we didn't give in. After about one week of this he learned the new policy and now he never gets up until he is completely done because he knows I will take his plate and he won't get anymore. This might sound a little harsh to some, but I knew if I followed through with this he would learn this is how it is, and he did.

*Kareen '98*

I'm afraid that Todd is (eating us out of house and home). He can drink a gallon of milk in less than 24 hours, eat a pound of cheese in an afternoon, empty a jar of jam in a couple of hours, or eat 3 cartons of yogurt in just a few minutes. He's the human vacuum cleaner who quits eating when there's nothing left that he likes. I should only keep cans of garbanzo beans on hand! Thank goodness he is still growing.

*Carole '98*

## FXTAS

My husband Vince's falling and walking difficulties began sporadically in 1999, gradually worsening until the end of 2003 when he could no longer walk unattended for fear of falling. In the past year or so, he has not worsened, and on some days, he walks several steps at a time pretty well; but I always stay with him because he can go off balance in an instant. However, the progression of FXTAS is probably different for everyone.

With Vince, severe walking difficulties occur because of lack of balance and coordination, not because his legs are weak. His legs work, but his brain cannot communicate with them. I have found that I can get him to walk if I tell him what to do, step by step, using a gait belt and/or walker for support.

- Gait belt (or pants belt): I hold the back of the belt with one hand and put my other hand wherever needed to keep him from falling. On better days, just holding the belt is enough. Vince will often lurch forward without moving his feet. I hold the back of the belt with



one hand and put my other hand in front of his shoulder to keep him from lurching forward. I say “pick up your feet” repeatedly. Or just saying “walk, walk, walk...” often works. I stop him when he starts to lose balance or go forward too fast. I say “put your feet down flat and balance your weight on both feet.” Sometimes when he’s walking, I gently rock him from side to side to distribute his weight evenly; this has become instinctive for me. If he’s leaning to one side, I put my hand on that shoulder to straighten him up while walking.

- I got the gait belt from a caregiver who watched Vince while I was still working. You can get one at a medical supply store or from AliMed at [www.alimed.com](http://www.alimed.com). A gait belt is a strong fabric belt and a great way to hold onto someone.
- Walker: I hold onto the walker AND my husband. I stand behind Vince and to the side, with one hand on the part of the walker closest to us and the other hand on his arm or the back of his pants (or the gait belt if he’s wearing one). I tell him to pick up his feet and walk. He does a few steps at a time. He holds the walker, but my hand needs to be on it also so he doesn’t push it away too fast, which can cause him to fall. His mind gets fixated on “pushing” instead of “walking”.
- I try to get him in correct posture before walking: buttocks need to be tucked in, legs straightened as much as possible, shoulders back, head up.
- If his knees start to bend and give out, I say “straighten your legs” which usually works. If he gets stuck, can’t move, and won’t respond to verbal prompts, I sit him down to rest (which clears his brain) and have him pick up his legs while seated so he remembers that his feet CAN come off the floor. He can then usually get up and continue walking. We’re never far from something he can sit down on if need be, and his walker also has a seat.
- Sleep helps clear Vince’s brain. Movement is very difficult for him when he’s tired. Heavy meals tend to cloud his brain. My bland cooking works much better than restaurant meals!
- When we go out of the house, we use a transport chair. It’s too dangerous for Vince to try to walk outside. A transport chair is a lightweight wheelchair (under 30 lbs) that folds up easily. It has small wheels, so Vince can’t wheel himself around in it, but it works well for going from the house to the car and then wherever we need to go. He stays in the chair when we go to the doctor or to a restaurant. We rent it from a medical supply company; it’s covered by Medicare and Blue Cross.
- Simple exercises for leg muscles and simple workouts with weights for arm muscles have made Vince a little stronger. His legs don’t give out as much as they did before, and if he falls, he’s now strong enough for me to help him up without calling the rescue squad!
- He often needs coaching to transfer into chairs or bed, in/out of shower, etc. I give step-by-step directions as needed for moving his feet and placing his hands (holding onto whatever is near to help hold him up).
- It’s vital to keep him moving to prevent muscle atrophy, cardiovascular problems, etc. I watch his diet and give him lots of vitamins and supplements.

Vince’s condition overall has not worsened in the past year since he was diagnosed with FXTAS; we just have better days or worse days.

*Terri Corcoran, Falls Church, Virginia ‘05*

My father is currently 63, and he has had the symptoms for easily more than 10 years. He originally thought that he had nerve damage from a skiing fall.

My boys were diagnosed with FX three years ago at 10 and 4. My father had been having difficulties for a few years, but had been diagnosed with CMT, a disorder that I had found online before finding Fragile X. He brought the information to the doctors, and that was how he was diagnosed. After we received our diagnosis for the boys, I continued to research, and FXTAS came up. I spoke to Randi Hagerman at the conference in Washington, and introduced him to her. As a result of our conversation with Randi, we all went out to California in September where we all participated in their study. My father has so many issues that they thought that he might have both CMT and FXTAS. We recently found out that he does not have CMT.

My father has always been fanatical about exercising, and that has not changed. He refuses to give in to the FXTAS. He pushes himself physically, and I believe that is what has kept him mobile. He can no longer walk or run for exercise, but he does ride his bike or go to the gym every day. He continues to fish and go boating. We have a remote cabin that we go to every summer, which we wonder how much longer he will be able to use. We have to get there by boat and there is no electricity. There is a lot of physical labor involved in the maintenance and daily operations which he still pushes himself to do. Our cabin has always been his paradise, and it will be devastating when he can no longer go there.

He has neuropathy in his extremities, with extreme pain or no feeling in his legs. The muscles in his legs have severely atrophied, less severely in his arms. He has poor balance, and is falling more and more, but I think he hides as much of that as he can from us. He has a very bad tremor, and can hardly write anymore.

We feel that he has lost ground cognitively, although he has always been very forgetful and absentminded. We see some personality changes, including sometimes making inappropriate comments at inappropriate times. He can be quite moody and sarcastic, and sometimes hurtful. My father really is a great guy, but as with any of us, he can be difficult to live with.

*Nancy, Upstate New York '05*

*G is for ...*



# Genetics and Genetic Testing

Males have one X chromosome from their mother and one Y chromosome from their father. The Y chromosome is what makes a male a male. The X and Y chromosomes are called the 'sex chromosomes' because they determine the sex of the baby. Sperm are cells used in reproduction to produce offspring. Sperm only carry one X chromosome OR one Y chromosome. They carry only one sex chromosome because eventually after fertilization this sex chromosome pairs with the sex chromosome (one of two X chromosomes) from the mother to form a pair of sex chromosomes for the offspring.

If a male carries the Fragile X mutation (mutation = change), then it will be on his X chromosome. The Y chromosome will not carry this gene mutation. Therefore, if sperm bearing the Y chromosome fertilizes the egg to form the new embryo, this male would have a son who would not be at risk for the Fragile X gene mutation. However, if sperm bearing the X chromosome (with the gene mutation) fertilizes the egg to form the new embryo, this female would inherit the Fragile X gene mutation.

Now, this is the really important point... The sperm only carry the premutation on that X chromosome from the male. It does not matter whether or not the male parent has the premutation or the full mutation, his sperm will ONLY carry the premutation. Hence, ALL the daughters of a male parent who carries the Fragile X gene mutation will inherit the premutation only.

We do not know the why of this. Nor do we know when the full mutation in the sperm becomes a premutation (before or after fertilization?). People are really working on this as it is a puzzle.

*Louise W. Gane, M.S., Genetic Counselor '98*

What really is the difference between DNA testing of children and cytogenetic testing?

Karyotype - The general appearance or structure of a set of chromosomes within a nucleus. Karyotyping is inspecting the appearance of chromosomes under a microscope to look for defects. Under the right conditions the defect that causes Fragile X **\*\*MAY\*\*** appear on a karyotype as a kink or break near the tip of the X chromosome (thus the name Fragile X Syndrome)

Cytogenetic testing - A more generalized term for basically the same thing as karyotyping, but may also include looking for other changes in the cells that can be caused by inherited conditions.

DNA testing - This term is used to indicate that direct analysis of the DNA is done. The test looks at specific snippets of genetic code taken directly out of the chromosome. This is distinctly different from karyotyping or cytogenetic testing.

Southern Blot - This is part of DNA testing and is the resulting chartlike "blot" that shows how big the defect is on the snippets of genetic code that are being analyzed.

PCR test - this is also part of DNA testing and it stands for polymerase chain reaction. This is part of the test that can give the specific CGG repeat count (as long as it's not too big).

OK, since "karyotyping", "cytogenetic test" and "DNA test" could all be confused by a well meaning but Fragile X-ignorant MD, anyone requesting testing must be very specific when asking for the test. Ask for: **direct DNA analysis by Southern Blot along with PCR.**

Their jaw will hit the floor but they'll be sure to get the right thing. One additional thing: the type of tube used for drawing the blood is also important. They need to use the right tube or the preservatives pre-packaged inside the tube destroy the blood sample for DNA testing. This means the lab asks for the blood to be drawn again causing delay and aggravation.

*Paul '98*

I'm new at writing to this list. I've been watching for months and have had so many concerns that I just feel overwhelmed. I have a 2½ year old boy with Fragile X and I have a 7-month-old daughter who has not been tested. We found out about our son in December after a diagnosis of Fragile X for my nephew. By the way, this nephew is 10 years old and is a classic Fragile X-affected child. However, no specialist or physician ever seemed to figure it out. They called him an anomaly, thus I was never concerned. I'm still feeling bitter about this. Anyway, I want to know how everyone feels about testing their children who have not yet been tested. The geneticist originally told me to wait until I suspected, if ever, there was something wrong with my daughter. It's driving me absolutely crazy because no matter what my daughter does, I think the worst. I see no signs cognitively; she's very different than her brother as a baby. She has malleable ears, velvety skin, gastroesophageal reflux. Now these are all things that CAN be normal in any child. Some days I want to know, other days I don't. If I have her tested and find out she is affected, will it be worse than not knowing?

*Nancy '98*

*In response to the above ...*

While reading your letter I felt like I was listening to my own story. I am also new to this list, which I think is great in so many ways. My 2.5-year-old son was also diagnosed with Fragile X in December. At that time, my 11-month-old was 7 months old. I think I was even more reluctant to have him tested, because he was born with *Posterior Urethral Valve*, which caused reflux, with damage to his kidneys and bladder. We did decide to have him tested in January and it also came back positive. We were very surprised, because he seemed so different from our older son. It was very hard to learn the second child also had Fragile X, but I think we made the best decision. My 11 month old is now in speech therapy, and both receive occupational therapy from our Early Intervention program. I feel like they are getting a jump start on everything they need. They are doing great!

*Marilyn '98*

My son, age 4, was diagnosed with Fragile X when he was 15 months old. We did not bother to test his older sister for years, because she had always been ahead of the game in all areas: cognitive, motor skills, etc. Imagine our surprise/shock to find out that she, too, had the full mutation! After my initial dismay, I realized how God had blessed us. Fragile X or not, she is still in the gifted program at school, honor roll every semester, and is quite talented in art, piano and athletics. I guess what I'm trying to say is, if you do find that Allison carries the gene, don't despair. The range of expression of this disorder is huge. Best wishes to all of you!

*Theresa '98*

For my family the answer came in 1994 when we found out that my then 32 year old brother's problems were caused by something called Fragile X, something with a name and possible consequences for my sister and me. My sister and I had to know. I was tested and the results were positive (full Fragile X mutation). My sister tested negative. While feelings of relief came for my sister, my husband and I had a hard pill to swallow. Did I pass the gene on to our two children? My son, Kai was 4 years old at the time. He always functioned normally, even what you would consider above normal, but my 1 year old daughter's speech and other behavior pointed toward her being a little developmentally delayed. My daughter showed no physical signs of Fragile X. We were concerned for Leah since she showed these subtle signs. My husband and I both wanted our kids to be tested right away, the not knowing drove us nuts. We also heard you can carry Fragile X and not be affected (my own case). The results came in. My son was negative and my daughter positive. I had started reading some literature and Fragile X explained a lot of my daughter's actions even at her young age. I was also relieved to know that Kai did not carry the gene FOR SURE. I felt it gave me a start.

*Celeste '98*

### **Websites on genetics and genetic tests:**

<http://www.ygyh.org/> - **Dolan DNA Learning Center**, Cold Spring Harbor Laboratory. Your genes, your health, a multimedia guide to genetic disorders.

[www.geneclinics.org](http://www.geneclinics.org) - **GeneTests**. This is a publicly funded medical genetics information resource developed for physicians, other healthcare providers, and researchers, available at no cost. To review information on Fragile X Syndrome, FXTAS and POF select the "geneReviews" option and perform a search on "Fragile X".

[www.ncbi.nlm.nih.gov/entrez/dispomim.cgi?id=309550](http://www.ncbi.nlm.nih.gov/entrez/dispomim.cgi?id=309550) - **Online Mendelian Inheritance in Man (OMIM)**, John Hopkins University.

[http://ord.aspensys.com/asp/resources/gen\\_info.asp](http://ord.aspensys.com/asp/resources/gen_info.asp) - National Institutes of Health, Office of Rare Diseases, has an extensive list of genetic resources (genetic information, genetic research, genetic testing laboratories and clinics, and genetic counseling services) available on the internet.

## **Girls with Fragile X**

My daughter Jennifer is 23 and a Fragile X carrier with a normal IQ, but has had many problems connected with the syndrome, such as math problems and social/emotional problems. I would be glad to answer any direct questions and/or compare notes. I know how difficult it is to find other families who have Fragile X girls.

*Debbie '98*

*The following is taken from a presentation by Gail Harris-Schmidt, Ph.D., a Fragile X parent:*

### **Females with Fragile X Syndrome**

1. Females with full mutation Fragile X tend to have less severe impairments than males.
2. Those who inherit the Fragile X gene from their fathers inherit the premutation rather than the full mutation, which means that they do not usually have learning disabilities or mental

impairment. Girls who inherit the gene from their mothers can inherit either the full mutation or the premutation.

4. Retarded or borderline IQ is found in 35-50% of Fragile X full mutation females; many have delayed language acquisition and autistic-like features.
5. Learning disabilities (especially non-verbal learning disabilities) are common in normal IQ females who have the full mutation.
6. Performance IQ may be lower than verbal, with difficulties in block design, arithmetic, and digit span on Weschsler Scales.
7. Strengths may be found in rote verbal memory, verbal reasoning, semantic memory functions; weaknesses in short-term memory, quantitative skills, and visual motor tasks.
8. Females with specific learning disabilities often have disorders in mathematics; language and reading scores are much higher.
9. Social perceptual problems are common in full-mutation females with learning disabilities; interpersonal difficulties increase with age.
10. Shyness and social anxiety may be shown by eye gaze aversion, blushing, and withdrawal from social situations.
11. Attention deficit disorders may require medication; may be without hyperactivity and so go unnoticed at school.
12. Poor executive functioning results in inability to sum up intentions, form plans and execute.
13. Mood instability, anxiety, and/or depression affect some women with mild disabilities; medication and counseling may be indicated.

*Gail '98*

## Goodness

Deborah (Utah) asked that folks on the listserv submit stories about the good qualities we see in our children. Here are some good ones:

**W**e could all write a book, right? But, I'll keep it brief. We have learned patience and empathy, courage and advocacy, goal-setting and hope. The most endearing thing (one of several)--Amy, our 20-year-old Fragile X daughter gave me a necklace at Christmas several years ago that said "Special Mom" - bought by her own money she saved for a long time. I almost went crazy when I misplaced it a few months ago - I keep it in a very special place and do not wear it everyday anymore because I was wearing it out!

*Mary '98*

**I**'m so grateful for Eric's natural sense of 'goodness'...and the smile he has on his face 95% of the time. That totally amazes me! And, he does not EVER forget someone's name, even if he meets them only once. If they are driving a car and he sees them in it, he can even recall the color of the vehicle! What have we learned? Patience, tolerance, and the truest meaning of love I think. Unconditional, total love. This has been the biggest blessing of Fragile X being in our lives.

*Margie '98*

**K**yle loves everyone and has no judgments towards anyone. He doesn't notice if they're disabled or not, he will give them a hug. We were in the grocery store and another more severely mentally handicapped boy was sitting next to him, waiting for us parents to bag the groceries. Kyle scoots up next to him and says "Hi" and when it was time to go gave him a hug and a smile. It warmed my heart!

Gail '98

## Grief and Guilt

**I** remember my family doctor telling me that there would be times when I would revisit the pain, tears and depression that come with a special needs child. The pain and hurt tend to erupt from nowhere at different milestones in a child's life. I felt the most gut-wrenching pain when Josh realized he wasn't a regular boy during his high school years. Some parents feel the pain at birthdays, high school graduation or seeing other children the same age achieve goals they know their child will never attempt let alone achieve.

All parents have a dream for the children they bring into the world. Some of us lose the dream when we have to face the stark cold reality, that we have a handicapped child. Our life and the lives of those around us change forever.

*Chronic Sorrow, A Living Loss*, by Susan Roos provides information about the very natural grief we experience. Roos offers insight on the effects of the griever from a personal standpoint as well as professional. Roos explores and explains the many complicating factors that come with chronic sorrow.

Roos offers a historical overview of mental retardation. I caution the readers that Roos is graphic in her description of the treatment of those who are handicapped. After I dried my tears I thanked God for giving me Josh.

Those of us dealing with chronic sorrow often feel alone and isolated. We often feel ashamed for crying, for feeling angry, for feeling hopeless when others are saying "get over it--move on." We often feel guilty because we believe we did something wrong and are being punished by God.

Chronic sorrow is a very neglected topic. Any parent suffering with depression, hurt, anxiety, or struggling to cope should seek out help. Parents need to know it's okay to hurt, to grieve -- it's very normal. Unfortunately most doctors just don't understand this concept.

Eileen, Indiana '05

*Also suggested by Eileen:*

*The Grief Process*

Virginia P. Johnson, MD Carol Christianson, MS  
University of South Dakota, School of Medicine

URL: [www.vh.org/pediatric/provider/pediatrics/ClinicalGenetics/Lesson4/GriefProc.html](http://www.vh.org/pediatric/provider/pediatrics/ClinicalGenetics/Lesson4/GriefProc.html)

## *Grief can be a gift*

PUBLISHED: August 1, 2004, The News-Herald, A Heritage Newspaper

With the dog days of summer upon us, I was sitting at this silly computer trying to find the direction for a column. My mind wandered far from summer to a personal experience.

It's a unique experience that only a parent of a child with a disability can understand: the grief that one experiences with a diagnosis of a disability. These thoughts were brought on by the images of Nancy Reagan having to be coaxed from her husband's coffin, so weary and grief-stricken. It's a vision some of us won't quickly forget. It intensified with a column I read for the Grosse Pointe News by close friends Mary Beth Langan and Ted Coutilish on "D-Day," which had nothing to do with World War II. "D-Day" for them was "Diagnosis Day."

Having a child with a disability is not something one ordinarily chooses. The beginning, the diagnosis stage, is one of the most difficult.

We all have dreams for our children that may be shattered with a diagnosis of a disability, be it physical or developmental. With the loss of those dreams comes grief and all the emotions that go with it: denial, fear, guilt, blame, anger, sorrow and acceptance. Grief doesn't exclude things we can't see or touch.

Grief over our shattered dreams can be as intense as that for the death of a loved one.

Denial came first. "They can't be right, look at what he can do, at how bright he is?" Why do they measure our children on what they can't do and not by what they are capable of doing?

Fear of the unknown is always present. As a parent, you want to know as much as possible and have all the answers. Unfortunately, you quickly discover there are no answers for the important questions.

Will my child have friends? Will my child be happy? Will my child be able to live independently when he's older? What will happen to my child when I'm no longer able to care for him?

Guilt and blame quickly followed, which for me was an easy trap to fall into. After all, my son's disability, Fragile X syndrome, is genetic. Prior to his diagnosis (he was diagnosed when he was 4) I had no idea that I had a 50/50 chance of passing a developmental disability to my child.

Anger became apparent when I questioned why this happened to me. I wondered why I had to be the one to pass it on and not one of my sisters? It didn't seem fair, but is life ever fair?

At times, my anger has been misdirected. My son has a condition that he was born with and he will die with. At least that's how one insurance company explained a denial of service to a parent of a child with Fragile X syndrome. At this time, it's not curable and it's not terminal.

There's no Make A Wish or Rainbow Connection for my child or other children like him. Sometimes it seems as though no one cares about the quality of his life, or others like him.

Sorrow was never as intense as it was in the beginning. It's difficult to explain the depth of your sorrow: It was, and at times still is, immeasurable. Surprisingly, sorrow didn't occur immediately, but happened a little later when hearing the words "mentally retarded" used to describe my son's disability.

Grief may never completely end, but its intensity can subside. From time to time it will resurface and I've learned to welcome it, as it gives me the opportunity to be reborn.

In the movie, "Harry Potter and the Chamber of Secrets" there is a special bird called a phoenix. The phoenix has some unusual characteristics.



When he reaches the end of his life, he bursts into flames and is reborn from his ashes. His tears can heal the wounded and he has the ability to carry incredible loads.

There are times when I feel like the phoenix. I need to burn up so I can start over. From the ash comes additional strength and courage to go on and never give up.

My tears may not heal the wounded, but they do heal me. Lastly, it feels as though the weight on my shoulders is almost unbearable, but I've managed to carry it.

With the passage of time my grief has become a gift. Another door has opened in which my life has become more meaningful. One day, my husband asked me to imagine our lives without our son.

I could describe it with a single word: "shallow." I've found you can live a "shallow" life just as easily as you can drown in shallow water. It's only a matter of choice.

Strangely, many years ago "perfect" was something I strived for. Now, I strive for less than perfect.

All because of a child who may never be "perfect," who may never be "normal," but who will simply love me with all his heart, no matter what.

A lesson learned through the process of grief.

*Sally Nantais, Wyandotte, Michigan '05*

***H is for ...***



## **Hands in the Pants**

The one thing I noticed with Pat, 12, is that now that we make him keep something around his neck to chew on (instead of his shirt) he doesn't spend so much time with his hands in his pants. I don't know if it distracts him or just fills the need to be doing something with his hands. I definitely have him put his 'chewie', as we call it, on before we go to the store so he doesn't have his hands in his pants.

*Sue '98*

Our son, Blaze, has the same tendency. We haven't found anything to avoid it but have used the following method to get him to stop. We first started with the 'keep your hands out of your pants' and found that it only drew attention to him. Then we used the following: say 'hands up' and we would hold up our hands. At first he thought it was sort of a game like cops and robbers, but he eventually caught on that it was a way for us to remind him that certain things are done only in private. After he got used to that, we devised two methods to remind him to stop when he is doing it:

- if he looks at me, I can just slightly hold up my hand and he is reminded;
- if I don't have his attention, I can just quietly say 'hands up' and he is reminded and no one else knows what I mean unless they have noticed him.

Hope it works as well for you as for us.

*Jean '98*

I received a suggestion for "hands in the pants" at the 2004 International Fragile X Conference, in Washington, D.C. Instead of constantly repeating, "Take your hands out of your pants," say "Go wash your hands." It was hysterical to see the role-playing videos that Marcia Braden had reference this. When told to wash his hands, the "actor" looked puzzled and smelled his hands, just as so many of our guys would do. It was so accurate! Upon returning from the conference, I immediately tried this with my boys, and it worked like a charm! It took about a week, but the behavior almost stopped. Now I only have to say it occasionally.

*Nancy, Upstate New York '05*

## Handwriting

For those looking for ways to develop writing skills, here are a few ideas we use in our classroom:

**Gel packs:** Put about ½ c of hair gel into a quart zip freezer bag along with a couple of drops of food coloring. Zip shut after squeezing out as much air as possible.

Tape the opening closed with strapping tape, so that it won't accidentally come open. Knead gently to mix the color. On paper or index cards, using a wide black marker, make a set of alphabet letters about 5 inches high. Place the letter card under the gel pack. Smooth the gel pack flat. The letters show through. Now, guide your child to trace the letter or number with his finger using enough pressure to press the gel away from the letter. The letter will show through brightly! It is fun, has a neat 'feel' to it, and smells good, too! My students often beg to do the gel packs. Of course, the amount of supervision required would depend on the child.

**Reversed Letter Cues:** Lower case "d" can be drawn as a drum with a drumstick next to it. The auditory cue when writing is "drum—stick." Lower case "b" can be drawn as a bat with a ball. The auditory cue is "bat the ball." Of course, the left-right progression is necessary.

A poster we use is color-coded to show a capital B (in blue) with a lower case b (in green) over it. The idea is that the lower case "b" goes in the same direction as the capital "B" and, if we can

remember which way the “b” goes, the “d” goes “the other way.” Whatever seems to work for one student might not work for another.

An idea for the capital “M” and “W” is to draw the “M” as a mountain. Since we start at the bottom to climb a mountain, we start on the bottom line and go “up, down, up, down.” Draw the “W” as being filled with water dripping from the top, like rain, so we start on the top line and go “down, up, down, up.” Some children do better not having to stop and raise their pencils when making a letter, especially ones with diagonal lines.

*Anonymous ‘98*

Use a drafting table so the paper is on a slant (inexpensive at places like Office Depot) with very large paper. Using a crayon or marker, draw a letter and have your child go over and over it. We use the same drafting table and large paper to work on spelling words. I have my son write three words three times each, and then we go to another place in the room and ask him to spell the words. He learns them very quickly this way. We always use bright colored markers.

Put a whiteboard or chalkboard on your wall to teach your child to copy from it – a skill that wasn’t emphasized in the early years of a contained class, but is very important if your child later becomes included in a regular classroom.

*Pattie Devlin, Burlington, New Jersey ‘05*

We have had great success with finger tracing to help with handwriting. The concept is this: You create about 3" letters out of many different textures (glitter glue, beans glued to paper, thin foam, packing peanuts, and my all time favorite cardboard with one side of paper taken off). Take the child’s finger and trace over the letters of 3-4 of these "sensory" letters every day. The brain will motor plan much better with texture. After several days, end the lesson with a pencil and try to get the letters out of their "mental memory." Austen now writes his first and last name! Keep making the letters smaller and smaller until they are classroom paper size.

*Dian Bolling, Roanoke, Virginia ‘05*

### **General Educational (and in some cases Craft) Websites:**

[www.enchantedlearning.com/](http://www.enchantedlearning.com/) - Provides tracer pages that can be printed out for shapes, numbers and letters. You can also create your own books.

[www.kidzone.ws](http://www.kidzone.ws) - Provides tracer pages that can be customized (you can do your child's name, address, phone number, spelling words - anything you want).

### **Writing Websites:**

[www.thehappywriter.com](http://www.thehappywriter.com) - Ideas on specialized hand writing materials that are available.

[www.handwritingworksheets.com](http://www.handwritingworksheets.com)

### **Handwriting Without Tears:**

A program geared for children and others who need to learn or relearn basic writing skills.

[www.hwtears.com/](http://www.hwtears.com/)

[www.easyhandwriting.com](http://www.easyhandwriting.com)

# High Functioning

That's what my full-mutation Fragile X son Spencer is considered. He's also considered unusual by physicians and educators who say they *just can't believe* he has Fragile X. Many people do not understand that Fragile X is a spectrum disorder and have not met high functioning individuals with Fragile X.

I want others to know about him because I think there are many undiagnosed Fragile X people in the world. I fear there are kids punished for bad behavior and not trying hard enough in school – behaviors and deficits beyond their control.

Although Spencer seemed to be an early reader during preschool, by age 7 he wasn't reading at grade level. Our pediatrician referred us to a behavioral pediatrician who told us he was testing Spencer for something he felt sure he didn't have, because his IQ tested within the normal range. A medical school professor told him to always test for this when a child presented with learning disabilities. That something was Fragile X.

Upon diagnosis, we made an appointment with Dr. Randi Hagerman at the MIND Institute, who was among the first to ask us how he was diagnosed. At one point during that week of appointments, she paraded Spencer and me in front of a group Fragile X researchers from all over the world to see how normal Spencer looked and acted.

For years, Spencer saw a pediatric neurologist. At every appointment he told us what an unusual Fragile X patient Spencer was. During one visit he said “You know he's going to college, don't you?”

We don't face many of the challenges associated with Fragile X. He walked, talked and potty-trained within the normal range – although later than my first two non-FX children. Shopping, eating out, traveling, going to the movies, attending church, patronizing concerts --- we do all those things with few problems. Spencer has always played regular sports, including soccer, basketball, bowling and in-line hockey. For three years he danced with a ballet folklorico troupe. He sings in our church praise band, rings in our church handbell choir and is active in our church youth group. He has best friends, sleeps over at friends' houses, rides his bike independently all over our small town and pesters us for Play Station games, pets, and Dallas Cowboy memorabilia. I don't hesitate in leaving him home alone while running errands or going on lunch or dinner dates.

OK, that's the positive side of Spencer. Here's the hard side: Spencer struggles in school. A 14-year-old 8th grader, he reads at grade level 6.8 (6<sup>th</sup> grade, 8<sup>th</sup> month) and testing now indicates his IQ to be 68. He is always the weakest player on any team or group. He occasionally has horrible meltdowns. He is very distractible. Although older and younger children enjoy his company, most typical kids his age recognize he's different right away and do not seek out his company. He is scared of a circus or an amusement park and if he goes, he will often have a meltdown. He sometimes has bowel accidents and he is an occasional bed-wetter.

Like all Fragile X parents, we get tired of explaining what Fragile X is. We are so glad Spencer is high functioning, but it is frustrating explaining that he's not poorly behaved, overreacting or not trying hard enough – there really is something wrong with him even though he appears to be typical. Although he'll attend college, it will probably be a vocational school or a special program where he'll have many supports.

People are curious about these facts so I'll share them:

- Spencer's CGG repeat number is 297

- 8.1% of his FX genes are methylated (turned off)
- my CGG repeat numbers are: 69 and 28
- my mother's CGG repeat numbers are: 71 and 30

At our last appointment with Randi Hagerman she seemed surprised at his progress and congratulated us on doing such a good job with Spencer – she's wonderfully supportive of all FX parents. It's true we try very hard to do the right thing with Spencer, but we are just typical Fragile X parents doing everything we can to help our child. I believe his progress is due more to his genetic makeup than anything else.

*Mary Lee Shelton, Mesilla, New Mexico '05*

## Hitting

**H**itting has been a big part of our behavior issues with our son Morgan. He would hit when he was overwhelmed with a situation, he would hit when he didn't get his way, he would hit his brother for just being loud and startling. We wanted to replace that behavior with a more acceptable one. Morgan is 6 ½, and about a month ago we began to prompt him to clap his hands together instead of hitting. It is helping a lot. First, his hands are always with him (obviously) and second, clapping provides him with sensory feedback similar to hitting. If he does hit, we always take him to a time out. The clapping thing provides him with a chance to make "good choices." Then he receives praise, which always works better with him than punishment.

*Elly Scott, Atlanta, Georgia '05*

**M**y 15-year-old son's hitting occurs most often when he is anxious. When I see all the signs, I start getting into my defense mode. I stay close to him, but not in his face. If we are around other people, I remove him from the situation immediately! I will stand beside him and put his one hand around my waist and hold the other arm to his side while we walk out quickly. Yes, it looks odd, but it's a lot less embarrassing than getting slapped or hit in front of people! If the hitting happens to someone else before I can stop it, I apologize, quickly explain the problem and make a hasty exit. I don't try to make him apologize because that only escalates his anxiety at this point. He does get consequences for hitting--no TV or Playstation for an afternoon--but I try to remember it is a side effect of his anxiety and not intentional.

*Jackie, Marysville, Ohio '05*

**I** recommend the book "Hands Are Not for Hitting" by Martine Agassi. There is also "Teeth Are Not For Biting" by Elizabeth Verdick. Both are available through Amazon.com (yet I picked mine up at Toys R' Us - just jumped out at me one day - it was meant to be).

"No" just doesn't work, it's important that you teach what *is* appropriate, i.e. hands are for helping, hands are for hugging, etc.

*Sally Nantais, Wyandotte, Michigan '05*

# Horseback Riding

**H**ippotherapy (therapeutic horseback riding) involves speech, occupational or physical therapists who have had additional training. Our son's position is changed on the horse and he is asked to do things, such as grab objects, open mailboxes, put objects on and off spindles, etc. The horse might trot or go up hill so that his body has to change position. The therapist has evaluated his needs and adjusted the session accordingly. Although there certainly is a recreational component, the purpose is to improve areas of dysfunction. In my son's case, these areas involve coordination, motor planning and apraxia (not speaking). His trunk area also is being strengthened in order to help speech develop. The horse is matched to the client because the temperament and gait of the horse are very important. For example, our son does well with a Tennessee Walker with a smooth stride, as opposed to a horse that sways back and forth. The latter would have reinforced problems that our son has. Often a therapist will alternate horses from week to week in order to address different areas of need.

Insurance may cover Hippotherapy. A prescription is required. Do not use the words "Hippotherapy," use Speech/Language Therapy (SLT), Occupational Therapy (OT) or Physical Therapy (PT) depending upon the credentials of the therapists. I'd suggest a tour of the facility. Also, the insurance company requires a letter from the doctor, detailing the need and an intake evaluation. SLT gets 30 visits a year, OT or PT get 60 under our policy. I would have the doctor write one to three sessions per week. I personally think two is ideal but what we get right now is one hour long.

*Susan, New Mexico '05*

**T**herapeutic Horseback Riding/Hippotherapy has been a wonderful addition to the therapy plan for our son. He recently turned three and has been riding for a few months. He gets so excited when we pull into the driveway of the facility. He knows exactly where we're going and always has a smile on his face when we get there. He rides once per week for 1/2 hour each lesson. They incorporate several different types of therapy into the riding session. Hippotherapy helps to enhance Alex's balance, posture, mobility, coordination and strength. He has even ridden backwards which most definitely challenges his vestibular system! He gets OT through the sensory experience and some fine motor activities he does while on the horse. He has recently started to babble much more than before, making all sorts of attempts at vowel imitations and some consonants as well. Not sure if that can be attributed to the riding since he also recently switched schools, but it's possible. Before he started I thought he would just be riding around in circles, but it's so much fun to watch all of the activities they have the kids do. He throws a small ball into a hoop from the horse, matches colored pool rings to colored cones set up throughout the stable while on horseback, and other matching activities as well. We are lucky that this brand new facility is about five minutes from our house and the instructors are top notch!

*Julie, Maine, '05*

## **Additional information/Websites:**

### **What is Hippotherapy? *From American Hippotherapy Association (AHA).***

Hippotherapy is a physical, occupational and speech therapy treatment strategy that utilizes equine movement. Hippotherapy is utilized as part of an integrated treatment program to achieve functional outcomes.

In Hippotherapy, the patient engages in activities on the horse that are enjoyable and challenging. In the controlled Hippotherapy environment, the therapist modifies the horse's movement and carefully grades sensory input. Specific riding skills are not taught (as in therapeutic horseback riding); but rather a foundation is established to improve neurological function and sensory processing. This foundation can be generalized to a wide range of daily activities.

#### **AHA Inc.**

136 Bush Road

Damascus, PA. 18415

Phone: 888-851-4592

Internet: [www.americanhippotherapyassociation.org](http://www.americanhippotherapyassociation.org)

#### **American Equestrian Alliance**

P.O. Box 6230

Scottsdale, Arizona 85261

Phone: 602-992-1570

Fax: 602-992-8327

Wats: 800- 874-9191

Internet: [www.americanequestrian.com/hippotherapy.htm](http://www.americanequestrian.com/hippotherapy.htm)

#### **Additional Contacts:**

**Del Mar, CA, Phone:** 858-759-9191

**Denver, CO, Phone:** 303-377-9180

#### **North American Riding for the Handicapped Association, Inc (NARHA)**

PO Box 33150

Denver, Colorado 80233

Phone: 800-369-RIDE (7433)

Fax: 303-252-4610 ..

E-mail: [NARHA@NARHA.ORG](mailto:NARHA@NARHA.ORG)

Internet: [www.narha.org](http://www.narha.org)

[www.strides.org](http://www.strides.org) -

Therapeutic riding is practiced in some form in most countries in the world. Great Britain formed the Riding for the Disabled (RDA) program initially to promote competition and equine sports for the disabled. Germany and Switzerland have been in the forefront of developing and establishing Hippotherapy as a medical model of equine-assisted therapy. The North American Riding for the Handicapped Association (NARHA) in the United States puts forward a model that incorporates therapy, education, sport, and recreation/leisure activities.

[www.rightsteptherapy.com](http://www.rightsteptherapy.com) - This site has a great description of the difference between Therapeutic Riding and Hippotherapy and numerous other resources if you are interested in learning more.

*I is for ...*



## **IEP (Individualized Educational Program)**

The IEP meeting should just be the formal milestone of a continuous relationship between parents, classroom teacher and professional school staff. Ideally, there should be no surprises at the IEP meeting. Everyone should be personally comfortable with each other from prior interactions. The burden is on the parent to provide the school personnel with an understanding of your child's specific situation and background, what things seem to work best for him and how you can be a partner in and out of the classroom, to help work toward the best possible for your child within what the school has to work with. Again, this is IDEAL, but the degree to which YOU can make it happen is what it is all about. If you and the school personnel are meeting and sharing this information in depth for the first time at the IEP you are already in a tough situation. The challenge is wherever possible to become a positive member of a team to maximize the possible. If all else fails you have to take an opposition position.

*Marvin '98*

Before Brian's last IEP I had given a copy of Educating Boys With Fragile X, by Gail Spiridigliozzi, Ph.D., to each of the key players (his teachers, OT, speech therapists). When we gathered for the IEP meeting they had all read it and had a basic understanding of what to look for with Brian. Additionally, I had a list of very specific concerns I had for Brian. I found that the meeting, which lasted about 2 ½ hours, was very friendly and productive. I had also asked that the area director of special education be the school board rep, as opposed to someone lower on the organizational ladder. All in all, it was a good experience. I know that our future IEP meetings may not all be as successful, but I think preparation and showing that you mean business helps a lot.

*Theresa '98*

On the IEP thing, I'm afraid teachers get a great deal of pressure from administration to show that they are achieving something with the extra monies they receive for our children. So when they have certain guidelines and goals they want to meet, and the child does not reach them, the teacher is called to task, as to why the child has not. This in turn tends to have the teachers press the children to make these gains, which pressures the parents, and on and on. There's no easy



solution for this. I'm sure you'll get differing opinions on this. What I do for our son is keep his IEP goals broad, and then keep in close contact with the teacher and therapists and make weekly or monthly goals, instead of trying to peg down any highly detailed annual goals. For me to guess where he will be for the entire year is not possible; he changes daily in his acquisition of skills. This works for us. But you need to decide which will work best for you."

*Anonymous '98*

**I**t is always best to remind yourself and the special education team that we are here for the kids.

*James '98*

**I**EP meetings can be very complex, because of the legal nature of the meeting and the emotions brought to it by parents and professionals. As a psychologist, I go to 50 or 60 IEP meetings a year. Some are pleasant fun, some routine and mundane, and a few...well...I'm glad I have some impulse control.

First, good practice dictates that parents should not be surprised by anything that the child's teacher, therapist(s) or psychologist says at the meeting. The building-level team should have met with the parents explained test results, problems and strengths. Their plan and recommendations should be clear to the parents. This preparation is very important, especially when the child's disability is more severe. Also, except in very small districts, the IEP committee should be separate from the evaluation/treatment team. There needs to be checks and balances.

By knowing the building team's recommendations, the parents can come to the meeting better prepared, to support or challenge the building team. It also gives everyone the opportunity to seek mutually acceptable alternatives so a fight in committee can be avoided. With more challenging cases, or when there is disagreement, I like to think of the parents as the 'loyal opposition.' We're both committed to the same goal, educating the child, although we may disagree on some of the particulars.

While most meetings between parents and schools are informal and oriented to the child's education, the IEP meeting is a legal meeting specifically designed to protect children's and parents' rights while trying to provide a free appropriate public education (FAPE), with an emphasis on protecting the child's rights. The law does not take lightly identifying and segregating children from the mainstream. That's why there are the appeals procedures available to parents.

It was mentioned that listening to a team of teachers and therapists say negative things about the child is painful and unnecessary. Unfortunately, the nature of IEP meetings, in my experience, dictates that more time be spent on describing the child's deficits rather than strengths. The first phase of any IEP meeting is to determine whether a disability is present. No programming decisions can be made until it is determined that a child is educationally disabled. In order to prove the disability, the focus must be on what cannot be done by the child, i.e. that the child is failing to learn. It is clearly based on a deficit model and medical model: diagnose, then treat.

The second phase of the meeting is to determine appropriate placement and educational goals. Again, the focus is on what the child isn't doing and what needs to be done to address those needs. Or, in the case of placement in a more restrictive setting, why the child cannot be maintained in a less restrictive manner.

I have been to meetings where a well intentioned teacher set out to describe how well the child was doing in sharp contrast to what my test findings said and the descriptions the child's mother

was giving about her son. The IEP committee I was presenting to heard all this positive stuff and said “It looks like he’s made good progress. No disability.” And therefore, no services for this boy. So, I tell teachers now, to keep positive statements about the child to a minimum and keep them generic. “He’s a nice boy” “I really like him, but he’s struggling to read” and so on. I tell them to focus on the child’s learning difficulties and the child’s failures.

I hope this helps some parents to understand the process and why we focus on the child’s negative characteristics. It’s not that we want to discourage the parent or disparage the child, it’s the way the rules are written. As parents I caution you to place more emphasis on the informal meetings you have with teachers and the positive feedback you get there. Also, meet with the building-team--before the IEP meeting, so you can get a good picture of your child without the pressure of having to prove the disability.

If you choose to have an advocate, select one carefully. Some are good and can facilitate the process. Some are antagonistic, seem to have their own agendas, and impair the process.

Finally, to have the most success with the school, build relationships with the key players, the teacher, therapists, and psychologist. You don’t always have to agree with them, but if you earn their respect, your child will be better off.

*Dave Lochner, School Psychologist ‘98*

**We** had Chris’ IEP last Friday. Both Lee and I attended. This is really the only way to go. We learned this a few years ago. We have found that sometimes one of us will pick up on something that the other one did not. There is not a human alive that will hear and comprehend 100% of what is being presented to them. The mind moves too quickly for this. I realize that some households only have one parent, or that it is just impossible to get both parents there due to work schedules. If this is the case, find someone you can take along. It would be best if this person already has experience in these matters. If you belong to a support group, is there a parent there who would be willing to go along with you? A close friend, neighbor, or relative can help as well. You really need that extra person so that you don’t feel all alone in the world. You will be surprised how much it helps having that second person there. Take it from one who has done this alone and would not want to do it alone again.

*James ‘98*

## **Resources for IEP information/Websites:**

[www.cesa7.k12.wi.us/sped/index.html](http://www.cesa7.k12.wi.us/sped/index.html) - This school website won numerous awards related to web site design and information provided for special education.

[www.wrightslaw.com](http://www.wrightslaw.com) - The Wrightslaw website is an excellent resource for advocating for your child. Great resources for helping to understand special education laws and how to advocate for your child. You will find articles, cases, newsletters and resources in the Advocacy Libraries and Law Libraries. Excellent books available for purchase and they offer workshops across the United States.

They also have a link for Yellow Pages for Kids, which is a list of resources by state.  
<http://www.bridges4kids.org/IEP.html#top>

### **Creating Goals and Objectives**

These sites offer ideas to assist you in creating goals and objectives for your child.  
[www.iep4u.com](http://www.iep4u.com) and [www.ieps.net](http://www.ieps.net)

# Inclusion

School-age children with Fragile X are in a variety of school settings/placements. Inclusion is one of the options in many school districts today.

Our two boys were classified under “*Multiple Handicaps*” at our request. It may sound crazy for us to have requested this, and the school district wasn’t sure about it initially, but we felt it best described the boys. The category the school district recommended “*Significantly Limited Intellectual Capability*” described some aspects of the boys’ learning challenges, but not all. We felt *multiple* was appropriate for them because they also had significant “speech and language” delays, “perceptual/communicative disorders”, and one son had some mild “physical problems”. These are all labels the district usually assigns kids individually. The *multiple* category allowed us to group them. The label did not seem to limit them in any way. Basically it applied to funding that the district receives from state and federal sources. Under *multiple* there are also some guidelines about the student-to-teacher ratio in special education classes. We felt that was a plus while our boys were in those classes.

Both boys went on to be included in a variety of regular education classes. They were in special education only for math and speech and language. They participated in regular science, history, basic English, PE, choir, yearbook, etc. Their inclusion required additional supports during academics in the regular classroom, but most situations worked very well. A paraprofessional modified curriculum, allowing them to participate with the rest of the class. I truly believe being in regular classrooms made a tremendous difference in our sons’ academic achievement and social development. Besides, how can we expect our children to learn to live in the world if they have been separated from it for all of their lives? (Sorry, I’ll climb down off my soapbox now).

President Clinton’s call for standardized education may make inclusion even more challenging. I wonder if he’s thought through the implications of his mandate for special needs students. I worry that it will throw us back twenty years to where special education students were in a totally separate class at the end of the hall. As parents we are going to have to be valiant in fighting for our children’s rights to be actively included in the school they attend. One thing I’ve learned through the years is that there is no one right answer for all kids with Fragile X. Some may work well in an inclusive setting, while others may need more intense support in a special education setting. I believe most fall somewhere inbetween, with a mix of both. Whatever you decide, I wish you only the best.

Jeannie ‘98

I would certainly push for inclusion, but with the proper supports in place—a speech therapist who either sees the child in the classroom or in some pull-out time, maybe an OT who works with him on fine motor skills, and someone training the aide. Our son Dave was in inclusive kindergarten and first grade, and both were wonderful. In kindergarten, the OT saw a group of kids for fine motor, and the speech therapist saw a group for language work, so Dave got a lot of his special help with other kids. The main advantages to me have been in his social language and play skills. His academics have moved along nicely; he never would have been as far as he is in a self-contained cross-categorical class. He has exceeded our expectations, as the kindergarten and first grade teachers believed in him so much.

Gail ‘98

I wanted to share some uplifting news--we sure could use it. We have been in the planning process for Brian (age 12) to go to the middle school. It is going to be a major change for him and he is scared, as am I!

I decided to organize some of his friends into a circle of support. We called it "Brian's Buddies." We invited five of his most supportive friends at school these past five years, all from his general education classrooms. We met on Friday night and my friend facilitated the meeting. We asked them how they could help Brian in the middle school and their ideas were great. They all want to eat lunch with Brian. They think at least one of them should always be in his classes so they can "interpret" for the teachers. They want to take cooking class together and think Brian's locker should be next to theirs so they can help him. I am sending the principal a copy of the minutes of the meeting so she can begin to arrange for some of these ideas to come to fruition.

The best part is that this is supporting all of them. Each one admitted to being scared of middle school. This is what inclusion is all about. I could not have imagined the acceptance these kids have for Brian. They treat him completely naturally, telling him to stop when he does something inappropriately. They will be meeting on a regular basis to strengthen this circle and develop new ideas. They left with their faces beaming. They feel really good about themselves because they know they are helping Brian. Naturally, Brian was thrilled too, as was his mom!

Orah '98

*Continuing the above:*

If anyone would like detailed info on how to develop a *circle of friends*, the best sources are the people who created it, Marsha Forest and Jack Pearpoint from Canada. You can get some info from their web site, the Inclusion Press at <http://www.inclusion.com/index.html>. There is a specific book entitled "All My Life's A Circle, Using the Tools: Circles, MAPS, and PATH. You can order from:

INCLUSION PRESS  
24 Thome Crescent  
Toronto, ONT M6H 2S5 Canada

Phone: 416-658-5363 Fax: **416-658-5067**

I suggest you get someone from outside the family to facilitate it--someone the kids will trust and open up to. It can be a teacher, and the circle can be organized through the school, though I have found in most instances it's been more successful if first developed outside. Our next meeting for Brian's Buddies is in two weeks and we will explore opportunities for Brian to increase his social activities outside of school. I will keep you updated!

Orah '98

### **Inclusion Resources:**

[www.wholeschooling.net](http://www.wholeschooling.net) - The Whole Schooling Consortium is an international network of schools and individual teachers, parents, administrators, university faculty and community members. Focus on inclusion.

[www.tash.org/inclusion/index.htm](http://www.tash.org/inclusion/index.htm) - TASH

# Inspiration

Treat people as if they were what they ought to be, and you help them to become what they are capable of being.” Goethe ‘98

## *One of Those Days*

Did you ever have one of those days, when you didn't know where to turn or what to do?

Did you ever have one of those days, when no matter how hard you tried, you simply cried and cried?

Did you ever have one of those days, when you simply couldn't cope, you had lost all hope?

Did you ever have one of those days, when you prayed and prayed for the wisdom to guide you on your way?

Did you ever have one of those days, when you suddenly found yourself in uncontrollable grief, with no relief?

I want you to know, you are not alone, and you share something with me that nobody else knows.

And as I sit with my heart and soul just weeping, there is the sweet touch of someone who's just two, with three little words that will get me through, "Mommy, it's okay"

*Sally Nantais, Wyandotte, Michigan '05*

I guess most (maybe not all) of the most noble professions are based on the misfortune of others. I don't like being on the misfortune end, but I suspect my son is making a bigger difference than I will ever know. There are a number of people employed because of his very existence. Whereas it isn't *his* success, it certainly is someone's achievement.

My son has also experienced what I never have: recognition. He has a shelf full of trophies, and a binder full of awards. I spent my life never recognized for academics, sports or otherwise. I was just - ordinary. Nothing about me ever stood out.

Pattie Devlin, Burlington, NJ

I don't usually take Inspiration from T-shirts, but this one reminds me to focus on the fun and wonder of my son—who by *some* measures, doesn't keep up with other kids: “Childhood is a journey, not a race.”

Susan Cohen, Maplewood, NJ

## ***J is for ...***



## **Jumping ...**

**J**umping is a great calming technique for David. Any heavy work or exercise works as well, but a full-size trampoline is fun! He can get on whenever he needs to (depending on the time of year around here.)

*Cindy Saracino, Geneva, New York '05*

## ***K is for ...***



## **Knowledge (And Incidental Learning)**

*Many individuals with Fragile X have strengths in incidental learning. Learning that takes place throughout everyday occurrences often when we're not even aware....*

**I**'m not much for swearing, but I occasionally let loose when I drive. Well, one day I was driving and another driver swerved at me and scared me enough that I gasped. Then I heard a voice from the back seat, "That's an asshole, Mommy, right?" I think Simon was 5 years old at the time. He's now nearly 15. It's interesting what he's picked up. He can tell you about current events. He's really picked up a lot of information about Princess Diana. He knows who Lee Harvey Oswald is and Jack Ruby. He knows that President Lincoln was shot in the theater (though he calls it "the movies"). He loves the History channel and the Discovery channel. Once his brain decides to remember something, it is in there forever!

*Nancy '98*

My daughter can remember where things are (especially other people's VCR's, toys, things of her interest) even if she's only been to their home or office once. We may go back 6 months later and she immediately knows where to find what interested her the last time! She even knows if I'm going down the wrong road to our destination--if it's somewhere she wants to go!

Leslie '98

## *L is for ...*



## **Life**

Welcome To Holland  
by **Emily Perl Kingsley**

© 1987 by Emily Perl Kingsley. All rights reserved

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But ... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things... about Holland.

*Emily Perl Kingsley, Westchester Co., New York*

### **Life is different now... not necessarily better or worse**

PUBLISHED: June 24, 2004, The Grosse Pointe News

10-10-02.

That was our family's D-Day.

In this instance, D-Day means "Diagnosis Day."

It's an easy date to remember. The day Mary Beth took the call that informed us that the blood test came back positive. "Andrew has Fragile X Syndrome."

It's so easy to remember the date because Mary Beth had to tell Ted about their son's diagnosis on her husband's 38th birthday.

Looking back now, life seemed pretty chaotic for a while. Well, more chaotic than the normal chaos!

More doctors to see. Research to do. Books to read. FX groups to join. The frenzy hadn't really stopped. The frenzy simply changed from finding a diagnosis to finding out more about the specific diagnosis. And dealing with it.

It all seemed so sad for a while. Tears came very easily. Dreams seemed shattered. Plans seemed obliterated.

But it really did improve. New dreams replaced the old ones. Little achievements became more exciting to watch. The good times seem more fulfilling than before.

Life is just different now... not necessarily better or worse.

It's still easy to remember those first weeks of stumbling through a diagnosis, especially when you hear of a family going through a similar process. Or you read their first post on a listserv. Or hear them ask you jumbled questions in a school hallway.

You want to say, "It'll be okay. Just take a breath. You'll get through this and keep going."

We still have a long road ahead of us, but, in a relatively short time, we have already learned that "the diagnosis" was not the end of the road. It just brought us down a different road than what we had mapped out for ourselves.

Depending on printing schedules, you will probably receive this column on a day that Mary Beth is participating in Fragile X Syndrome Advocacy Day on Capitol Hill. She'll be sharing our story of FX. And explaining how money would help with FX education and research.



Advocacy Day is part of this year's International Fragile X Conference in Washington, D.C. Mary Beth is going in order to gather more information about how to help Andrew be his best. She'll be attending for the first time and learning from FX experts – the professionals and the parents.

Ted will be taking a few vacation days to parent Andrew full time while she's out of town.

Perhaps some dads take vacation days so the mom and dad can take their child to Disney World or some place like that. Andrew would detest the sensory overload of such a place at this point of his life. He would much rather stay home and do his usual routine of therapies and have regular ol' roughhousing and play time with his daddy.

Life is simply different now... not necessarily better or worse.

*Theodore G. Coutilish and Mary Beth Langan, Grosse Pointe, Michigan '05*

### **What is it like to parent a child with Fragile X?**

*Julie Adams wrote this on the listserv to help a student who needed information for a school project.*

**I** applaud the person who came up with the idea of a report on Fragile X Syndrome! I'll try to sum up for you, in a few short sentences, what Fragile X Syndrome means to me.

Anything a parent might know about child rearing goes right out the window. Raising a child with FX begins with the relearning of everything we think we know or did raising our other children. As a parent or sibling of a person with FX, you must work daily on becoming more tolerant, develop the patience of a saint and pretty much become self-less or at least greatly control your own emotions.

You have to face an entire community of health professionals, educators, neighbors, friends and family who do not understand why you do what you do for your child with FX. The general belief is that the child's problems have much to do with your parenting skills, or lack thereof. I have spent 11 years fighting three different school districts to assure that my daughter's basic safety issues are met while at school.

My daughter with FX has very limited access or understanding of what life is like compared to her peers. She can't stand loud or unusual noise levels, so she doesn't go to dances, malls, roller rinks, etc. Just being in school is stressful for her. She's not aware of clothing styles, hair/makeup trends. Her best friends are her stuffed animals.

It is very difficult for her to learn. She needs much repetition (months, years) to learn any academics. She will probably never drive a car, although she thinks she will when she turns 16. She will not go to college or have a career (she wants to be a fire fighter). She will probably not marry or have children (she has a 50% chance of passing on the gene that causes FX, nor could she care for a baby or a husband!)

She is the most loving, compassionate person I've ever known. Her sense of humor frequently has me in stitches. While I may feel she is far too sensitive or naïve, her desire and will to fit in with the rest of the world inspires me and gives me meaning and purpose.

Parenting a child with Fragile X Syndrome must certainly be one of the hardest tasks on the face of the earth. At times it feels like a test of endurance; a test we fear we might not pass.

Thank you for coming to this listserv to get the information you need for this most important topic. Do us all a favor by writing an excellent report!

*Julie Adams, Wisconsin '05*

**M**y husband and I are the parents of four daughters and a son. They are all are adults now. Our two older daughters are not carriers of Fragile X. They have been tested more than once. During their pregnancies, they had amnios especially to check for Fragile X. Happily, none of our five grandchildren are carriers or Fragile X-affected. The two younger daughters are unmarried and they are carriers affected with learning disabilities. Our son Todd is fully-affected. He has mental retardation, behavioral disabilities, and ADD. He is 21 and still in the public school system, but will be out of school in June 2005 and into the world of sheltered workshops.

Life for us is definitely different. Todd looms large in our lives and he has a profound effect on the family. He is a good-looking, friendly, affectionate young man who tries to do his best and loves music, Elvis especially. He gets a kick out of "I Love Lucy" and is a big fan of TV chef Emeril Lagasse. Unfortunately, he is prone to sudden changes in brain chemistry and can have a heavy-duty meltdown for no apparent reason. It is distressing for him and for us and we haven't found a way to treat it yet.

He has a psychiatrist and we are working on finding the right combination of meds for him. We are older parents who are discovering that we aren't as energized by the challenges Todd presents as we used to be, though we keep at it because we want him to have a life outside the family so that we can have a life outside of Todd. He will always be on our minds, though, and in our hearts, no matter what.

*Carole Hellman, Salem, Oregon '05*

**W**e were visiting my son's future in-laws and my daughter Renee, who was 23 and most affected by FX, had been politely sitting. The mother-in-law-to-be asked her a question and Renee replied with her still little girl voice. The lady quit talking to her and the husband started to carry on a conversation instead. A few minutes later Renee came to me saying "Mommy, why doesn't that lady like me?" I asked "what do you mean?" and she told me what had happened and that as soon as she had started to answer the lady turned the other way. I gently explained that she picked up on your disability in your voice and didn't know how to talk to you. She came back quick as a wink "Just like you talk to anyone else!" I said "Honey, you are so right" and gave her a hug.

When Renee was two years old, she would not stay with my friend who was going to babysit my children while I had an appointment. My first two daughters went into the house to play with their friends, but Renee would not budge one step no matter how much the other mother coaxed. I had to take her to my appointment with me.

The problem was that my friend knew my first two were slow (in those days FX was little known and still is in Canada for the most part) and was talking down to my kids. Like me, Renée can sniff out a phony right away. My friend did not know better than to talk down to small children.

Most parents know better, but others seem to talk differently to a disabled child, even their own. We always treated all of our children the same. They all have to live by the same rules, the same manners and do the same jobs. They were close in age and had the same bedtime. Then Mom could sit in front of the TV and fold the clean diapers and other laundry.

My point is that our FX children need to be treated as much as possible just like any other child, especially our non-FX children. We may have to explain things differently and some may learn things earlier or later than others, but they are loved and are just as much an integral part of our family no matter who they are.

*Patty, Saskatchewan, Canada '05*

Someone mention putting together a "lessons learned" anthology of posts. We are all learning, all the time, in what it takes to raise our kids and it often feels overwhelming. I have always loved reading the posts from the parents of older adults with fragile X, hoping it will give me some insights as to what lies ahead. As the mom of a 20 year old (how is that possible, as just yesterday he was in preschool?), I hope to also provide some inspiration to others. As the end of another school year is quickly coming, it's a time for retrospection and planning for what's ahead.

After some very difficult years, I'm happy to say we are seeing some of the fruits of our labor. Last week my son Brian (20 yrs. old) received two different awards for the exemplary volunteer work he does, one in a work setting and one in the high school library. He received one award in front of a huge dining hall filled with people and he went up to the podium while his boss talked about the great work he does. He stood there beaming and replied, "Aw shucks!"

This is a huge turnaround from the Brian we knew two years ago, who was punching holes in our walls and having huge meltdowns. His transition back to his high school after being in a private school last year was difficult but he loves his school now. He has learned to handle being in a 2000+ students high school with lots of noise and transitions. His teachers say he is a great example for all the students, as he is attentive and focused on doing a good job in his classes.

Many of you are struggling with young children and wondering what the future will hold. How will things turn out for them? I have learned that there are good years and bad years. Hopefully you will have more of the former. Most importantly, I've learned never to take the good times for granted. There will be wonderful people working with your children and some who have no right to be near children (what were they thinking when they said they wanted to be teachers?). There are times you wonder how you can go on for one more day but you do because you have to.

Brian's success has been a validation of all that we have worked so hard for, and while I know the road ahead to adulthood is not an easy one to travel I have to allow myself this moment to be proud of all he has accomplished. So... I will pour myself a glass of wine, or two, and then I will buckle up and get ready for the next stage.

*Orah Raia, New Jersey '05*

## Life Planning

### Reference materials/websites to aid in planning for the future:

*"Planning for the Future: Providing a Meaningful Life for a Child with a Disability After Your Death"* by L. Mark Russell and Arnold E. Grant. ISBN: 0912891203.

[www.TheArc.org/futplan.html](http://www.TheArc.org/futplan.html) - Future Planning Resources

Become familiar with your state's laws, agencies and services which affect future planning. For additional information contact your local or state chapter of The Arc.

[www.nichcy.org/pubs/newsdig/nd18txt.htm](http://www.nichcy.org/pubs/newsdig/nd18txt.htm) - Estate Planning, NICHCY News Digest, Volume 2, Number 1, 1992, #ND18, Resources updated 1994. A publication of NICHCY, National Information Center for Children and Youth with Disabilities.

[www.ndss.org/content.cfm?fuseaction=InfoRes.LifePlanarticle&article=231](http://www.ndss.org/content.cfm?fuseaction=InfoRes.LifePlanarticle&article=231) - Futures & Special Needs Planning For Persons with a Disability, By: Barton Y. Stevens, ChLAP, Source: 2001 NDSS Compendium

# Listserv - Fragile X

## What is The Fragile X Listserv?

The Listserv is a virtual support and information exchange group (an electronic mail support group) for all interested parties, including parents, other family members, educators, and medical professionals. We are grateful to Emory University for sponsoring this listserv. FRAXA started the Listserv in 1995 to serve the entire Fragile X community. The Listserv is open to all.

### **To Join:**

Send email from your email address to [LISTSERV@LISTSERV.CC.EMORY.EDU](mailto:LISTSERV@LISTSERV.CC.EMORY.EDU) with this as your e-mail message:

In the subject and body of your message type: SUBSCRIBE FRAGILEX-L *myname*

“*myname*” is whatever name you want to appear as the “from name” on your Listserv postings. Type it in the way you want it to appear in upper/lower case letters.

### **To Send a message:**

Send email from your email address to [FRAGILEX-L@LISTSERV.EMORY.EDU](mailto:FRAGILEX-L@LISTSERV.EMORY.EDU)

### **To Reply to a message:**

Only send a message to the entire list (Reply to All) when it contains information that everyone can benefit from. Send messages such as "thanks for the information" or "me, too" to individuals--**not** to the entire list. **Some members may only have free e-mail accounts or accounts that are only checked randomly from a library. WHAT DOES THAT LAST SENTENCE MEAN? CAN IT COME OUT OR BE CLARIFIED?** These accounts might also have message size limitations.

### **To Sign Off:**

Change your send to address to: [LISTSERV@LISTSERV.CC.EMORY.EDU](mailto:LISTSERV@LISTSERV.CC.EMORY.EDU)

In the subject and body of your message type: SIGNOFF FRAGILEX-L

### **Helpful Note:**

This is an active discussion group. If you find that too many messages are filling your inbox, you can choose the DIGEST option. The DIGEST sends you one batch message each day, with a list of all individual listserv messages included.

### **To choose the digest option:**

Change your send to address to: [LISTSERV@LISTSERV.CC.EMORY.EDU](mailto:LISTSERV@LISTSERV.CC.EMORY.EDU)

In the subject and body of your message type: SET FRAGILEX-L DIGEST

*If you haven't joined yet, this is a great way to connect with others who love someone with Fragile X Syndrome.*

# Listserv Etiquette 101

- Text portions of the message should be exactly that, **text only**. Some individuals work on computers that might be considered dinosaurs compared to yours. Colored backgrounds, flashing smiling faces or embedded pictures may cause severe problems on their systems.
- Do not use offensive language. Be courteous.
- Include a short signature tag on messages. Include at least your name and location, but do not include pictures. Embedding poems is nice but creates a lot of unnecessary information for digest readers who have to scroll through it all.
- Include only the relevant portions of the original message in your reply, delete any header information, and put your response *before* the original posting. This helps digest readers, who get one message at the end of the day containing all messages for the day.
- State the topic of the comments in the subject line so members can respond appropriately to your posting and search the archives by subject.
- The Fragile X listserv is hosted by Emory University, free of charge. The number of messages processed can affect the size of the list and the amount of maintenance required by Emory.
- When someone replies to you privately, send your return reply privately as well. Respect their confidentiality; information they may have shared with you privately is information they may not want shared with the entire list or as part of the list archives.
- Warn other list subscribers of lengthy messages either in the subject line or at the beginning of the message body with a line that says "Long Message."
- Resist the urge to "flame" someone. Flaming is harsh criticism intended to be destructive and hurtful. If you get flamed, ignore it.
- Be respectful of the opinions of others. Do not challenge or attack others. The discussions on this list are meant to stimulate conversation, provide resources, not to create contention. Let others have their say.
- If your message could be considered "Off Topic" add "Off Topic" at the beginning of the subject line.
- Do not attach files on messages to the entire list. Attachments can spread viruses and worms. Some users may not have computer systems that easily support attached files or can screen out viruses.
- Last but not least, remember that nothing is confidential or private when using the web to communicate. Double-check your message before sending it. If it contains personal or confidential information it might be better to use another form of communication.

# *M is for ...*



## **Math**

Last semester I took two math courses especially designed for teachers. What was so interesting is the way math is taught now compared to when we were in school. EVERYTHING is hands-on using manipulatives and pictures. There is no longer one way to do things. Shopping is an excellent way of “reinforcing” math skills. Along with this new way of teaching math is a new principle! Kids do not need to be taught math, they already know it. As teachers, we are enforcing what they already know and calling it math.

Let me explain. Ask a kindergartner to divide 2 by 3. You will get a blank stare, right? Give that same kindergartner 2 pieces of gum and ask him to share it with his three friends. Same problem, right? But I bet he could do it with incredible ease. Take a look at your daily routine. Ask him to help with dinner...preparing it, and serving it. Help him to follow directions. Then ask him to help serve...everyone gets EQUAL amounts, etc. As far as adding and subtracting, money is an excellent way to practice. Take him to the store and allow him \$3.00 to spend. Take a calculator, scratch paper, and figure things out in the store. Hey, old ladies do it, so can you!

Important: after the shopping excursion is over, sit back down and go over what you learned. The main purpose of these activities is to enforce learning. If he understands that going to the store and buying chips is really practicing math, he can relate that to his school work.

*Anonymous '98*

It's not uncommon for a child to learn a sequence without the meaning behind it. Many times I've had parents or teachers say that their Fragile X child doesn't have the difficulty with math concepts that are reported because the child they work with can count, sometimes to quite high numbers. The trouble begins to creep in when the child is asked to manipulate the information by displaying what '3' means by counting out that number, or by adding two numbers together.

*Darryl '98*

*Many parents report success with the Touch Math program (Innovative Learning Concepts, Inc. 800-888-9191 and [www.touchmath.com](http://www.touchmath.com))*

**T**ouchMath teaches basic math mastery. The numbers have touch points on them corresponding to the value of the number, e.g. 5 has 5 touch points, 9 has 9 touch points. So to add  $5 + 9$ , the student would say 9 (the largest number) and then touch each of the points on 5 saying 10, 11, 12, 13, 14.

*Randy '98*

# Medication (for FXers)

The use of medication in the treatment of Fragile X must be an individual decision. For those who choose to use medication, an excellent resource for you and your physician is:

**Medication Guide for Fragile X**, by Michael Tranfaglia, MD, Psychiatrist, Fragile X Parent, FRAXA Medical Director. Updated August 2004.

This is a detailed guide to medications commonly prescribed to help manage symptoms of Fragile X. This 100+ page text will help parents understand the behavioral symptoms of Fragile X and how medications act on these symptoms. Reference pages rate each drug's effectiveness, safety, convenience, and cost.

The guide is not a medical textbook and does not take the place of a physician. It is designed to serve as background and reference to help parents talk with their physicians.

This guide is available from FRAXA Research Foundation at [www.fraxa.org](http://www.fraxa.org) or 978-462-1866. The guide is also included on the FRAXA CD in an easy to search PDF format. The **FRAXA CD** contains FRAXA's video, "First Down Towards a Cure" (in MPEG format), 5 years of newsletters, a multimedia website about Fragile X, articles on Fragile X, our brochure (all in Acrobat PDF format). Also on the CD: the Medication Guide, Fragile X - A to Z, and a Powerpoint presentation on Fragile X and FRAXA.

## 10 Meditations on Medication

1. This list has devoted a lot of net time to the topic of medications - to medicate or not, what medication(s) to use, what might your child gain, what might your child lose, what non-drug alternatives are there? I have read all of these sometimes-heated messages. I would like to offer MY personal feeling about this. NOTE WELL: these are MY feelings. I do not expect that all or many of you will share them. If you do not, please do not take offense. I do not mean to suggest that my feelings are the only correct ones. They are just mine.
2. Sarah was 9 before she was diagnosed. At the time she was diagnosed she was in a special day class half days and mainstreamed in 2<sup>nd</sup> grade half days. Behavior modification techniques had been used since pre-school with some success in certain areas and none in others. The most successful behavior modification was of the teachers and the aides. They were beginning to learn to see signs that Sarah was becoming over-loaded and to help Sarah step back from what she was doing and take a time-out to compose herself. The teachers and aides were helping Sarah recognize when she was becoming overloaded and initiate a time-out herself. Many of the other behavior mod suggestions we received just did not work with Sarah. Because of her impulsivity, the period for rewards had to be very short and the rewards became old hat very fast.
3. Beginning in 2<sup>nd</sup> grade (which Sarah repeated), Sarah's pediatrician prescribed Ritalin for ADD-like symptoms (at Sarah's spec. ed. teacher's suggestion). There was some improvement. Eventually we eliminated the evening dose to avoid some sleeping problems. The Ritalin did not seem to tone Sarah down emotionally, it did not take her smile away or make her less zest-filled. It helped in concentration and distractibility in the classroom. Did it

make me happy to have my daughter on Ritalin? No, but I was satisfied that it did help her learn more.

4. At 9 in 1990, Sarah was diagnosed. In 1991, the FMR1 gene was cloned and the cause of Fragile X was known. Before she was diagnosed, we didn't know why Sarah was impulsive, why she had such problems with math, why phonics were so hard, why she flapped her hands, why she perseverated (repeated the same phrase several times in a row), and why she had so many of the other behaviors associated with Fragile X. The reason my daughter Sarah had these problems was because HER BODY CELLS DID NOT MAKE ENOUGH OF A KIND OF PROTEIN. It was NOT because her mom had a glass of wine while she was pregnant, it was NOT because we were bad parents, it was NOT for the many other reasons we had contemplated. It was a relief to know.
5. (Flashback) Before Sarah was born we lived next door (in a row house in Baltimore so that is really next door) to a couple and their newborn baby boy named Mikey. Before Mikey was 9 months, it was clear that he had some developmental delay. His mom was a nurse and his dad was a consulting pharmacologist at Johns Hopkins Hospital so they both (esp. the mom) pushed hard to find the reason. It turned out that his body did not produce (enough) thyroid hormone and that if he continued untreated he would become retarded So they gave (and still give) him synthetic thyroid hormone. Mikey (now just Mike or Michael) grew up to be pretty much unaffected. Although he did have some learning disabilities that required help at school, he is doing very well..
6. (back to the present) So when Sarah was diagnosed and the FMR1 gene was identified, I knew what treatment Sarah should really be getting - she should get synthetic FMR1 protein(s). Newborns with the FMR1 expansion should get the synthetic FMR1 protein as soon as possible. (Which by the way is why I support FRAXA-as well as NFXF)
7. Problem: My daughter has a disease but the proper treatment is not (yet) available. So what is the next best course? It has been our choice to consult with many different physicians who have the most experience treating children with Fragile X and to try (under close supervision of Sarah's local doctor) to help my daughter take command of her life. It has been our experience that finding effective and acceptable medications and dosages is a trial and error process. We listen to Sarah. If it makes her feel bad in any way, it is dumped or the dosage is reduced. The two side effects Sarah has experienced are problems getting to sleep (Ritalin) and gas (Zoloft).
8. Right now, Sarah takes 40mg of Prozac at breakfast and 10mg of Buspar at breakfast, lunch, and dinner. Will Sarah be on meds next year? Probably. Will she be on meds the rest of her life? Probably. But then Mikey will also take meds (synthetic thyroid hormone) the rest of his life, too.
9. We still use lots of other treatments; the speech and hearing therapist and the psychologist have been especially effective. Will Sarah be receiving these or other therapies in a year? Probably. Will she be receiving these therapies the rest of her life? Maybe some of them.
10. Thanks for reading this far. Am I pro-drugs? I am pro-sensible, balanced use of any help your child can get. The drug Sarah needs is not (yet) available. Others may help until that one is ready.

*Charles '98*



## Medications – A Parent’s Opinion

The decision to use medications can be a difficult one for any parent. When we started, we were doing wonderfully in the home environment but the school environment was a disaster. At first, I didn’t like the thought of using medications, but I later decided that if a medication was available that would help my child it would be wrong not to medicate. If you decide to try medications there are a few steps I’d suggest:

1. Determine if the symptom (behavior or otherwise) is one that can be corrected in the environment first. This can be done in the home environment simply by keeping a log of symptoms. Provide the date and time it occurred, the type of symptom and comments on what happened prior. Keep in mind the trigger to the symptom may have not immediately preceded the symptom. I did this for three weeks and was surprised when I found that one of our biggest triggers was the word “no”. I also discovered that we used the word more than we needed to when another alternative could have been redirection. In the school environment they can do this as well by conducting a Functional Assessment of Behavior.
2. Start a medication journal - don't rely on the professionals to keep track of what med your child was on and how he/she responded.
3. Always remember you know your child best. If you think a med is ineffective or creating adverse behavior, trust your judgment--you are probably right.
4. For ADD/ADHD drugs I've always heard that FXS children responded best with the lower dose, so make sure they start out on a low dose and not typical for a child of their age and weight. You may want to purchase the medication guide by Dr. Michael R. Tranfaglia on FRAXA's website, [www.fraxa.org](http://www.fraxa.org).
5. Keep in mind that what could be a wonder drug for one child can be a disaster for another. Case in point: Strattera was awful for us, created a very explosive and violent child, yet I know another FXS child who does very well on Strattera. Ritalin worked for a bit, but it also created agitation and irritability, which was displayed in aggressive behavior. Of the three ADD meds we tried, Clonidine was the most effective for the longest period; and now there is a Clonidine patch available. Our son took it in pill form and when the medication would peak, he would have a major meltdown. Having him only take a single dose at bedtime averted this. Those are just a few of the meds used for ADD/ADHD. I’ve given up on treating the ADD.
6. Prioritize the symptoms you want to treat with meds. ADD/ADHD symptoms aren't anything I can't tolerate. Yes, it may difficult for anything to hold his attention long, but for us it’s not something that truly interferes with his life, so it's not a priority. Something that stabilizes his mood and lessens his anxiety is a priority med.
7. When trying meds, you may need to try a few doctors as well. We consult with a Child/Adolescent Psychiatrist.

- With our first doctor we didn't have any success with medications. Our medication journal was created out of necessity because with every visit it appeared that she didn't remember what we had tried.
- I liked the second doctor but couldn't stand the therapist who I had to work with (utterly useless) and the office was run very poorly. The second doctor wanted to treat all symptoms, so we were on a med cocktail -- which is hell, to be honest, when things aren't working and you're trying to figure out which med is the culprit.
- Our third (and current) doctor told me during our first visit that I needed to be the expert on my child, I knew my child best, he was only there as a resource. I knew right away that he was worth keeping.

The Winter 2004 Newsletter, from the National Fragile X Foundation, had an excellent article on the decision to medicate by Dr. Elizabeth Berry-Kravis. In the article, Dr. Berry-Kravis states:

“In FXS, medication is virtually always an adjunct to behavioral, therapeutic and specific educational interventions. Medication will not be successful if the learning and/or living environment are a poor fit for the individual with FXS, and particularly if the individual perceives the environment as aversive, threatening, or humiliating. Therefore one of the first steps in the medication decision process is always an assessment of the home, school or work environment, what behavioral measures are already in place, and interactions between the individual with FXS and his/her peers, educators and supervisors. Sometimes there is a specific problem in the environment that can be identified and modified, effecting a much larger improvement in behavior than would be seen with medication. Thus, it is important to maximize the environment first in order to get a reasonable baseline from which to evaluate the effects of medication.”

*Sally Nantais, Wyandotte, Michigan '05*

## Medication (for carriers)

I think for many carrier women, especially the ones who are moms of FX'ers, meds are crucial to survive daily life. As carriers, we may also face challenges, some greater than others. Many of us deal with anxiety, ADHD, shyness, and that big one: depression. I don't know how any parent can receive the FX diagnosis and not go through a period of depression. You have to face the reality at some point that this is not the life you have prayed or wished for your child (and yourself). Some of us work through this period quickly, others of us hold on to this state for a long time or return to it. I'm amazed at how often I was told (usually by the school) that I needed to “face reality” or “get real”. Well, what if you don't like reality? What if “getting real” means hours of therapy for your child and/or a child with severe aggression – possibly a lovely reality where you have a 5-year-old who is stronger and faster than you are. The reality that your world will spin out of control if you don't find a way to cope. For lots of us, this means meds. We need to get a grip on our busy lives, depression, and/or irritability.

I've taken my share of antidepressants since our 2003 FX diagnosis of our two children, Parker and Allison. I can say from my experience, I loved how I felt and functioned on Zoloft. I felt

like myself again – happy, dependable, I didn't cry at the drop of a hat. I also felt something else: hungry all the time. So that was the end of Zoloft. Next came Prozac. I know it works well for some. For me, I was the “Queen Bee” and my husband suggested we put a stop to that med! I tried Lexapro with little to no side effects, but also little to no change in how I was coping. A few more were added and subtracted from my life over the next several months. I must admit, I am the worst pill taker in the world. I have no patience when it comes to waiting for results. Many meds take up to 6 weeks before you notice a change. Six weeks is a long time for me to be patient and take pills. I am excellent at making sure my children get their meds like clockwork, but when it comes to me, I just don't have the discipline it takes to take a pill each day. After many meds didn't work for me, Dr. Hagerman suggested Wellbutrin. I loved it! I felt great, I wasn't hungry and I don't know if you've heard this about Wellbutrin, but unlike many antidepressants that take away your sex drive, Wellbutrin generally increases it! You'd think, sounds great, I bet she's taking it now. Actually, I'm currently medication-free, due to not having the discipline for pills. But when a Wellbutrin patch has been invented, I'll be the first in line!

Time has helped me. As time passes, I get stronger emotionally. We have our setbacks, but we leap ahead too. Despite being a terribly shy person, I now love public speaking. Put me in front of 200 people, let me talk about FX and I'm in my element. I love to be that center of attention when I know what I am talking about, my eye contact is great, my speech is slow, and I'm loving it. However, put me in a group of 200 (or even 2) people and ask me to be *social* and I'm trying to keep my heart in my chest and my eyes off the floor. I have to tell myself repeatedly “slow down” as I talk, and if I can avoid making the first move, I will. Once I warm up, I'm fine, but those first few minutes, I'd rather just curl up and cry.

For me, the best medicine is getting involved. Finding a good support group has been crucial. Even if, like in my case, they live hundreds or thousands of miles away, they are by far the most supportive group of people I have ever met. My family is the backbone to who I am. They are amazing, supportive, involved and strong. Since the diagnosis, I've thrown myself into learning all I can about FX and special education law. I not only advocate for my children but for others in our area, including those without FX. We are also active in fundraising, organizing a walk to raise awareness and money for FX every year. I stay busy, I learn as I go, I listen to those who have walked this path before me. I take life one day at a time. I don't look at my children as “Fragile X” – I look at them as Parker and Allison. They are my world and I intend to make their world as wonderful a place as they make mine.

And yes, when need be, I take the time to be alone and cry. It's OK to say sometimes this stinks. That doesn't make you love your children or family any less. It's not always going to be fair or easy. When you see other children your child's age, there will be times it will hurt and frustrate you. You won't always have the answers for your children, for the teachers, or your friends, but you will always find a way to work through the current issues. You will always feel your child's pain, sometimes even when they don't or can't. If the best way for you to work through these days is to take a medication to help clear your mind and reduce your frustration, take it and enjoy life. Never feel guilty about needing to take something to help you through, to make your life more normal. Taking care of yourself is the first step in taking care of your children. Find that time for yourself. If it's a 5-minute walk around the block, an hour at the gym or sitting at the park, even if it's only once a week... take that time for yourself. You deserve it.

*Holly Roos, Canton, Illinois '05*

# *N is for ...*



## **Noise**

Since there have been a lot of messages regarding our children and the problem that some have with noise, especially in the car, I spoke with Mouse (our speech and language person) and Becki (our cognitive specialist). Here are the suggestions they offered:

- use earmuffs or ear phones
- use foods that take some time to get through (i.e. string cheese)
- use Bazooka bubble gum, 2 pieces
- allow the child to watch cartoons in the car
- have activities that the child likes, but can ONLY do in the car (no exceptions)

*Louise Gane, MS '98*

Where I live they have a huge support group for parents for children with autism spectrum disorders. Occasionally, they all get together at a local theatre and have a special viewing of a new movie specifically for kids with special needs. The theatre isn't as dark as usual and the sound is not as loud. The best part of all is that everyone understands when your child starts talking, starts rocking or does excessive hand-flapping in their seat. My son has never been able to tolerate or make it through a regular showing of a movie but he has made it all the way to the end at the special showings and loved every minute of it!

*Jackie, Marysville, Ohio '05*

My boys have always been very sensitive to noise, especially Nick, but his tolerance has improved with frequent exposure. The school bus was always very difficult, but it took us awhile to figure out that the noise was the problem. Nick would just sit in his seat, trembling with a terrified expression on his face, but unable to remove himself from the situation even when the bus was at our house. He was so disturbed that he could not verbalize the problem either. We got him on the small bus when it finally dawned on us what the problem was. We have had issues even there over the years with kids practicing their instruments on the bus or the driver playing the radio too loud. Of course, once again Nick could not tell us the problem, even though he is highly verbal. It takes a lot of detective work, and stubbornness in not listening to those in charge telling us that he is having discipline problems!

Movies, sporting events, shows, etc. have all caused similar reactions, but Nick has adapted by covering his ears, wearing hats or hoods, and most recently wearing ear plugs. My daughter is

active in sports, so we spend a lot of time in gyms and arenas. We have always taken the boys, and for the most part they have gotten used to it, and deal with it quite well. Thankfully the sports started out young and mild, and gradually worked up to noisier and more intense. The same goes for musical concerts and plays at school. They have been eased into them, and now they love them!

Jake is not as sensitive to noise as Nick. While Nick will pretty much crawl into as small a ball as possible, and cover his ears, Jake will run around like the hyper kid that he is. It seems like the more overstimulated he is, the crazier and wilder he is. Sometimes, he will sit, and just ask me to cover his ears, but we haven't been able to get him to wear the ear plugs yet.

Nick went to Medieval Times last week with the entire sixth grade, and his teachers were worried about how he would handle it. But he had his ear plugs and did just fine. As a matter of fact, he loved it!!

*Nancy, Upstate New York, '05*

In order to help decrease the noise for our kids we bought them ear protection headsets from the local sporting goods store. Each set was about \$15.00 so they aren't expensive. They are the same protection headwear that people use at target practice. OK, they are bright yellow and big but they block out all the extra noise for our kids when we take them to places with lots of people and noise. Our son uses them at the amusement park and community picnics. I keep a set in the house and a set in the car.

*Deborah Parker, Pennsylvania '05*

Noise, big noises especially, were traumatic for our son. Fireworks on the Fourth of July dropped out of our lives for a few years there. We celebrated with sparklers and were lucky to get by with those! What helped Christopher was gradually exposing him to big noises and telling him what was going to happen before it actually did. It wasn't a surprise then and he seemed to get used to noises over time. In fact, he goes to the NASCAR races every June with his dad and he loves them. Me? I don't go -- it's a noise thing!

*Carol Collins, Sandusky, Ohio '05*

Noise is the most profound thing affecting my ten-year-old FX daughter.

From the moment she arrived in this world, she was startled by noise to the point of hysterics. Voices, singing, laughter, clapping, thunder, music and general commotion--you name it and she freaked out because of it. It has been a chore finding ways to help her cope with a noisy world.

We didn't sing "Happy Birthday" until she was eight, because she couldn't handle it. We have banned her from watching the weather channels in anticipation of the next thunderstorm. We have trained ourselves and our immediate families to stifle laughter as much as possible when she is in the room. We don't walk into a movie theatre until the REALLY LOUD previews have finished. She can't sleep in a room with someone else because she cannot stand the sounds of other people when she is trying to sleep.

We make accommodations where we can and remove her from situations when she is losing her grip on control. Having said that, she turns the TV on too loud, dances to Avril Lavigne blasting in her room, and cannot hear me calling her to make her bed from 10 feet away. Go figure!

*Lori, Ontario, Canada '05*

## *O is for ...*



## **Obsessions**

What were actually early signs of Fragile X in our son Spencer we saw as cute eccentricities. Now we know they were obsessions that he just can't seem to control.

The earliest one we remember was when he wanted to take me (his mom) on a date. He was four. At first, I just thought "Oh, how cute." He could not stop talking about it, thinking about it, planning it. Finally, we had to "scratch that itch" as I now say regarding his obsessions. We *had* to go to a Chinese restaurant. It *had* to be just the two of us. I *had* to dress up, and he *had* to wear a coat and tie. When we got there, he *had* to pull the chair out for me. As I recall, we drew a crowd that evening. Everyone thought it was so cute.

The next one was along the same line, although it involved another "woman." In kindergarten, he fell head over heels in love with a little girl named Meredith. He always had to sit by her, go with her, and be with her. Fortunately, she was an adorable, sweet girl, very patient and easy-going. He decided that he wanted to marry her. He spent months thinking about, talking about, planning it. (Sound familiar?) We couldn't walk by a jewelry store in the mall without a scene because he wanted to pick out a ring. When we saw bridal shops he begged to go in. This went on and on with us constantly trying to minimize the importance of what he was asking for over and over and over and over again. Finally, one day here comes Spencer down our hallway, dressed in navy blazer, white shirt and tie, khaki pants and rolling a suitcase behind him. I asked the obvious question, "Where are you going?" His response was "I'm ready for my honeymoon." Then he parked the suitcase and headed out the back door. "Now what?" I asked. "I'm picking some flowers for the wedding," he responded. This ended only after kindergarten graduation, when he didn't see her as much. Spencer was the only boy invited to her birthday party that year.

It seems like Spencer is always obsessing about something. Here's a list of obsessions he's had: Power Rangers, shoes (comes and goes – typically about Converse, Vans, Adidas), CD players, cameras, backpacks (comes and goes), school supplies--school supplies--school supplies, hooded sweatshirts, and right now small pets (like hamsters).

He can obsess over just about anything and this is only a partial list. It can drive you crazy!

*Mary Lee Shelton, Mesilla, NM '05*

# Occupational Therapy (OT)

*See also Sensory Integration*

I can offer a few suggestions for you to try with your child at home. However, without knowing anything about your child's abilities or sensitivities it is impossible to know if these activities will be appropriate. Just keep in mind that you may need to start these activities in very small doses. If your child is like our son, he'll have no difficulty telling you if something is too difficult or uncomfortable for him. And that's OK. The idea is to start small and work up his strength and his tolerance.

Here are some ideas for the proprioceptive system:

1. Wheelbarrow walk around the house (Your son is upside down, 'walking' with his hands while you hold onto his ankles).
2. Pretend you're making him into a 'sandwich'. Place him lying down on a pillow and place another pillow on top of him. Gently apply pressure. The idea is to give his muscles the input from the pillows and the pressure. Then switch - let him apply pressure to you.
3. Wrap him up in a blanket - some kids love it (mine does); others HATE it.
4. Consider a mini-trampoline. I never felt that it was safe for my son because of attention and balance problems. However, other people swear by them.
5. Pretend you're going shopping. Have him carry around some heavy items or a plastic shopping basket filled with a few items to give it some heft.
6. Place marbles in modeling clay and have your son try to dig them out.

For the oral/motor you may want to try:

1. Popsicles. Encourage him to lick and suck on the popsicle rather than bite it.
2. Use straws whenever possible. See if he likes to 'drink' pudding or applesauce through the straw - great for oral motor.
3. Lick peanut butter off a spoon or plate. Or have him lick pudding off a plate.
4. Encourage him to eat crunchy foods.
5. Consider an electric toothbrush.

Lastly, get him out on the playground as much as possible. Encourage as much hanging, sliding, running, jumping and swinging as he can do. Have fun!

*Anonymous '98*

We've used brushing on one of our sons with some success. It was difficult to maintain the intense schedule, but when we did we saw some gains. He was going through some difficult times and it helped ease the anxiety. He no longer does it, though he's going through some changes at his work and we may begin again. Perhaps the brushing can be done between classes. I don't feel it is appropriate to have this done in your son's classroom in front of other children. This is especially true if your son is in junior or senior high. Kids can be tough on each other.

There are some simple things (deep pressure) that your son might be able to learn to do for himself. We offer our son a sour candy, such as a lemon drop or sweet tart. The tartness draws the focus to it and thus calms. Having a calming toy in his pocket that he can use to focus on is another idea (our son used theraputty and a small foam ball). This worked extremely well for situations where he had to go into a large group or new situation.

You mentioned you were using surgical brushes for the brushing technique. You might try “corn brushes” (used to clean silk from corn) – they are the same consistency and work just as well. They are available at kitchenware stores at a much cheaper price. We bought one for each of us.

Another tool for calming is a long, curly straw. The child has to suck so hard to get the drink up through it, it takes all of their energy and focus. I hope some of this helps. I know how hard it is to deal with anxiety issues. In fact I would suggest it is one of the most, if not *the* most, difficult things with Fragile X.

*Jeannie '98*

*P is for ...*



## **Picture Exchange Communication System (PECS)**

We started using PECS about a year and a half ago and it has helped Alex to communicate. From the very beginning, he has been able to see a symbol once, remember what it is and use it appropriately. He can have two different symbols for the same thing and use them interchangeably. He does not need actual photographs of the items/actions, but will respond to very basic black and white symbols.

He's now able to use the strip with the "I Want" symbol, paired with whatever he's asking for. He will tear it off and go find someone to give it to. He will point to each symbol to make a request. He will also flip through the binder to find whatever he's looking for. Since kids with FX are visual learners, I would recommend trying PECS. Alex signs also, but as with many kids who have FX, fine motor challenges can make the signs difficult for some people to understand.

*Julie, Maine, '05*

Using PECS we started with the “point to what you want,” graduated to “tell me what the picture is,” then on to taking away the pictures unless desperate. I got lots of our pictures from Ebay -- type in *autism* or *autistic* and they come up. The black/white stick PECS pictures were often too vague for Nicholas. I also have a program called "Picture It" and used it to create my own. I'm not a fan of the Boardmaker pictures either--vague concepts. We are using the pictures again since we had the words at the bottom for sight reading practice. We have the pictures and words and I made some of just the words. We are making slow but steady progress.

*Lexi Weber, Michigan '05*



## Website information:

[www.pecs.com](http://www.pecs.com) -

PECS, the Picture Exchange Communication System, was developed in 1985 as an augmentative/ alternative training package that teaches children and adults with autism and other communication deficits to initiate communication.

PECS begins with teaching a student to exchange a picture of a desired item with a "teacher" who immediately honors the request. The training protocol is based on B.F. Skinner's book, *Verbal Behavior*, so functional verbal operants are systematically taught using prompting and reinforcement strategies that will lead to independent communication. Verbal prompts are not used, thus building immediate initiation and avoiding prompt dependency. The system goes on to teach discrimination of symbols and then how to put them together in simple sentences. In the most advanced phases, individuals are taught to comment and answer direct questions.

The company which created PECS, Pyramid Educational Consultants, offers consulting services and products for educators and parents of children and adults with autism and related disabilities.

# Planned Failure

There are always stories on the listserv about the difficulties of taking FX children to public places or places where they will have to wait in line or stand still for a long (or short) period of time . When my two FX boys were little it took tremendous effort to get them to stand still and be quiet. During shopping trips they would try to run free and I realized that I was spending more time chasing kids and calling them back than I was shopping. This multiplied the effort I put into shopping by several times. I was tempted to just walk out of the store and come back later.

Then I realized something significant: my boys, even though they have a learning disability, do understand a lot. I came up with a strategy I call "PLANNED FAILURE".

It goes like this: Since it is difficult to continue shopping with screaming kids, and is too time consuming to drop everything and re-shop later, I would occasionally make a PLANNED FAILURE shopping trip. That is, I would go to the store with a very small list of non-essential things. This would allow me the freedom to say "If you boys don't stop making noise we are going home." Of course, they would continue to make noise. Then I would take them home. No matter how much they promised to be good. The next time we went to the store they believed me when I said they should behave.

It was not as simple as I have made it sound; it actually took many trips, with some improvement each time and the occasional "refresher course".

It also works in the car. If the boys were wild in the car I would take them home, get out of the car and go in the house for 15 minutes. I would let them think that we were done. The second time we left the house, I would tell them the rules: "If you make noise we're going home." "If you cry, we're going home." The boys were better behaved on the second trip. I would also make it a point to repeat the rules when we were driving past the same spot where we turned the car around.

Small children get three warnings, older children get one warning. The fewer the warnings the better, (but give at least one)

*Pat, San Jacinto, California'05*

# Preimplantation Genetic Diagnosis (PGD)

The Reproductive Genetics Institute (RGI) in Chicago is now doing Preimplantation Genetic Diagnosis (PGD) for Fragile X. Couples who are carriers may choose to screen their embryos for Fragile X before becoming pregnant. RGI specializes in genetic testing and has been doing PGD for many other disorders since 1990. Beware of other clinics that claim to test for Fragile X – they are sometimes only doing gender testing for females and eliminating males. Fragile X is very complicated to test for, and currently (October 2005) I only know of one other clinic in Belgium that can do it.

PGD for Fragile X involves in vitro fertilization (IVF) in which fertility drugs are taken to increase the number of follicles (eggs) produced in a cycle, the follicles are retrieved, fertilized with the father's sperm, and the resulting embryos are tested for Fragile X. The non-Fragile X embryos are then replaced in the mother's uterus to hopefully grow. In many cases, it is possible to work with a local fertility doctor, which works well since there is a great deal of monitoring involved throughout this process. When the follicles are ready for retrieval, RGI sends a lab technician (at your expense) who takes the biopsies of the embryos and sends them to Chicago to be tested. Families can also travel to Chicago for the retrieval and stay through the embryo transfer if you prefer.

Not all families are eligible for PGD. The way RGI tests for Fragile X is by establishing genetic markers on as many members of the immediate family as possible. Those markers are used to detect Fragile X embryos from non-Fragile X embryos on about day three after fertilization. Some families aren't considered "informative enough" and in those cases those families aren't eligible for PGD. This means there weren't enough differences in the family's DNA to be able to establish genetic markers to accurately detect the Fragile X embryos. Science is sometimes not simply black or white, so the more genetic markers RGI is able to identify generally relates to a higher degree of confidence in the diagnosis of each embryo RGI is able to give. The process is considered non-invasive and safe for the embryos because RGI tests a naturally discarded genetic material called polar bodies. If pregnancy is achieved, RGI recommends confirming the PGD diagnosis through either amniocentesis or chorionic villus sampling (CVS). In a high percentage of cases, the same forces that are responsible for 13% - 25% of Fragile X carriers experiencing premature ovarian failure also can mean that a carrier's reproductive age might differ greatly from their chronological age. This can make the fertility process more difficult and some cases not possible.

The following plan can help a Fragile X carrier prepare to be as receptive to the fertility medication as possible. A cycle for a Fragile X carrier should be considered successful if 7-9 healthy follicles can be retrieved. I do not have a medical background. This plan is based completely on my personal experience, including my experience of being a mother to Taylor (9, FX), James (7, non-FX) and Samantha (4, non-FX, PGD baby).

You should check with your own physician if you have any concerns at all and listen to your own body. I do think following this plan is critical for most Fragile X carriers to make the IVF process work and it could also be helpful when trying donor eggs as well. For more information about RGI's services, contact Christina or the genetic counselor on staff at 773-472-4900.

The plan to follow to get the most out of an IVF cycle (begin as soon as you know you will be trying IVF):

- Follow any medication instructions from your doctor exactly! Help your doctor by telling him/her before the stimulation process begins that Fragile X carriers have a history of reduced response to fertility medications. Though most doctors start with a moderate protocol so as to not over-stimulate, this is critical information your doctor will need to create your protocol and evaluate your progress.
- Eat at least a tablespoon of seeds such as sunflower seeds or other nuts a day.
- Absolutely NO caffeine. No exceptions.
- Absolutely NO smoking.
- Limit refined sugar intake.
- Take vitamins daily. In addition to a prenatal vitamin, I would also include vitamin A 10,000 mg, vitamin B complex 100 mg, vitamin C 500 mg, vitamin E 800 IU, calcium 500 mg, iron 18 mg, magnesium 250 mg.
- Try to incorporate a relaxing activity into your routine as often as possible such as yoga, massage, some simple stretching or an easy walk.

During the stimulation, continue everything above and add the following:

- Again, follow any medication instructions exactly! It is important you have a drug protocol that is right for you, so don't hesitate to get a 2nd opinion, research the drugs yourself, or ask your doctor about trying higher doses or different medications if the current protocol is not working.
- NO strenuous or aerobic exercise. It is more draining to your system than helpful during this time.
- Take 1 baby aspirin or low dosage adult aspirin a day.
- It is now CRITICAL that you limit stress in your life as much as possible. It's only for two or three weeks, so you can do it.
- Increase the relaxing activities if possible during this time.
- A nap a day is extremely beneficial during the stimulation--even if it is a short one.
- DO NOT limit calorie intake. A low calorie diet is not conducive to pregnancy.
- Think very positive thoughts, imagine everything working, be positive and don't get anxious. If it doesn't work you can try again. You must be positive.
- Keep in mind that this is a lot to ask from a busy person, but it's only for a couple of weeks.

After the egg retrieval:

Continue everything above but discontinue the supplemental vitamins at this point. Take only 1 prenatal vitamin a day (or as directed by your doctor). Very soon you could become pregnant and high doses of supplemental vitamins can actually do more harm than good.

After the embryo transfer:

- Stay off your feet for 72 hours. It's best to literally stay in bed. It is the best way to give everything the best possible chance of working. Plan in advance to have other people care for other children. Read, watch TV, even brush your teeth in bed and simply relax. People I know who have not done this have not had much success. For the first couple of weeks, it's best to try and limit physical activity.
- Absolutely NO alcohol or any medications other than the prenatal vitamin (other than what your doctor has prescribed) until after a pregnancy test. My doctor also prescribed progesterone oil injections for the first 12 weeks of the pregnancy. He felt that the

injections are dramatically more effective at helping your body keep the pregnancy than any other form of progesterone.

Most of this information was compiled from natural fertility books combined with common sense and prior experience. None of the items are in any particular order of importance because they are all equally important. I just did all of these things exactly, every day.

I hope all this information is helpful and good luck!

*Debbie Stevenson, Parent & FRAXA board member, New York '05*

**P**reimplantation Genetic Diagnosis (PGD) is a process that is used to test for single cell genetic disorders (like Fragile X). When my husband and I started planning for a family, we were referred to a genetic center because of my age. The genetic center asked about my family history, which revealed my nephew with autism, which led to me being tested for FX. After receiving the test results "positive - FX carrier," I began to investigate just what it was going to take for us to have children. I visited six in-vitro fertilization (IVF) specialists and five OB-GYNs before we were told we had a chance. I wasn't giving up! I'm not an expert in PGD or IVF, nor do I have a medical background... I'm just a female carrier looking for a way to conceive a child. This is what I found out:

PGD is a process that goes hand-in-hand with IVF. The first part of the process is to have markers established so the lab techs can identify the FX in your DNA. This requires the DNA of family members - those who have FX and those who do not - to establish a marker of what FX looks like in your family's DNA. Once the marker analysis set-up is complete, the next step in the process is to start an IVF cycle. After a cycle of hormones and blood work, when your body's prepared, you go in for egg extraction. They extract as many eggs as possible. The eggs are then fertilized. After fertilization, a cell is extracted from each embryo and its DNA is tested for FX. The egg(s) without FX are then implanted. This process is new and many IVF specialists are unfamiliar or don't have experience in it. I live in California and have been very fortunate to have found Dr. Daniel Potter at the Huntington Reproductive Center. I'll be flying a lab technician in from Reproductive Genetics Institute (RGI) in Chicago to perform the testing of the embryos. My husband and I will be starting this process this fall and with God's will, we'll become pregnant! This process is quite expensive and usually considered "experimental" by insurance companies and therefore not covered, but you can't put a price on a gift from God, that of a child. The pricing I've received so far is \$3,500 for the marker analysis set-up, \$4,500 for the PGD testing, \$2,500 for lab costs. All and all, with IVF and PGD, the cost reaches \$27,000 - \$30,000 (some insurance plans cover some of the IVF). The costs will vary depending on the IVF clinic, PGD clinic and labs you use.

Here are some helpful websites I've found on PGD:

[http://www.religioustolerance.org/abo\\_pgd.htm](http://www.religioustolerance.org/abo_pgd.htm)

[http://www.pgdcenter.com/pgd\\_ivf\\_centers/](http://www.pgdcenter.com/pgd_ivf_centers/)

<http://www.assisted-reproduction.com/pgd.htm>

Also an insurance website to read an example of what they don't cover (for Blue Cross/Blue Shield): <http://medicalpolicy.hcsc.net/medpolicies/disclaimer>. You have to accept the disclaimer, then it takes you to the appropriate screen.

*Corrinne Reese, California '05*

**D**eciding to have another child when you already have one with Fragile X Syndrome is difficult to say the least. It's also a very personal choice. We started to consider our options when Alex was only 9 months old because we knew it would take time to figure out what to do. We discussed all of the ethical issues and several months later decided to try PGD through RGI in Chicago. They have a wonderfully helpful staff who were very caring and sympathetic to our situation. We went through all of the preliminary testing and then I began the stimulation meds. We were so excited at the prospect of having a "healthy child" but were told by the staff at our fertility clinic in Massachusetts that the chances weren't too great given my age, the fact that I'm a FX carrier and the hormone levels they had tested for. Still we went into it with a positive outlook.

After several ultrasounds it became clear that I just wasn't going to produce enough eggs to make the retrieval worthwhile so the cycle was cancelled. We took a month off and then tried again. This time the meds were increased. We were cautiously optimistic. After another round of ultrasounds it was clear that it just wasn't going to work. This time I had even fewer eggs and wasn't responding well to the meds-- not uncommon for FX carriers. We had the option of trying a third time but realized that it was very stressful and difficult to go through the disappointments.

We then looked into adoption but soon realized that this just wasn't a viable option for us at that time for many reasons. We finally decided to just put it in God's hands and try naturally. We figured that if we had 2 kids with FX then it was meant to be. At least they'd have each other and Alex wouldn't be alone. We got pregnant quickly and had an amnio so we'd know what we're dealing with. Thankfully, the test came back negative...no FX and not even a carrier. Now we have 2 beautiful boys who are each so amazing and special in their own way.

*Julie, Maine '05*

## **Premature Ovarian Failure (POF)**

**F**or years, I was told I couldn't conceive because I had POF. At that time, they didn't know the reason. I took hormones and adjusted to a life without children, enjoying my nieces and nephews. After 7 years of marriage and never using birth control, I got pregnant. I almost fainted from the news. My pregnancy was uneventful, although we were terrified something would happen. My son was born perfectly healthy and he came home with us a few days later. When I was a teenager, I never had regular periods. After I went off the birth control pill, I never had a natural period again, only the ones induced by the progesterone.

*Jackie, Marysville, Ohio '05*

**A**fter my 21-month-old son was diagnosed with FX and I read that carriers had a chance of POF, I realized I had probably been in perimenopause for quite a while. I asked my doctor to check my hormone levels. They were normal and she said I probably didn't have to worry about POF. Because I was still getting used to the FX diagnosis, I didn't push myself to make a choice about whether or not to do IVF/PGD. I kept telling myself I had time to consider my options since the doctor said my perimenopause was all in my head. Well, I was right to think I was in perimenopause. At age 37, I was told I was postmenopausal after a blood test confirmed postmenopausal hormone levels (specifically FSH and LH). I no longer had a choice in having another biological child – that made me feel a bit sad. But I finally had medical proof that my menopausal symptoms were not just “in my head” – that made me happy.

**Additional Resources:**

[www.pofsupport.org](http://www.pofsupport.org)

<http://dir2.nichd.nih.gov/nichd/deb/geuPOF/>

## Puberty

When my son entered this stage I saw a lot more interest in girls but no real problems. One of the medications he is taking for anxiety (Paxil) has greatly reduced his libido. He is a typical teenager in many respects. He often tells me, "Whatever!" when he is irritated with me about something. He has always had aggressive outbursts but the bigger he got the more dangerous it was becoming. Thankfully, we discovered a relatively new medication, Abilify, and it has helped immensely in reducing the outbursts.

*Jackie, Marysville, Ohio '05*

I am by no means an expert but here is what I remember. Puberty is a **bear** to deal with for any pre-teen, teenager or older. It seemed to take forever. It affects everyone differently and there is no predicting reactions to anything; it could be tears, anger, giggles or hostility. For want of another reason, we blamed it on puberty and raging hormones.

Once, I found Glen watching professional cheerleaders in very skimpy bathing suits on TV. When I asked him why he was watching it, he said it was his favorite thing to watch. I replied that they were very pretty girls and I could understand why he liked watching them. I'm not sure if he watched them again but I guess my approval or at least lack of disapproval made it less of a forbidden thing to do and more acceptable.

The masturbation increased a bit and we did not get excited about telling him that if he wanted to do it (and we understood that it felt good), he needed to do it in his room or the bathroom only because it was a private thing that others did not need or want to see. Maybe it was the tone of voice that we used, quiet and calm so he could hear us, but I think it helped.

I remember smoking in my room when I lived with my parents and my father coming in, catching me flicking ashes out the window. His reaction was classic. He said "wait a moment, I'll get you an ashtray." It took all the fun and feeling of doing something I shouldn't be doing out of it.

*Dani, Virginia '05*

## *R is for ...*



## Reading

I have been very impressed with the posts that indicate children are reading. I wish John had learned to read better, but he didn't, or can't, except Logos and words at a first grade level... I called the Talking Library branch of Lighthouse for the Blind and they are sending me an application for John to be a member of their tape-lending program. Also, a newsletter from CITE contained an item that may provide a source of information for other kids who do not have strong reading skills, but are still interested in the world around them. It's called BOOMERANG, an audiotape magazine for kids 6 to 12. It is recorded in children's voices with a magazine's typical features: letters, jokes, historical articles, current events. The guy I spoke to said adults also subscribe because they enjoy the presentation of history. If you are interested, the number to call is 800-333-7858. There is an introductory price of I think \$40 for 12 (70 min) tapes. I do not know if it's a good value, but I want to try any avenue that will teach John how to access news of the world around him! Just thought I'd pass it on.

*Tonii '98*

David is in the regular grade seven class and has been in regular classes with his peers since grade three, with program support. When he reads to me he reads very quickly and skips many passages, however when I have him read instructions or directions he reads each word. When it was silent reading time, I could never tell if he was reading or not. He would flip through the book very quickly and seemed to be very upset. He really never seemed to enjoy it at all. I got a book on tape from another teacher and an extra copy for myself so I could ask him some questions about the story. I was amazed! His eyes followed along, I could see them leave the bottom of the left page and go to the top of the right page, and David would turn to the next page. He did this without cueing. Sometimes I would pretend I did not know where we were and motion to him "Where are we?" -- he would point it out for me and be right back on track. When reading was finished and we had to move on, it was always a struggle. He would shake his head and point to the book. Tapping it vigorously, showing me he did not want to put the novel down. (how about the rest of us - does it sound familiar?) During journal time (writing something interesting about something we just read) which is right after reading, he will talk about the book and reiterate complete passages he read in the book. Before talking books, journal time consisted of the same passages, which always started off with "my mom is nice..." With talking books David is able to slow down, and concentrate on the *story*. He enjoys reading very much now, and is always pleased when a new talking book arrives. My hopes with the talking books were to

gain his interest in books and reading. I hope to interest him so much that he just may slow down and read the book on his own. He can read, but he just seems - not calm enough - to settle down to it. David also wears headphones while he listens and reads along. I think the headphones are a big part of helping him to remain calm.

Jennifer '98

Alex has been blessed with some higher functioning skills. Although I remember when he was first diagnosed and thinking reading and writing would never be attained! But through a devoted special education teacher, working with Dr. Marcia Braden and her *Logo Reading*, attending many workshops, giving Alex the time and patience, and reading to him A LOT, he continues to make progress in reading. One of the most useful 'tools' we use is a 'window card.' Cutting out a window in the center of a 3 x 5 card, helped him to focus on one line at a time. You can begin with a small window to go word by word, and gradually make the window longer. Just placing the card on the page and moving it along kept the other words out of sight so there weren't as many distractions. We still use the window card, especially at night when meds have worn off and attention to task is brief! Obviously there isn't much 'flow' when reading this way, but Alex has the accomplishment of reading the words himself and feeling less frustrated or distracted. Also, use everyday logo's (as in Dr. Braden's *Logo Reading*) to help encourage word recognition. Since so many of our kids have a harder time phonetically, memorization seems to be what they use.

Jane '98

We started with *Hooked on Phonics* to memorize the sounds of the letters (at about 9 years) then because I am so random (personality) left it alone. Jordan started asking what things said as we were driving in the car and we would sound them out. We also played the alphabet game some times when we drive--although this largely depends on the day, atmosphere, processing, temperament--Jordan's and mine:). This lasted through age 10 ½. For Christmas, Jordan's aunt gave him a book on dogs, a Level One reader. He just took off. Reading is not his favorite activity, but he totally surprised me by getting his reading book (I found an old Ted and Sally book *a.k.a.* Dick and Jane, where there is a lot of repetition), and read about three stories. The other reward that we worked out was for every 10 stories read, he gets a pack of Baseball cards, and when he has read 240 minutes (a level determined from school), he gets a personal pan pizza.

Louise '98

Explode the Code is a series of workbooks. My son started using them when he was about 18. It uses pictures and phonics. He can still only read on a first grade level, but I think he memorized the words and he can decode sometimes if he has to. It also has them writing the words, so handwriting can be improved at the same time. [www.epsbooks.com](http://www.epsbooks.com)

Randy Green, Florida '05



### ***Reading Resources:***

#### **Books:**

“Reading Reflex: The Foolproof Phono-Graphix Method for Teaching Your Child to Read” (Paperback) by Carmen McGuinness and Geoffrey McGuinness. ISBN: 0684853671

#### **Websites:**

[http://www.riverdeep.net/products/edmark\\_reading\\_program/index.jhtml](http://www.riverdeep.net/products/edmark_reading_program/index.jhtml) - For Edmark Reading Programs.

<http://www.nrglearning.co.uk/phonographix.asp> - Phonograpix is a revolutionary way of teaching reading. Especially for children with Dyslexia, Phonographix makes sense of the complicated English language.

[www.Phonicsoup.com](http://www.Phonicsoup.com) – Phonics Soup is a language-based phonemic awareness program for teaching early reading skills.

<http://www.lblp.com/programs/conceptimagery.shtml> - Lindamood-Bell curriculum

[www.starfall.com](http://www.starfall.com). The Starfall learn-to-read website is offered free as a public service. They also provide writing journals and books at a very low cost that can be used with the website or separately. Teachers around the country are using Starfall materials as an inexpensive way to make the classroom more fun and to inspire a love of reading and writing.

## **Resources**

### **Fragile X Organizations and helpful Fragile X links:**

The following organizations are excellent sources of practical information and support.



#### **FRAXA Research Foundation**

Run by parents, relatives, and friends of those with Fragile X, as well as by medical professionals. Promotes and funds scientific research aimed at the treatment and cure of Fragile X. Publishes a newsletter and other materials, including a CD-ROM, about Fragile X; maintains a Web site and a listserv about Fragile X; and organizes advocacy and fundraising events around the country.

FRAXA Research Foundation

45 Pleasant St.

Newburyport, MA 01950

Phone: 978-462-1866

Fax: 978 463-9985

E-mail: [info@fraxa.org](mailto:info@fraxa.org)

Internet: [www.fraxa.org](http://www.fraxa.org)



### **National Fragile X Foundation**

Provides free information, telephone consultation and support to individuals with Fragile X, their families, educators, and health professionals. Sponsors conferences and publishes a quarterly newsletter, lesson planning guide and numerous special topic pamphlets. Promotes and funds scientific and clinical research aimed at the treatment and cure of Fragile X. Organizes a yearly national Advocacy Day in Washington DC. Has 65 affiliated Resource Groups/Parent Contacts in 45 states. Offers print and other media materials about Fragile X for families and professionals. Maintains 1500 + page website about all aspects of Fragile X and provides information in Spanish.

National Fragile X foundation  
PO Box 190488  
San Francisco, California 94119

Phone: 800-688-8765  
Fax: 925-938-9315  
E-mail: [NATLFX@Fragilex.org](mailto:NATLFX@Fragilex.org)  
Internet: [www.Fragilex.org](http://www.Fragilex.org)



### **Conquer Fragile X Foundation**

Seeks to create strong, dynamic linkages between Fragile X researchers in the United States and those abroad. Supports Fragile X research projects and encourages creative approaches to strengthen the body of Fragile X research through cooperation and coordination of research efforts.

Conquer Fragile X Foundation  
189 Bradley Place, Suite 1  
Palm Beach, FL 33480

Phone: 561-833-3457  
Fax: 877-275-1192  
E-mail: [mail@cfxf.org](mailto:mail@cfxf.org)  
Internet: [www.cfxf.org](http://www.cfxf.org)



### **Fragile X Information Center**

Providing Objective Information on Fragile X Syndrome to Parents and Professionals.  
Fragile X Information Center

FPG Child Development Institute  
University of North Carolina at Chapel Hill  
CB 8180 Chapel Hill, NC 27599

Internet: [www.fpg.unc.edu/~fxic/](http://www.fpg.unc.edu/~fxic/)

### **The National Institute of Child Health and Human Development (NICHD)**

The NICHD Information Resource Center is your one-stop source for NICHD brochures, booklets, and other materials related to the health of children, adults, families, and populations.

They have an excellent booklet titled “Families and Fragile X Syndrome” which is available free. Follow the order form instructions on their website. To order:

<http://www.nichd.nih.gov/publications/pubskey.cfm>.

You can contact the NICHD Information Resource Center at::

Phone: 800-370-2943

E-mail: [NICHDInformationResourceCenter@mail.nih.gov](mailto:NICHDInformationResourceCenter@mail.nih.gov)

Internet: [www.nichd.nih.gov](http://www.nichd.nih.gov)

### **Fragile X Clinics**

Clinic information may change and new clinics may form. For up-to-date information on Fragile X Clinics please visit FRAXA’s website at [www.fraxa.org](http://www.fraxa.org).

### **California:**

## **UCDAVIS M.I.N.D. INSTITUTE**

### **M.I.N.D. Institute**

Families with children who have neurodevelopmental disorders have found few answers to how they can help their children grow into healthy adults. UC Davis M.I.N.D. Institute offers these families new hope in unraveling the mystery that has long surrounded autism and autism spectrum disorders, Fragile X syndrome, and other developmental disorders. Drs. Randi and Paul Hagerman, well-known in the Fragile X world, are at the M.I.N.D. Institute.

The M.I.N.D. Institute  
2825 50th Street  
Sacramento, CA 95817

Toll-Free: Phone: 888-883-0961

Phone: 916-703-0280

Internet: [www.ucdmc.ucdavis.edu/mindinstitute](http://www.ucdmc.ucdavis.edu/mindinstitute)

### **U.C.L.A. Behavioral – Genetics Clinic**

The Lili Claire-UCLA Family Resource Center (FRC) was established in January 2001 under the partnership of the Lili Claire Foundation and the Tarjan Center for Developmental Disabilities of UCLA's Neuropsychiatric Institute and Hospital.

In affiliation with the UCLA Medical and Behavioral Genetics Clinics, the Family Resource Center offers a unique blend of medical, psychological and social services to children and adults living with Williams Syndrome and other neurogenetic developmental disabilities.

The Center provides clinical, informational, family support, and outreach services to help persons with neurogenetic developmental disabilities and their families.

U.C.L.A. Behavioral – Genetics Clinic  
U.C.L.A Psychiatry & Biobehavioral Sciences  
Box 951759  
58-24C NPI  
Los Angeles, CA 90095-1759  
Phone: 310-794-9516  
Internet: [www.liliclairefrc.ucla.edu](http://www.liliclairefrc.ucla.edu)

### **Colorado:**



### **Developmental and Fragile X Resource Center**

Developmental FX is a not-for-profit organization specializing in clinical services for families with Fragile X Syndrome and other neurodevelopmental disorders. Our co-founders are internationally recognized for their expertise and dedication to these areas. Together, they have assembled a highly experienced team of psychologists, therapists and physician-consultants to provide developmental assessments, intervention and training.

Developmental FX  
90 Madison Street, Suite 202  
Denver, Colorado USA 80206  
Phone: 303-333-8360  
Fax: 303-333-8380  
E-mail: [info@developmentalfx.org](mailto:info@developmentalfx.org)  
Internet: [www.developmentalfx.org/](http://www.developmentalfx.org/)

### **The Children's Hospital**

#### **The Child Development Unit- Fragile X Treatment & Research**

B-140

Denver, CO 80218

Phone: 303-861-6630

Internet: [www.tchden.org](http://www.tchden.org)

or [www.thechildrenshospital.org/pro/cs/detail.cfm?RecordID=214](http://www.thechildrenshospital.org/pro/cs/detail.cfm?RecordID=214)

### **Georgia:**

#### **Fragile X Syndrome Clinic**

The clinic serves children from newborn to age 18. The team includes physicians, scientists, and staff who have extensive experience in genetics and development with an emphasis on the needs of individuals with Fragile X syndrome and their families. During your clinic visit, we will

review your child's genetic results, complete a physical examination, provide a comprehensive developmental evaluation, discuss the recommended healthcare guidelines for children with Fragile X syndrome, offer genetic testing for family members, and, most importantly, address any concerns or answer questions you might have.

- Current focus – newborn to 18 years
- Medical & developmental assessment
- Treatment & interventional strategies
- Genetic Counseling
- Consultation
- Referrals
- Network with support groups
- Current educational resources
- Access to research projects

Emory/Baylor National Fragile X Center  
2165 N. Decatur Rd  
Atlanta, Georgia 30033

Phone: 404-712-8232

Internet: [www.genetics.emory.edu/genservices/peds\\_adult\\_genetic\\_services.php](http://www.genetics.emory.edu/genservices/peds_adult_genetic_services.php)  
[www.genetics.emory.edu/pdf/F-X%20brochure-final.pdf](http://www.genetics.emory.edu/pdf/F-X%20brochure-final.pdf)

## **Illinois:**

### **Fragile X Clinic**

The clinic at Rush was started in 1991 to serve the unique needs of the Fragile X population. The clinic maintains affiliations with specialists in pediatrics, neurology, genetics, optometry, child psychology, special education/education psychology, speech and language, occupational therapy and dentistry who have experience working with individuals with Fragile X.

Patients must have a diagnosis of Fragile X syndrome to make an appointment, which are often made two to three months in advance. In clinic, Dr. Elizabeth Berry-Kravis can make recommendations regarding medical problems, all neurological issues (for instance, seizures), medications for behavior, prescriptions and referrals to therapy, some aspects of educational management, and genetic testing and counseling.

Fragile X Clinic  
Rush University Medical Center  
Dr. Elizabeth Berry-Kravis, Pediatric Neurologist  
1725 West Harrison St., Suite 718  
Chicago, IL 60612

Phone: 312-942-4036

Email: [contact\\_rush@rush.edu](mailto:contact_rush@rush.edu)

Internet: [www.rush.edu/rumc/page-R12247.html](http://www.rush.edu/rumc/page-R12247.html)

**Maryland:****Kennedy Krieger Fragile X Clinic**

Kennedy Krieger clinical programs for Fragile X Syndrome are serviced through two different centers:

- Center for Autism and Related Disorders (CARD)
- Center for Development and Learning

Kennedy Krieger Institute

Fragile X Clinic

3901 Greenspring Ave

Rm. 208

Baltimore, MD 21211

Phone: 800-873-3377 (Care Management Office for initial appointments)

Phone: 443-923-9200

Internet: [www.kennedykrieger.org/kki\\_diag.jsp?pid=1086](http://www.kennedykrieger.org/kki_diag.jsp?pid=1086)

**Massachusetts:****Fragile X Clinic**

Massachusetts General Hospital

50 Stanford St., Suite 504

Boston, MA 02114

Phone: 617-726-1562

Internet: [www.mgh.harvard.edu](http://www.mgh.harvard.edu)

**New York:****New York State Institute for Basic Research**

Fragile X Center of George A Jervis Clinic

1050 Forest Hill Road

Staten Island, NY 10314

Phone: 718-494-5369

Internet [www.omr.state.ny.us/journal/20aniv/hp\\_journal2ibr.jsp](http://www.omr.state.ny.us/journal/20aniv/hp_journal2ibr.jsp)  
(informational, not specific for the clinic)

[can we get descriptive paragraphs for the above two?]

**North Carolina:****Duke University Medical Center Fragile X Clinic**

The Fragile X Clinic at Duke University Medical Center was started in 1987. The medical director is Dr. Ave M. Lachiewicz, a developmental pediatrician. The clinic is also staffed by Dr. Gail Spiridigliozzi, a clinical child psychologist, and Dr. Allyn McConkie-Rosell, a genetic counselor. Clinic visits include educational evaluation and recommendations as well a medical evaluation including discussion of developmental and medical interventions. Genetic Counseling is also provided. Recommendations are provided in a written report. Dr. Lachiewicz, Dr. Spiridigliozzi and Dr. McConkie-Rosell work together as a team. The clinic can also refer to other medical and developmental specialists including physical, occupational, and speech therapy. Families are typically seen for follow-up on an annual or biannual basis depending on need. Individuals with fragile X syndrome being seen for management of medicines are frequently seen more often.

Duke University Medical Center  
Dr. Ave M. Lachiewicz, Medical Director  
Duke Child Development Unit  
Community Guidance Clinic Building  
2nd Floor, Room 233  
402 Trent Drive  
Durham, NC 27705

Phone: 919-416-7218

Phone: 919- 684-0263

Fax: 919-286-6069

Internet: [www.dukehealth1.org/childrens\\_services/child\\_development.asp](http://www.dukehealth1.org/childrens_services/child_development.asp)

Email: [lachi002@mc.duke.edu](mailto:lachi002@mc.duke.edu)

## **Ohio:**

### **Akron Children's Hospital**

Carol Delahunty, MD, FAAP  
Neurodevelopmental Center  
Developmental and Behavioral Pediatrics  
Akron Children's Hospital  
One Perkins Square  
Akron, Ohio 44308-1062

Phone: 800-262-0333, ext. 38050

Phone: 330-543-8050

Fax: 330-543-8054

Internet: [www.akronchildrens.org/press/programs/2005/fragilex.html](http://www.akronchildrens.org/press/programs/2005/fragilex.html)  
[www.akronchildrens.org](http://www.akronchildrens.org)

## **Pennsylvania:**

### **Children's Hospital of Pittsburgh Fragile X Center**

The Fragile X Center provides evaluations, treatment, and support for children with Fragile X and their families. Staffed by a multidisciplinary team, we work together with hospital and community specialists to provide resources for your child and family.

Specialists from the Fragile X Center provide:

- Comprehensive developmental and behavioral assessment
- Appropriate referrals
- Research information
- Resource information
- Training, education, and support
- Continuity of care
- School Intervention Program

Children's Oakland Medical Building  
3420 Fifth Avenue  
Pittsburgh, PA 15213

Phone: 412-692-7027

Fax: 412-692-5679

Internet: [www.chp.edu/clinical/03a\\_fragilex.php](http://www.chp.edu/clinical/03a_fragilex.php)

## **Australia:**

**The Fragile X Alliance Clinic** was established in 1998 and is currently the only FXS-specific evaluation and treatment center in Australia. Families and caretakers bring both children and adults to be seen. For children, the emphasis is on identifying the educational, behavioral and support options that will enhance family life and optimize the child's abilities. Adults and premutation carriers together with their families are also seen for broader issues including medical and allied health management, counseling, lifestyle issues, provision of information, monitoring of progress and follow-up. The clinic is staffed by a multi-disciplinary team.

Fragile X Alliance Clinic

Contact: Bev Sher

Phone: (03) 9528 1910

## **Research Organizations**

For an up-to-date listing of research organizations, visit FRAXA.org and/or fragileX.org

The following organizations have research registries, databases in which you can register yourself and/or your child(ren) through the internet or via the telephone. Registration doesn't mean you have to participate in a study, but it will keep you informed of upcoming studies.

## **California:**

### **The M.I.N.D. Institute**

2825 50th Street

Sacramento, CA 95817

Toll-Free Phone: 888-883-0961

Phone: 916-703-0280

Register online: <http://www.ucdmc.ucdavis.edu/mindinstitute/research/studysignup.html>

## **Stanford University**

The Stanford Psychiatry Neuroimaging Laboratory (SPNL) research includes structural and functional imaging of the living brain utilizing primarily magnetic resonance imaging (MRI).

To join Stanford's Research Registry (to be contacted about future studies):

Phone: 888-411-2672

Register online: [http://spnl.stanford.edu/participating/participating\\_fragilex.htm](http://spnl.stanford.edu/participating/participating_fragilex.htm)

## **North Carolina:**

University of North Carolina – Chapel Hill

Register online: <http://www.fpg.unc.edu/~FXSRegistry/>

## **Wisconsin:**

Research Participation, Waisman Center

University of Wisconsin-Madison

1500 Highland Avenue

Madison, WI 53705

Phone: Len Abbeduto, 608-263-1737 or Susan Vial, 608-263-5192

Register online: [www.waisman.wisc.edu/rpc](http://www.waisman.wisc.edu/rpc)



## **Miscellaneous Organizations**

### **The Arc**

The Arc of the United States works to include all children and adults with cognitive, intellectual, and developmental disabilities in every community.

The Arc of the United States  
1010 Wayne Avenue, Suite 650  
Silver Spring, MD 20910

Phone: 301-565-3842

Fax: 301-565-3843

Fax: 301-565-5342

E-Mail: [info@thearc.org](mailto:info@thearc.org)

Internet: [www.thearc.org](http://www.thearc.org)

Sibling Support Project

Internet: [www.thearc.org/siblingsupport/](http://www.thearc.org/siblingsupport/)

### **National Dissemination Center for Children with Disabilities**

Formerly known as NICHCY, National Information Center for Children and Youth with Disabilities.

The center that provides information to the nation on: disabilities in children and youth; programs and services for infants, children, and youth with disabilities; IDEA, the nation's special education law; No Child Left Behind, the nation's general education law; and research-based information on effective practices for children with disabilities. Anyone can use our services—families, educators, administrators, journalists, and students. Our special focus is children and youth (birth to age 22).

National Dissemination Center for Children with Disabilities  
P.O. Box 1492  
Washington, DC 20013

Phone: 800-695-0285 · v/tty

Fax: 202-884-8441

E-Mail: [nichcy@aed.org](mailto:nichcy@aed.org)

Internet: [www.nichcy.org](http://www.nichcy.org)

NICHCY State Resources:

Internet: [www.nichcy.org/states.htm](http://www.nichcy.org/states.htm)

# *S is for ...*



## **Safety**

### *How do we keep him safe?*

PUBLISHED: September 9, 2004, The Grosse Pointe News

Many things may run through a parent's mind after he or she reads about certain tragedies.

In the past month, you may have heard of three people with autism who died after wandering from their homes. One died as the result of being hit by an automobile; two drowned within a short distance of home.

How do we keep Andrew, our 3 1/2-year-old son, safe? How does anyone keep his or her child safe?

To learn more, Mary Beth began by visiting [www.leanonus.org](http://www.leanonus.org). L.E.A.N. On Us, or The Law Enforcement Awareness Network, was founded by two police officers, who also happen to have a son with autism. The organization's mission is to create a network for first responders, advocates, individuals with hidden disabilities and families of loved ones affected to come together to provide resources and information.

L.E.A.N. On Us wants to help alleviate the occurrence of unfortunate situations such as those mentioned above. The organization feels by providing first responders with some additional tools, they will be able to provide more appropriate responses to individuals and also stay safe themselves.

One important thing a parent can do is to complete a Child Safety ID card for each of their children. If a child wanders off or is missing for any reason, it is very hard to remember or find all of the information that is needed while you are under such stress. L.E.A.N. On Us recommends updating a card each year and keeping the card in a spot where it will be easily found should it be necessary.

Mary Beth visited [www.leanonus.org](http://www.leanonus.org) to easily download and print a safety ID card.

Within 45 minutes of calling Lt. Ron Wiczorek of the City of Grosse Pointe Police Department, Andrew was being fingerprinted for his safety ID card. All of the Grosse Pointe officers they saw were friendly.

We hope Andrew will continue to learn officers are not people of whom to be afraid. If he's afraid of them, he may run away from them at a time when he actually needs them and should be running toward them.

There are even more reasons to teach this lesson to a child with special needs:

- \* It is five to 10 times more likely for a person with a disability to have contact with the police.
- \* Individuals with a disability are four to 10 times more likely to be victims of crime.
- \* Individuals with a disability are 50 to 99 percent more likely to be victimized by someone they know, such as a relative, teacher or bus driver (“Protecting Loved Ones With Autism,” C. Gammicchia, ASA Advocate, 2003, 2<sup>nd</sup> edition).

While at the police station for the fingerprinting, Mary Beth and Andrew dropped off a flier that invites folks, including first responders, to a Dennis Debbaudt presentation on September 27. Debbaudt is an internationally recognized authority on Autism Spectrum Disorders and safety issues. His presentation that morning will be “Autism Spectrum Disorders – Preventing Unfortunate Situations and Recognizing the Needs of Individuals with ASD in Our Communities.”

By the end of the day, Mary Beth had Andrew’s safety ID card completed, including his little fingerprints, and the knowledge that the City of Grosse Pointe Police Department was sending someone to participate in the training with Debbaudt. She slept a bit more sound that night knowing she had done a little to help keep Andrew safe.

Visit [www.leanonus.org](http://www.leanonus.org) to download the flier on the Debbaudt training. Do it for yourself, your police department or others who might need to know some ways to keep your children safe. And while you are at the site, download the safety ID card if you do not have one already.

It may help you get a good night’s rest, too.

*Theodore G. Coutilish and Mary Beth Langan, Grosse Pointe, Michigan ‘05*

**T**his is a story of fate and human error. I'm still working on keeping Todd safe and he is now 21 going on 22. He is currently occupied at Garten Foundation, which is set up to employ people with all kinds of disabilities and he rides a special bus called Wheels, which is curb-to-curb service. A few weeks ago, he missed the bus after work. He isn't high-functioning enough to go back to the workplace and tell someone that he missed his ride, so he began walking down a busy street to find the bus. Fate stepped in.

Some close friends of ours who are rarely in that neighborhood just happened to be driving down the street and saw Todd out in traffic. Cars were stopped in both directions. Thankfully, our friends quickly rescued him and brought him home. I called Garten and their people were very upset that something like this could happen. I did not upbraid them, but told them that he could not be there if something like this can happen. They were upset and extremely apologetic. I am told that they are making every effort to prevent a reoccurrence. I called Wheels and made them aware. I was told that the bus Todd tried to board was full and that another one was coming to get him. If that's the case, then the people who take him to the bus have to make sure that he is supervised until his ride comes. I couldn't imagine what would have happened if our friends hadn't found him. I'm convinced that there is no way to keep him completely safe, but working to reduce human error is one way. I can't always depend on fate!

*Carole Hellman, Salem, Oregon ‘05*

**Websites on Safety and/or products to keep our children safe:**

[www.childrensafetycorner.com](http://www.childrensafetycorner.com) – Children’s Safety Corner been created to act as a link to some of the best public access web pages dealing with children's fire safety and other life

safety issues. Children, parents, teachers, and safety educators should find this a valuable and efficient resource.

[www.cpsc.gov/cpsc/pub/pubs/chld\\_sfy.html](http://www.cpsc.gov/cpsc/pub/pubs/chld_sfy.html) - US Consumer Product Safety Commission, Child Safety Publications.

[www.safekids.com](http://www.safekids.com) - Your family's guide to making the Internet and Technology fun, safe and productive.

[www.saferchild.org](http://www.saferchild.org) - No one's born knowing how to parent. It's okay to ask for help -- and it's smart. But there's an overload of information out there, and sometimes you have to kiss a lot of toads before you find the prince. Our goal is to help you skip the toads. We want you to have the most professional and accurate links (with the most up-to-date and comprehensive information) so that you don't have to slog through the Internet yourself. In the process, hopefully we're helping your child -- and the other children of the world -- be healthier and safer.

[www.missingkids.com](http://www.missingkids.com) – National Center for Missing & Exploited Children, numerous resources and safety tips for parents.

[www.policeandautism.cjb.net](http://www.policeandautism.cjb.net) – Avoiding Unfortunate Situations by Dennis Debbaudt.

## Seizures

About 20% of boys with fragile X have at least one seizure during their lives; about half of them go on to have a seizure disorder, i.e. recurring seizures requiring treatment. A much smaller percentage of girls with fragile X can also experience seizures. Usually seizure activity in Fragile X will become fairly obvious---it is not usually subtle or difficult to diagnose. Even though some kids have mostly the minor or partial kinds of seizures when they are on meds, untreated kids with seizures will typically have at least one or two grand mal seizures, which are unmistakable. I have heard various neurologists at different conferences saying that it is unusual for Fragile X boys to start having seizures after age 4 or 5, however there are many folks on this list (including us) who can vouch for the fact that kids can start later than this. In fact, I have treated several adult patients with fragile X who suffered their first seizures as adults, with no obvious provocation. In many cases, the first childhood seizure is related to a febrile illness, but then the seizure disorder takes on a life of its own and seizures become more random and frequent if untreated. Most fragile X children respond to standard anticonvulsant therapies, with valproate (Depakote) often cited by pediatric neurologists as the single most effective agent.

*Dr. Mike Tranfaglia, FRAXA Research Foundation '05*

**H**is seizures began in 1993, were controlled by Tegretol until last year and he is now on Depakote. A growth spurt and hormone changes caused breakthrough seizures last year, including two grand mal along with many, many petit mal. He is fine now ... except the Depakote has caused a TREMENDOUS weight gain.

*Margie '98*

**O**ur daughter (3.5 years full mutation Fragile X) has a seizure disorder. It was one of the first signs of the stroke she suffered at or prior to birth. We tried to take her off the medication last

year, but her EKG showed extensive seizure activity even though we have not had break through seizures. She had been on Phenobarbital and was switched over to Tegretol. I like the Tegretol better; it seems to have less impact on her personality. The seizure activity is particularly severe when she is sleeping, which may explain some of her sleep disturbance. I will add that our daughter's recent Fragile X diagnosis has made her an 'interesting case' for her pediatric neurologist. His eyes get very bright and excited when he talks about it. I still can't decide how I feel about it.

*Anonymous '98*

**M**y son takes Dilantin for his seizures. Glen started on Dilantin at 18.5 years old after 2 grand-mal seizures. These are chewable tablets and the only side effects we have seen are increased hair growth and a thickening of the gums. We ensure the dentist knows that Glen is on Dilantin and get more frequent hair cuts - no big deal when it comes to side effects. Caffeine slows the way Dilantin works so Glen gets as little of it as possible. We also keep him as hydrated as possible and try to regulate the temperature in his room. Glen cannot take antihistamines or decongestants because they interfere in the way the Dilantin works. If necessary we can give him plain Sudafed. He has never had to take any yet.

The Epilepsy Foundation is a wonderful resource for seizure information and they are very helpful. They can be reached at 1-800-332-4050.

*Dani Feierstein, Chesapeake, Virginia '05*

Additional Resources recommended by Dani:

[www.epilepsy.com](http://www.epilepsy.com)

[www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)

## **Sensory Integration (SI)**

(See also "Toys with a Twist" for toys with a sensory benefit)

**I** recently attended the 11<sup>th</sup> Annual Fragile X Symposium in St. Louis. What a wonderful day! The symposium focused on hyperarousal and complex behaviors in FXS. Trust me, I paid close attention! Tracy and Mouse (Tracy Stackhouse, MA, OTR and Sarah "Mouse" Scharfenaker, MA, SLP from the Developmental FX Clinic in Denver) really put on a great day for us - so much information! It'll take me a while to have it all soak in!

**O**ne of the great things I brought back to try from the symposium was The 5 Finger Approach. Tracy and Mouse put this together. Not only did they show us how to do it and explain it in great detail, but they showed wonderful video of it in action. We are definitely going to give this a try at our house!

Here's how it works (from the worksheet we brought home).

Assign each of the 5 fingers on your hand an activity you can complete to relieve overstimulation:

1 - Quiet: find a place to get away from stimulation; a small sensory-free zone - under a box, a tent, even just under a blanket; make fidget and oral inputs and music available in this space.

2 - Breathe: breathe deeply - in through your nose and out from your mouth.

3 - Chew: and suck and blow! Busy mouth = calm self.

4 - Deep Pressure: try self-delivered hugs, pulls, squeezes, jumps; wall and desk pull- and push-ups; "pillow sandwiches".

5 - Engage in Movement: use a slow, rhythmic voice to calm; swing rock - engage in a rhythmic, repetitive and calming movement activity. Keep the hands busy - fidget and focus - busy hands = quiet body.

Side dialogues and social stories were also explained in great detail. It was a great day. As always, Tracy and Mouse were wonderful!

*Holly Roos, Canton, Illinois '05*

### **Tips for weighted vests or blankets:**

Some children with Fragile X find the deep pressure of weights and weighted clothing to be calming. Things such as ankle weights, wrist weights, a weighted vest, etc. Andrew often will draw a bit longer and is more calm while doing so if he wears ankle weights while standing in front of an easel.

There are many catalogs with deep-pressure clothing and weighted clothing and blankets, but these items can be expensive. I made a weighted vest for Andrew using a fleece vest and evenly sewing on a number of metal washers at the bottom of the inside of the vest. I mean the type of metal washer which is pretty flat, comes in different sizes/weights and has a hole in the middle, which made the sewing very easy. I asked an OT how much it should weigh for Andrew at the time and bought enough washers to add up to that weight.

For a weighted blanket, you could use a blanket or beach towel, something heavy enough to withstand the weight and sew the washers on one side and you're done. OR if you don't want the washers showing, sew another matching large beach towel (or blanket) on the other side of the washers. (Because the washers have a hole and I just sewed simple stitches around them, the pattern on the other side resembled a sunburst or flower, if this makes sense.)

*Mary Beth Langan, Grosse Pointe, Michigan '05*

Call around to some dentist offices and see if they have any old x-ray vests, they work really great! When they wear the dentists don't like to use them anymore and our dentist gladly gave us a boxful. They may not be the most attractive thing you ever saw but they more than serve the purpose and are free. They are a nice even weight too!

*Lisa Kowal, Buffalo, New York '05*

While at the teacher supply store buying items for home schooling, I bought a book about "SI: Practical Strategies and Sensory Motor Activities for Use in the Classroom" by Michael C Anderson. (ISBN: 0-7414-0268-1).

It's full of real ideas that would suit our kids. I bought a copy for my daughter's teacher, and she was very grateful. It was relatively inexpensive too.

*Suzanne S. Balvanz '05*

### **Additional Resources - Websites:**

[www.sensoryresources.com](http://www.sensoryresources.com) – Resources for raising children with sensory motor developmental and social-emotional challenges.

[www.sierf.org](http://www.sierf.org) – Sensory Integration Education & Research Foundation. An interactive website to be a valuable resource for education, research and treatment of Sensory Processing Disorder (SPD).

[www.sinetwork.org](http://www.sinetwork.org) - Excellent informational site.

[www.out-of-sync-child.com](http://www.out-of-sync-child.com) - Website has workshop listings and links to numerous sensory resources sites

[www.sifocus.com](http://www.sifocus.com) – The international magazine dedicated to improving Sensory Integration. Editor-in-Chief is Carol Stock Kranowitz, M.A., author of *The Out-of-Sync Child*.

### **Additional Resources - books:**

**The Out-of-Sync Child** by Carol Stock Kranowitz, M.A.  
Recognizing and Coping with Sensory Integration Dysfunction

**The Out-of-Sync Child Has Fun** -by Carol Stock Kranowitz, M.A.  
Activities for Kids with Sensory Integration Dysfunction

**101 Activities for Kids in Tight Spaces** by Carol Stock Kranowitz, M.A.  
At the doctor's office, on car, train and plane trips, home sick in bed... activity ideas that combine old standbys with new ones born of desperation and cramped quarters.

**Building Bridges Through Sensory Integration** – by Ellen Yack, M.Ed. B.Sc. (OT); Shirley Sutton, B.Sc. (OT); Paula Aquilla, B.Sc. (OT). 1998 – Syd and Ellen Lerer. Occupational therapy for children with Autism and other Pervasive Developmental Disorders. *Can be ordered from the Therapy Shoppe at 800- 261-5590 or Amazon at [www.amazon.com](http://www.amazon.com)*

**Sensory Integration and the Child** – A. Jean Ayres, PhD; 1979 – WPS –Los Angeles, CA. This book was written by the person who originally discovered, researched and named sensory integration dysfunction. It continues to be very worthwhile for the more intense reader. Intended audience is parents, but also an intense work for professionals. *Southpaw Enterprises 800-228-1698*

**Toolbox for Parents** – 2001 – Henry Occupational Therapy Services. Booklet of suggested home modifications and activities. The home suggestions include helping transitions, creating a homework environment, etc. *Order through Henry Occupational Therapy Services at 623-933-3821 or [www.ateachabout.com](http://www.ateachabout.com)*

**Toolbox for Teachers, Parents and Students** – 2001 – Henry Occupational Therapy Services. Booklet of activities that is practical and easy to understand. Most attention is given to the classroom. Inclusion based model that benefits all children. *Order through Henry Occupational Therapy Services at 623-933-3821 or [www.ateachabout.com](http://www.ateachabout.com)*

**Toolbox for Teachers, Parents and Students (video)**- 2001 – Henry Occupational Therapy Services. Makes the activities suggested in the book come alive and look easy. *Order through Henry Occupational Therapy Services at 623-933-3821 or [www.ateachabout.com](http://www.ateachabout.com)*

# Sibling Support

Josh's sister, Samantha (now 8 years old) is typically developing. We have not had her tested yet, but Fragile X is a common term in our home. She is fully aware that she may have a full mutation or may be a carrier. She also knows that she may not have it at all. We expect to have her tested within the next few years. We have been very fortunate to have a wonderful sister for Josh. She has taken on the role of big sister from day one. I think much of Josh's success can be attributed to his sister.

She has always provided a role model for Josh and challenged him to do things for which I didn't think he was ready. Samantha knows how to calm Josh down when he gets anxious about a situation. She has also come up with some silly games to play with him when he is having a difficult time transitioning. We do have some difficult times when Samantha realizes that she is missing out on something because Josh can't do it. I took the children to the movies when they were 3 and 4 years old. This was Josh's first movie. I thought I had a winner. It was "Elmo in Grouchland". We had popcorn (his favorite) and he loved Sesame Street. I thought "This will work out fine".

Well, as soon as the lights went down, Josh began to scream and cry. He didn't stop crying until I walked out of the theater (literally, as soon as one foot was out the door) with both Samantha and Josh, only five minutes into the show. We drove right to the Blockbuster and picked up "Elmo in Grouchland" and watched the movie at home. Josh did great. I think it was from that point on that Samantha began to understand that her brother had limitations on what he could handle. She is constantly cheering for him when he can do something that he hasn't been able to do. She will come running home to tell me that Josh was able to move to the second bar on the monkey bars before he fell off. She was ecstatic for him (along with mom) when he figured out how to ride his two wheel bike after his training wheels had broken (we had raised them so high that they couldn't handle the stress any more). Samantha is mature beyond her years. I know that we will probably have a time (teen years, ugh) when Samantha will want nothing to do with her brother. Hopefully, they have built a foundation of love and support that will carry them through to adulthood, when she can use the compassion and patience that she has learned in working with Josh for other things.

*Michelle Rocker, Charlottesville, Virginia '05*

## **Sibshops:**

Sibshops are pedal-to-the-metal celebrations of the many contributions made by brothers and sisters of kids with special needs.

Sibshops acknowledge that being the brother or sister of a person with special needs is for some a good thing, others a not-so-good thing, and for many, somewhere in-between. They reflect a belief that brothers and sisters have much to offer one another - if they are given a chance. Sibshops are a spirited mix of new games (designed to be unique, off-beat, and appealing to a wide ability range), new friends, and discussion activities.

The Sibshop curriculum is used throughout the United States, Canada, Croatia, England, Ireland, Iceland, Japan, New Zealand, Guatemala, Mexico, and Argentina.

[www.thearc.org/siblingsupport/sibshops-about](http://www.thearc.org/siblingsupport/sibshops-about)



# Sign Language

It took Andrew about 10 months to learn the sign for More. He was about 2.5 years old when he seemed to "get it" and use it. I thought (and hoped) the signs would start coming faster after that (like Helen Keller getting the sign for Water and then asking Anne Sullivan for the sign for everything else in her world). This was not the case. The good thing is that More can be a versatile sign. Andrew also uses it to mean Yes and I Want.

At 4.5 years old, he now uses the signs for: More, Eat and Please. Rarely he uses: Book and Drink. A new therapist is trying to teach: Go, On & a few others. It's been hard. He points and gestures a lot and we can understand a lot of what he wants to say, but it's not exactly optimal communication.

At school, they use PECS and say he's a pro, but we don't use it at home much because we don't have many icons and he "plays" us and just tries to use his favorite icons (bubbles, swing, bottle - and we're trying to switch to a cup). At home, we think PECS ends up being more frustrating for us and for him.

The IEP we just finished has, at our request, that we want an assistive technology evaluation this fall (by Nov 15 so they won't wait all year). That may show he's ready for an electronic device which could be used at home, school, all places. We borrowed a very simple one for the summer - only 4 buttons. He is learning Yes & No on the device, which he never learned in sign or PECS. I think he understands Yes more than No. We'll see. We knew when he answered Yes to "would you like to go get another haircut today?" that we had more work to do!

*Mary Beth Langan, Grosse Pointe, Michigan '05*

**W**e had a lot of success with sign language. When Josh was two (he is now 7) he was still not talking. We were concerned about his speech, as well as some other behaviors and we brought him to our pediatrician. Josh was evaluated and sent for several tests, one of which was Fragile X. We immediately started early intervention services and had a wonderful speech therapist assigned to Josh. She noticed that Josh loved balls and, during her sessions, she began using the sign for ball to get him to ask for it. It was amazing how quickly he learned how to do the sign. I asked if she could recommend a book of signing for simple signs. She recommended the book by Mickey Flodin "Signing Illustrated, a Complete Learning Guide".

We got the book and our family began learning all of the words that appeared to be important to Josh. Our daughter who is one year older than Josh, and was not showing any delays, was learning sign language with us, helping her brother do the signs. Before Josh turned three, he had learned over 100 signs. Most important were banana, popcorn, drink, please and thank you. During his first year in a pre-K program, Josh began to verbalize more words. I believe the signing was a great stepping stone for Josh to begin to communicate verbally. Josh now speaks beautifully. He can communicate in 3-5 word sentences, though sometimes he chooses not to. We still do some signs with him, especially when he is doing something off in the distance. If he is jumping out of line and looking at me during gymnastics, I will give him the sign for "wait". Many times he will still do the sign for "all done" when he is finished with something. I have also given him the sign for "sit down" as he is bouncing out of his seat as the bus drives off to school.

*Michelle Rocker, Charlottesville, Virginia '05*

# Sleep (How To Get More Of It!)

When my little one was very tiny, he started waking up at the crack of dawn and as I knew that my Fragile X cousin had never slept past 5:00 am I was very concerned. My little one wasn't getting enough sleep and was tired and crabby. I put black construction paper on the windows in his room so it was completely dark and immediately he began to sleep in! Now that he is a little older, I still have the windows blacked out by shades and mini-blinds but I do allow a little light to come in so that he knows it is morning. He is still a champion sleeper and we attribute it to the paper on the windows. It's also nice to get your kids to bed early in the summer for school, as his room is very dark early on.

*Angie '98*

We found little plastic stars that you glue to the ceiling. We put them up in our son's room. They glow in the dark. Now when we turn out the lights his room is like a planetarium. The stars seem to hold his interest long enough to help him calm down and fall asleep. He is 3 years old.

*Anonymous '98*

Tuck covers around very, very tight to sort of bind them in. Brent will now wake us to re-tuck his covers if he gets up in the middle of the night.

*Kim '98*

My unfortunate experience is that David did not sleep through the night until he was 6 years old. Now that he is 11 it seems like a different lifetime. Now he is a very good sleeper. Things that helped him: Having a transitional object--he called it a pet. It was Barney until just a month ago. Now we were able to switch him to a stegosaurus dinosaur that he called Steggi. When he wakened I would hand him his pet and that helped him go back to sleep; cuddling up with a down quilt in the winter and a light cover in summer. He needs something over him. His first down quilt had a very heavy cover and I thought this provided SI input. It didn't seem to prevent him from awakening but it did help him go back to sleep; our bedroom is right next to his and I would tell him that I was "right on the other side of the wall." This seemed to help him get to sleep.

*Anita '98*

Our son with Fragile X, 16 years old, has always had trouble going to sleep and always sleeps lightly (until the moment it's time to get up and get ready to go to school). We haven't had much trouble with nightmares, though we do have to have a night light on. You just kind of have to do your best. We insist that he stay in bed, keep his head down, and try to be quiet, but we don't try to make him sleep. He just eventually gives out.

*Paul '98*

Simon (now nearly 15) sleeps in a box. It's something he came up with about a year ago, on his own. He found a rather large box, turned it on its side, put it at the head of his bed, stuffed it with pillows, and draped a blanket over the top. After Princess Diana died, he added her picture to the

inside of the box. Every night, he lies down, sticks his head in the box, and goes to sleep. And now he rarely wakes up screaming. Don't know if this will work for anyone else.

Nancy '98\_

*Nancy Abrams of Millburn, New Jersey, would like the FX family to know that, at 22, Simon now sleeps well - without his Gateway box - and would sleep late every day if we let him!*

**W**e have been working really hard with our 4 year old son Keadon to sleep in his own room. He preferred to sleep with us for the longest time. I am so happy to say we have been successful by doing the following: we put him in his own bed when awake and read a story. In the beginning (probably 2 months) we would sleep on his floor until he fell asleep, and if he woke up in the night we would have to lay down on his floor again. Well, I am happy to say we don't have to do that anymore. I can now leave his room with him awake and he falls asleep on his own. Before I leave his room I do bribe him and let him know that in the morning he will watch his favorite cartoon and this makes him excited to get to sleep. He does wake up every night about 2:00 am to go to the bathroom, but he goes back to sleep right away.

Kareen '98\_

*Children up at first light? Not unusual for children with FX. The following are suggestions for making curtains that block out light. If you don't like to sew, and can afford them, JC Penney offers curtains that filter out daylight.*

**I** had to sew my own curtains for my son's room. We made simple cotton curtains and I sewed the blackout fabric on the underside to filter how much light can come through. We also have a room darkening mini-blinds set. With only the mini-blinds the light still sneaks through. The addition of the curtains helped. My son was up the minute the sun even thought about rising. In the summer that's pretty early. The blackout fabric is about \$6 a yard.

Lexi, Michigan '05

**W**e had the same issue. I went to the fabric store and purchased a material called blackout or blackout. They have two thicknesses. I bought the thickest one. I measured the curtain and bought that amount, sewing it to the back of the curtain. You could just tack it with thread and needle if you don't have a sewing machine. The material is thick. If you have a Joann Fabric store near you they frequently have 50% off coupons which can be used towards fabric purchases.

Faye, Florida '05

## Social Stories

**M**y daughter, Maddie, is 6 years old and we have used social stories consistently from the time she started early intervention at 2 years of age.

We first heard of them when we had our appointment with The Fragile X Clinic in Sydney. The people send a social story as part of the routine for each appointment. It contained a simple story with photos of all the therapists and their rooms and the routine that Maddie was to follow during

the day. We read the story to her a couple of times a day until she knew it off by heart. She took it with her on the day and pointed to pictures of the therapists as we saw them. It took the anxieties away about the new places and people and made the experience, for all of us, much easier, and less stressful.

We have used social stories for dentist and doctor visits, a hospital stay and the first day of school. We use the internet for pictures as well as photos taken on our digital camera. [www.do2learn.com](http://www.do2learn.com) has free pictures as does Microsoft clipart. Social Stories take the 'unknown' away from situations that can sometimes become overwhelming for some of our kids.

*Nicola Jones, Sydney, Australia '05*

### **Resources:**

[www.thegraycenter.org](http://www.thegraycenter.org) - The Gray Center For Social Learning and Understanding is a non-profit, 501(c)(3) organization dedicated to individuals with autism spectrum disorders (ASD) and those who work alongside them to improve mutual understanding. We approach the social impairment in ASD as a shared impairment. We work to improve social understanding on both sides of the social equation, helping individuals with ASD to communicate and interact more successfully with the people with whom they live and work

[www.sandbox-learning.com](http://www.sandbox-learning.com) - Sandbox-Learning. Personalized materials for each child are the ideal for learning and development. Sandbox Learning is dedicated to developing fun and engaging stories that help parents and professionals meet this need. Our collection of personalizable children's books addresses skills essential for development and truly allows children to identify with these skills through the personalization.

## **Speech, Language and Communication**

Casey had a very limited vocabulary up until 5 to 6 years of age. Around the 2 to 3-year-old level I think he had just a handful of words. When I put him in regular kindergarten his speech really picked up. Everything else did too. The point I want to make is that I think, for Casey, being 'in class' with those regular education children made it important to him to be understood. He had never cared about talking to adults or children prior to that time. He's 10 now and he speaks in sentences most of the time. His speech is still not clear but now he wants you to understand so he will repeat himself as many times as needed (for me). I've had the same kind of speech therapists for years-very structured, very stiff- and the same comment, "doesn't exhibit the proper listening behaviors." How I hate that statement...I've had them tell me that they could only work with Casey for about 5-10 minutes because of his attention span. Recently, I've had two different speech therapists on a new program we're on. One will work with Casey for a whole hour--no complaints--and they do the sessions on the floor, watching TV, playing ball, sitting and doing puzzles, doesn't matter. It's been great! Time and the child's own desire must be the real key.

*Becky '98*

I've seen this (stuttering) on occasion with our son. My feeling, and it's only that, is that this comes about as a result of over stimulation. If I'm talking to him and I see it happening I'll immediately look away or even turn my back so that eye contact is removed from the situation. My wife swears she's had some of her longest and best conversations with our son using this method. I'll also try to restructure the question or break up the information he is trying to provide into smaller segments so there's less pressure on each answer.

*Jeffrey '98*

Ditto on the stuttering! Our 9-year-old has been stuttering for the past 6 months. Also knows what he wants to say, but just can't get it out. His speech therapist has been trying this up and down motion type of thing. No scientific word for it yet that I am aware of. Justin is asked to slow down and then move your hand like a roller coaster up and down. It works for him 70% of the time.

*Teri '98*

From what I have seen with Fragile X children, they learn language in a different pattern from the non-Fragile X child. When we think of 'normal' language development we see one word, then two words and so on until the child is 'language competent.' I see a different pattern with Fragile X. They learn groups of words and phrases first, then start to break them down before building a more typical language pattern. With many children, I've been able to work within the 'starter phrase' mode to help guide them through the process. By that I mean that I teach them to use a phrase that would possibly start several different sentences, then adding completions so the child can see the patterns.

Patterns seem to be very important to these children, and with language, which is so abstract, the pattern needs to be presented in a very ordered way. NOT in a traditional teaching mode; that removes the usefulness of language from the reality of the child. But I digress. Sometimes in this build up and break down pattern, they revert to previously learned starter phrases that they discovered themselves. They have an ingrained language pattern that they might have used frequently in the past, but on this occasion they don't want to use that completion, and they know it. It bothers them. You can tell sometimes that there is some kind of struggle going on by the expression on their face. But the positive indicator to me is: where in the past we might have gotten a stock phrase or 'safe response,' the child is recognizing that there is something else that needs to be said, he wants to go down another path than the one his motor programming for speech is taking him down - he just can't find the path immediately. With FX children, I have found that to respond to the meaning of the message intended, and using correct modeling when understood, rather than the *form* he uses to express the meaning can be a positive tool for both the child and those around him. First, the child gets to understand that he doesn't need to fear possible communication breakdown--we can learn repair strategies. Second, we can be more relaxed around the child, and be a guide *vs.* a director. Think of a person with English as a Second Language. We tolerate their differences in language production so that we can exchange meanings and both our worlds can be enriched by the exchange. We don't spend time correcting their speech.

*Darryl (Speech Therapist) '98*

**J**ust thought I would add my two cents on the speech issue. Timmy is now six and his language development is at around a 3 year level. I spent 6 weeks with him constantly signing 'more' when he was about 2 and a half. He loved having candles lit so he could blow them out. So if he wanted them lit he would have to try and sign 'more.' If he didn't then I would motor him through it again. We went through a lot of matches but it worked.

It was easier to withhold lighting candles than withholding food or videos. After about three months of signing he started adding verbalizations with the signs.

*Mary '98*

**I** have a 6 year old who does not talk. He will pull us around to where he wants something, and then it is trying to figure out what he wants. Now that he is getting tall and used to our new house he is pulling chairs and stools to the counter to get what he wants himself. For not being verbal, he can communicate pretty well. Speech and sign are still top priorities, but they will come with time, I hope! I have a 13 year old FXS nephew who still doesn't talk.

*Teri '98*

**M**y son, who will be 6 in a few days, receives both private therapy and school therapy. I lobbied for and he is now receiving combined OT/PT and Speech Therapy in the same session. He also receives individual OT/PT & PT (physical therapy).

I would like to make a case for why I believe the combining of the two therapies is so important. The reasoning behind the combined approach is that receptively auditory impulses are processed by auditory nuclei in the brain stem and to the cerebellum, where the input is further mixed with motor messages. Which means that the auditory information being routed to the process areas is not purely auditory, but is at least partially dependent on motor information to have meaning. And because children with Fragile X have difficulty with motor sequencing skills, their auditory processing and intelligibility may be compromised.

Speech and language skill acquisition has frequently been linked to vestibular dysfunction. (Vestibular functions are: awareness of body position, movement position and movement in space; postural tone and equilibrium). So if you provide tactile and vestibular stimulation you can enhance your child's ability to organize sensory input and plan motor output (speech). Because by providing increased vestibular stimulation you will gain improved attention, body awareness, and motor planning, all of which effect speech and language development.

In a nutshell, the children who receive combined treatment make greater and faster gains, because during the therapy the children can see the language in action (remember also our children who have Fragile X are visual learners), and it promotes full use of gross and fine motor activities, adds the element of meaning and purpose to the movement. The most important reason, I feel, is that the speech and OT/PT therapists gain a greater knowledge of the whole child. His speech and motor abilities are taken as a whole, not separated into segments. So by combining their efforts they are able to share and come up with techniques that actually work toward integrating the whole child instead of breaking them into parts.

*Anonymous '98*

**I** had a comical conversation this afternoon. I was out in the driveway shooting hoops and Daniel came outside to play. He tells me, "I feel fine Dad." This is Daniel's code for something is

wrong. I asked, "Are you sick Daniel?" "No, I'm fine." "Do you need to visit the bathroom?" He says "No, I went." "Does your stomach hurt?" I asked. "I'm OK." he says. I continue probing, "Does your head or your throat hurt?" He says, "No, I'm fine." Finally I say, "Well, all right then, don't tell me you're fine unless you're really sick!"

Say what!!! Rewind the tape and play that again.

It turns out later this evening that he **is** sick after all. It seems to be the beginning of a head cold. The code works, it just causes funny conversations. I think he says "I'm fine" as his own form of positive thinking.

*Paul '98*

**M**atthew often speaks in 'code' or riddles when he wants something or wants to tell us something. For example, he came and got me the other day and asked "Where's Shortstop (our dog)?" I said, "In the house somewhere, I think." He continued to ask about her whereabouts until I began to worry we had left her out and she had run away. I followed Matt into the family room and he said "What's that?" and pointed to where the dog had had an accident on the carpet. Other examples: "I had a hot dog yesterday." Translation: would really prefer a hot dog today; "It's not cold out today" = I don't want to wear my coat. "Jacob's garage is open." = His friend down the street is probably home and he would like to go down there. "I did my reading today" = He probably didn't do his math. It has helped some for us to give Matthew the words/phrases he needs. For instance when he says "I think we have bagels" we ask him to say "Could I have a snack, please?" It seems to work after enough repetitions.

*Wendy '98*

**M**y son was non-verbal pretty much until he was 6 or 7. He could say a few basic words for things he wanted but not ever more than one word. One day out of the blue when he was 6 or 7 he said a real sentence! I wish I could remember the words he said. He was probably giving me a command, knowing him! Now at 15, he talks nonstop and I just think of all the hours we spent in speech therapy, when I agonized if he would ever talk!

*Jackie, Marysville, Ohio '05*

**M**any times I see everybody but me (the mommy) look confused and helpless when my son talks to them. I feel like a foreign language interpreter. Understanding my son's attempts at communication are critical to his feeling of success and self-esteem. Not to mention that "mommy always loves (and understands) you" security they need.

To help yourself and others, every time you get a sound or word "translated," WRITE it down in a journal you keep just for this purpose. I began sending a journal to my son's first special school with the first page reading:

poo means Winnie the Pooh bear

poppop means popcorn

oose means juice

zeezee means kitty

peas means please

nana means banana, and so on.

He had about 10 words. Most were only one syllable. And no, Mommy was not on the list for a year. As I look back to this page, I am reminded of how far he has come in two years. He still is difficult to understand for others... but I always repeat what he says to me so he knows the correct pronunciation... and to translate. If I have to guess the word, he tells me "yes" when I get it right. In the beginning, I would add words to the list and then review it to make sure I knew them and could reward my son with understanding.

*Susan McBurnie, Charlton, New York '05*

**F**ollow a child or teenager around for a day and you'll learn that language is central to virtually every encounter with the world. Much of what is taught in school involves adults and peers presenting information orally. Participating in games on the playground requires using language to invite others to play or to request "admission" to an ongoing game or group. Even getting food at lunch typically requires using language. For many youth with fragile X syndrome, however, learning to use and understand language is a great challenge, and for some affected children, spoken language is completely beyond their grasp. These limitations in the language arena make navigating daily life immensely more challenging. It is absolutely critical, therefore, that families and professionals work together to understand the challenges and strengths that each youth has in language so that they can devise ways to foster further language development and help the youth maximize whatever language skills he or she has.

My colleagues and I have spent the better part of 25 years trying to understand the language challenges facing youth with developmental disabilities, and the past eight years or so have been focused largely on fragile X syndrome. We have learned a good deal about the language challenges and strengths of youth with fragile X syndrome, and I am happy to have the opportunity to share some of our findings. Before I do so, however, it's important to recognize that there is incredible variability among children with fragile X syndrome as regards the severity and nature of their language challenges.

So, although our findings "fit" many youth with the syndrome, they do not apply to all. In our own research, we've worked mainly with children and adolescents who can speak using phrases or sentences. From a practical standpoint, these findings provide a starting point for thinking about the assessment and treatment of any child or adolescent with fragile X syndrome, but a good clinician will dig much deeper to understand the unique needs of the individual. So, with that rather lengthy preamble, here are a few things that we have found.

- Learning a language – in the sense of learning what words mean and the "rules" for combining those words into phrases and sentences – is a challenge for many youth with fragile X syndrome, particularly boys. At the same time, however, learning vocabulary and combinatorial rules is often much less of a challenge than is learning how to use those words and rules to talk and listen in everyday social interactions. This means that any language therapy that relies on flashcards or other highly didactic approaches probably won't have much of an impact on a youth's "everyday" speaking and listening skills. The most effective language intervention will incorporate language teaching into meaningful social activities, such as learning how to request desired objects at play, how to greet people, how to ask questions in the classroom, etc.
- Perseveration, or the repetitive use of language, is frequent among youth with fragile X syndrome, particularly boys, and it can interfere with full participation in social interaction. We've also learned, however, that perseveration is more likely to occur in relatively



unstructured interactions, like conversation, than in highly structured, goal-oriented activities, like describing pictures in a book. In addition, our research suggests that different types of repetition can reflect very different types of underlying problems; for example, repeating syllables over and over again might reflect difficulties with the mechanics of speech, whereas repeating the same phrase or topic might reflect difficulties in attention and planning. These findings suggest that adding structure to an interaction -- breaking it down into a series of smaller, highly orchestrated steps -- might reduce some types of repetitive language. The findings also suggest that some of the therapies designed for stuttering or word-finding difficulties may be helpful for some types of repetition in fragile X syndrome as well.

- In many respects, communication is simply giving people the information they need. In our research, however, we have found that this is an area of special challenge for youth with fragile X syndrome. These youth, for example, tend to use vague and inconsistent descriptions when describing objects, especially when they cannot rely on gestures, like when talking on the telephone or talking about objects that are not physically present. We believe that parents, teachers, and clinicians can help here by responding to uninformative messages with directives that clearly indicate the information that is missing; for example, “You said you want the hat, but there are lots of hats here. Tell me the color you want.”
- Being an effective listener means monitoring your understanding on what is being said so that you know when you don’t understand or are uncertain of the speaker’s intent. In our research, we have found that this is also an area of special challenge for youth with fragile X syndrome. They often rush to respond to directions, for example, and fail to recognize that the directions are incomplete or that they have misunderstood them. They seldom ask questions that clarify misunderstanding, like “which color did you mean?” Instead, these youth allow the misunderstanding to “snowball” over the course of an interaction, which means that the interaction is likely to be frustrating to them and to others. We believe that youth with fragile X syndrome could improve in this area if we occasionally tried to “slow them down” (e.g., by saying, “Not yet. Think about what I said first.”), if we provide them with corrective feedback when they act without understanding (e.g., “that’s not what I said to do.”), and if we periodically “test” their comprehension so that we can make their misunderstandings explicit (e.g., “which book did I want you to read?”).

We’ve learned a lot about the language challenges facing youth with fragile X syndrome, and we thank the many families who have participated with enthusiasm and patience. However, there is still a lot that we don’t know. Most importantly, we know very little about why some children with fragile X syndrome develop quite good language skills, whereas others end up with very limited skills. This is an issue that must be addressed if we are to provide effective interventions and therapies, and it’s the focus of our current research project, which is funded by the National Institutes of Health. If you would like to learn more about this project, please contact me at [abbeduto@waisman.wisc.edu](mailto:abbeduto@waisman.wisc.edu).

If you’re interested in reading more about our research or about our thoughts on language intervention, I recommend the following articles, although some are rather technical:

Abbeduto, L., & Hagerman, R. (1997). Language and communication in fragile X syndrome. *Mental Retardation and Developmental Disabilities Research Reviews*, 3, 313-322.

Murphy, M. M., & Abbeduto, L. (2003). Language and communication in fragile X syndrome. In L. Abbeduto (ed.), *International Review of Research in Mental Retardation*, Vol. 27 (pp. 83-119). New York: Academic Press.

We've also written some papers on Down syndrome that I think have relevance for understanding and treating language challenges in fragile X syndrome, including:

Abbeduto, L., & Keller-Bell, Y. (2003). Pragmatic development and communication training. In S. Buckley and J. Rondal (Eds.), *Language intervention in Down syndrome* (pp. 98-115). London: Whurr Publishers.

Abbeduto, L., Pavetto, M., Kesin, E., Weissman, M. D., Karadottir, S., O'Brien, A., & Cawthon, S. (2001). The linguistic and cognitive profile of Down syndrome: Evidence from a comparison with fragile X syndrome. *Down Syndrome Research and Practice*, 7, 9-15.

*Leonard Abbeduto, Ph.D., Professor, Dept. of Educational Psychology & Associate Director for Behavioral Sciences, Waisman Center, University of Wisconsin-Madison '05*

### **Additional resources:**

[www.speechfun.com](http://www.speechfun.com) - Speechfun is a website hosted by two Florida women – a speech pathologist and a parent of a child with autism. It offers “supplemental software for the classroom and home” for parents, teachers and therapists.

The offerings change often and are free, free, free! They have activity sheets, 2.5” PECS cards, sign language cards plus an excellent page with great links to other sites helpful in improving speech, language and communication. Check it out!

[www.promtinstitute.com](http://www.promtinstitute.com) - Information on PROMPT, a speech therapy method recommended for some children with fragile X. The site includes good links, resources and offers a means to find a local SLP who is trained in PROMPT.

[www.mayer-johnson.com](http://www.mayer-johnson.com) - The company which created the Boardmaker system using Picture Communication Symbols (PECS).

[www.superduperinc.com](http://www.superduperinc.com) - It's a great catalog/connection for speech/language information.

## **Sports**

**O**ur 9 year old son Michael loves swimming but we spent about 3 years getting here until we discovered he needed:

1. A hot or at least very warm pool (hydrotherapy or bath temperature). This is very important as there probably is an SI thing. I don't like cold water either.
2. The right instructor - empathic, warm, gentle, patient+++, able to go one very small step at a time, spend just a few minutes doing one thing, then something else ... present it as a game etc.

Let your child hang onto your neck until she gets used to it and bored. This could take literally weeks but don't give up. The end result is worth it. Michael can now dive and snorkel, float and when he does freestyle looks like he's drowning but now he loves it so much you can't get him out of the pool. He has also just started swimming underwater in very cold water and continually amazes us. Keep trying different things and it will happen.

*Dr. Jonathan Cohen '98*

**T**o teach any kid to swim easily, I have used the following strategy: We all like to be held securely, right? Especially in scary situations like unfamiliar water! Buy a swimming ring that fits snugly around the child. It should be tight enough that they can't slip out, yet leave plenty of

room for arms to paddle and splash. Just encourage them to get in shallow water and play with the ring on. Try to move them a little deeper each time in the water, but always with the ring. Next, as they are comfortable, and forget about falling underwater (because they have learned the ring will keep them afloat), let a TINY bit of air out of the ring when they are not looking. Each week, lose a little more air. Without realizing it, arm and leg movements will compensate for the loss of buoyancy from the ring.

*Tonii '98*

**K**arate, in the right setting, is a great individual sport, teaches self defense and in a lot of ways can be like an added PT or OT session. Find a non-competitive karate studio and start your child when they are young.

*Pattie Devlin, Burlington, New Jersey '05*

## Stress

**Stress Management for Parents** - Stress is a normal part of life and affects all of us in some way or another. Some stress is actually good in that it can motivate us to make changes or get things moving in a positive direction. One type of stress, often referred to as chronic stress, occurs in the context of a long-term, ongoing situation. Parents of children with special needs are particularly at risk for experiencing chronic stress. The impact of chronic stress is intensified for those parents who are also experiencing their own physical or mental health difficulties and perceive themselves as having little or no support. Chronic stress plays a role in many health problems, but has a particular negative impact on the cardiovascular system, nervous system, and immune system. It can lead to clinical depression and anxiety, concentration difficulties and relationship problems.

One of the good things about stress is that it is easy to identify--in that our body often gives us very direct cues if we know what to look for. The following is a list of some of the signs of stress.

### **Physical Signs of Stress:**

- Headaches
- Stomachaches
- Muscle Tension (stiff neck or shoulders)
- Backaches
- Teeth clenching or grinding
- Sweaty Palms

### **Emotional and Behavioral Signs:**

- Sleep disturbance – difficulty falling asleep, frequently waking up
- Feeling tired all the time
- Overeating
- Loss of Appetite
- Irritability
- Losing temper more often, yelling
- Concentrate difficulties
- More disorganized than usual, losing things
- Excessive worrying
- Difficulty making decisions
- Reliance on alcohol, nicotine, or illicit drugs

The intensity and duration of the above symptoms is important to consider. The more symptoms you have at the same time, the worse the stress may be. Typically, the symptoms worsen over time, which gives you a chance to intervene and do something to manage the stress before it becomes life-threatening.

Managing stress takes time--which can be a problem in and of itself for parents. However, if you don't take the time to manage your chronic stress, your children may find themselves alone in a

world without you. I suggest that **every day** you make a commitment to doing at least **FIVE** of the things below.

**General strategies to reduce the impact of chronic stress:**

1. Set a realistic daily “To-Do” list (anything else you get done is icing on the cake)
2. Organize things the night before as much as possible
3. Don’t be afraid to ask for help from family, friends, sitters, etc.
4. Don’t over-commit yourself
5. Get enough sleep (8 hours per night recommended for the average adult)
6. Drink 8 – 10 glasses of water per day
7. Eat healthy foods (fruits, vegetables), balanced diet
8. Find humor in things throughout the day

**Strategies to Immediately Alleviate Stress:**

1. Read
2. Exercise
  - a. Aerobic exercise – walking, bicycling, swimming
  - b. Stretching – relieves muscle tension
3. Breathing Exercises
  - a. Slow deep breath in to the count of 3 seconds, hold for 1 second, then release slowly to the count of 3 seconds.
  - b. Fast deep breath in, hold it, release breath quickly
4. Say positive things to yourself. Change negative thinking to positive thinking.
  - a. “I can handle this.”
  - b. “I’ve done this before.”
  - c. “What is the worst that could happen and is that so bad?”
  - d. “Slow down”
  - e. “This is not the end of the world.”
5. Take a bath or shower
6. Listen to music
7. Take a drive
8. Get a massage
9. Writing/ Journaling (10 –15 minutes/per day)
10. Talk to someone
11. Find a hobby – scrap booking, gardening, crafts, woodworking
12. Play with a pet

Managing stress, much like diet and exercise, is a lifestyle choice. Quick fixes rarely, if ever work. If you have been experiencing symptoms of stress for more than 2 weeks and the techniques listed above or in the self-help references listed below are not helping, it might be time to consider professional help. Taking the step toward seeing a counselor is not a sign of weakness, but rather a sign of strength in that you are using resources available to you to solve a problem.

**Recommended Reading:**

1. *Don’t Sweat the Small Stuff.... And It’s All Small Stuff* by Richard Carlson
2. *Relaxation and Stress Reduction Workbook, 5th Edition* by Martha Davis, Matthew McKay, and Elizabeth Robbins Eshelman

3. *Feeling Good Handbook* by David Burns, M.D.
4. *Instant Stretches for Stress Relief* by Mark Evans
5. *Learned Optimism* by Martin Seligman, Ph.D. (also available on Compact Disc)
6. *What you can Change and What you Can't: The Complete Guide to Successful Self-Improvement* by Martin Seligman, Ph.D.

*Dr. Pamela McCaskill is a Licensed Clinical Psychologist in private practice with a specialization in stress management and working with parents of children with special needs. She has extensive training in the evaluation and treatment of children, adolescents, and families with a variety of clinical presentations, including behavior problems, school difficulties, ADHD, anxiety and depression. Dr. McCaskill is currently practicing in Plymouth, Michigan.*

***T is for ...***



## **Therapeutic Listening**

I am a big fan of The Listening Program®. My son Zachary is going through the program for the second time and we have seen wonderful results thus far.

The Listening Program is a Music-Based Auditory Stimulation method that is used to train the auditory skills needed to effectively listen, learn, and communicate. It consists of an extensive series of high-quality audio CDs that integrate specially produced acoustic music, primarily classical, with innovative sound processing techniques.

The Listening Program benefits people of all ages starting as young as two. It is the only Auditory Stimulation method that has a patent pending process of music production and sound engineering. Advanced Brain Technologies, LLC (ABT) developed The Listening Program building upon key concepts originated by the late Alfred Tomatis, M.D., a pioneer in the field of auditory intervention. Additional information can be found at: [www.thelisteningprogram.com](http://www.thelisteningprogram.com).

*Kerry Huffman, Minnesota '05*

## **Therapeutic Materials – Resources**

(for ideas and/or purchases)

These are out of alphabetical order. Beyond Play should come 2<sup>nd</sup>.

**Abilitations**

Norcross, GA  
800-850-8602  
[www.abilitations.com](http://www.abilitations.com)

**Beyond Play**

Berkley, CA  
877-428-1244  
[www.beyondplay.com](http://www.beyondplay.com)

**Jump-In**

Hamburg, MI  
810—231-9042  
[www.jump-in-products.com](http://www.jump-in-products.com)

**Play with a Purpose**

Owatonna, MN  
888-330-1826  
[www.pwaponline.com](http://www.pwaponline.com)

**Sensory Resources**

Las Vegas, NV  
888-357-5867  
[www.sensoryresources.com](http://www.sensoryresources.com)

**Super Duper Publications**

Greenville, SC  
800-277-8737  
[www.superduperinc.com](http://www.superduperinc.com)

**Velvasoft**

Seguin, TX  
877-656-5228  
[www.velvasoft.com](http://www.velvasoft.com)

**Woodbine House**

Bethesda, MD  
800-843-7323  
[www.woodbinehouse.com](http://www.woodbinehouse.com)

**Flaghouse**

Hasbrouck Heights, NJ  
800-793-7900  
[www.SpecialPopulations.com](http://www.SpecialPopulations.com)

**Integrations/Sensory Solutions**

Atlanta, GA  
800-622-0638  
[www.integrationscatalog.com](http://www.integrationscatalog.com)

**Mancino Gymnastics Catalog**

Philadelphia, PA  
800-338-6287  
[www.mancinomats.com](http://www.mancinomats.com)

**S&S Discount Sports**

Colchester, CT  
800-243-9232  
[www.ssw.com](http://www.ssw.com)

**Southpaw Enterprises**

Dayton, OH  
800-228-1698  
[www.southpawenterprises.com](http://www.southpawenterprises.com)

**Therapy Shoppe**

Grand Rapids, MI  
800-261-5590  
[www.TherapyShoppe.com](http://www.TherapyShoppe.com)

**Wolverine Sports for Kids**

Ann Arbor, MI  
800-521-2832  
[www.wolverinesports.com](http://www.wolverinesports.com)

## Toilet Training

**H**ate to tell you this, but my son, Pat, now 12, was not trained until he was 6. That's not to say that others don't train earlier. I think it's hard for them to interpret their bodies' signals. What Pat's school behavior specialist suggested, and this worked, was to have Pat watch my husband peeing standing up, and also to find a squirt bottle, fill it with water, and have him squirt in the toilet, like pretending to pee. These visual things helped a lot.

*Sue '98*

### Potty Training in a Weekend

This is a procedure that worked for us. We did it over 2 days when our son was 4 ½. You have to decide when it's right to try it with your child and if and how to modify the procedure. If any

step seems too simple or too advanced for your child don't hesitate to make changes. Be creative and make it FUN and hopefully it will work.

**Keep in mind that:**

FX Kids are visual learners.

FX Kids have excellent imitation skills and can mimic well.

**Preparation:**

\*Check "Toilet Training in Less Than a Day" by Nathan Azrin and Richard Foxx and Videotape "Once Upon a Potty" out of your local library.

\*Arrange for a weekend alone with your child (book says 1 day you'll probably need 2). Have siblings sleep out.

\*Stock up on salty snacks like pretzels and potato chips and your child's favorite drink. Also, get a real special treat for successes. Don't worry about healthy foods.

\*Have at least 6 changes of underpants on hand.

**Procedure:**

\*Introduce the subject 1 or 2 days before to create excitement for the weekend together.

\*Start the morning with the Videotape. Learn the song with your child and sing it throughout the day.

\*Start the child drinking his favorite drink and as much of it as you can get in. Give as much of the salty snacks as they will eat to make them drink even more. This will maximize your opportunities for success. Keep that bladder full.

\*Break down going to the potty into very small component parts i.e. getting up off the couch, walking toward the bathroom, arriving at the bathroom door, walking in, lifting lid, pants down, sitting on potty.

\*You are the model and begin by doing each step yourself to try to get child to come along. Decide in advance who is going to be the model throughout. (It should be the person with the most patience). Each step the child does after you should be greeted with WILD praise. This will soon become a fun game and you will get into the bathroom and on that pot. Once on the pot if you have filled that bladder it shouldn't be long until a success. Greet that with WILD, WILD praise and give the real special treat (whatever your child fancies i.e. a toy, food, sticker or whatever really makes them happy.)

- After a success or if the child wants to get off the potty, go back and watch the video. Continue with salty snacks and the favorite drink.
- Time to begin Dry Pants inspections. Whenever you're not in the bathroom check the pants often. If they're dry that is cause for more WILD CELEBRATION.
- After the video and even during, begin the step-by-step trek back to the potty, celebrating each step back i.e. off the couch, pants off, etc.
- Repeat this process over and over again. Keep the salt and the drinks flowing. It will help if you sing along and talk about the video and what a great kid that is in the video. If you have more than 1 VCR watch it in different rooms. If you can't watch it any more talk about it or act it out. No other non-potty videos are allowed and no other TV shows or books are allowed. This is the only topic for the day.

**Accidents**

By now you have certainly had plenty. Let your child know that's not acceptable but don't get too upset. Accidents are opportunities for "dry runs"

- First have your child change their own wet pants. Have him take the wet pants to the laundry room himself and praise that.
- After dressing, demonstrate the route to the bathroom and the right thing to do from the location of the accident. If the accident happened in the kitchen, demonstrate how to get to the bathroom if you're in the kitchen and you have to go. Throughout the day you should demonstrate the route from every part of the house--many times. Whenever an accident happens follow the same procedure.
- After accidents go back to the video, the pretzels, the drinks, the dry pants inspections and the trips to the potty.

### **After the Weekend**

After 2 days we were 75-80% complete. The procedure finished gradually over the next 6 months but we never went back to diapers. Keep a close eye and continue to heap wild praises for successes and with dry pants inspections. Good Luck!

*Jeffrey and Arlene '98*

**I** have to prompt my son Brian, 12, to go even at home sometimes. You're right, the message that he needs to go just doesn't seem to get there! I have to say, Brian seems opposite from everyone else in that he hates to go to bathrooms outside our home. He refuses until he just can't hold it. Of course, my husband missed one of the most crucial scenes in Titanic (which by the way, Brian sat through all 3+ hours mesmerized by the story) to take Brian when he finally realized he just couldn't hold it anymore. By the time that comes around you have to go pronto! I have seen a reduction in how often we have to prompt but I think it's just like when they fill up their mouths with food, they just don't sense it's full!

*Orah '98*

## **Toys with a Twist**

I have always been impressed with Discovery Toys. They provide a description of the toy and what it helps the child with, such as: sensory, social, emotional, fine motor, creativity or thinking and problem solving.

Their toys are 100% guaranteed for life and you can purchase replacement pieces. I have found these toys wonderful for all three of my children. Their website is [www.discoverytoysinc.com](http://www.discoverytoysinc.com) and it is available in English, French and Spanish.

*Kerry Huffman, Minnesota '05*

## **Transitions**

(from one thing to another)

**F**ound a little thing that helps out with a difficult transition time: it has been getting increasingly difficult to get Mitchell (age 2 ½) to walk from the car into the preschool - a good 100 feet walk.



The preschool is in a regular public school, and there are lots of people, cars, bikes, strollers, etc...just lots going on. Watching all of this was much more fun than walking into school with Mommy. Anyway, someone who used to work at a camp for special needs kids told me yesterday to go and buy a slinky.

I picked up a rainbow colored plastic one for a couple of dollars - and it works GREAT! Mitchell holds onto one end and I hold the other - I walk along first and he loved it. It stretched out between us and then he would 'run' towards me and I would back up more and so on, all the way into the classroom. Now, regular classes also finished yesterday so there was a lot less activity this morning, which I'm sure helped out as well. Once we got into the classroom, he saw the other kids, ran over to play with them, and I just put the slinky in his backpack for tomorrow morning.

*Lori '98*

**W**e used to have terrible times with Timmy (now 12) when we would go places and it was time to leave. We would warn him we'd soon be going, etc. but eventually one **MUST ACTUALLY GO**. So when the moment arrived, we'd head for the door, dragging the crumbling rag doll darling along, as he clawed and screamed and kicked. One time he and I were at the beach with friends and the usual occurred, but this time he also dragged my swimsuit top down in the process. Now **THAT** was embarrassing...but I digress...

When Dr. Hagerman was here a few years ago for a conference, I posed this dilemma to her. She said that often, they found that if one just went ahead and left (leaving the child behind) he would just come along in short order behind you. This seemed **TOO** simple. But we tried it, and sure enough, he'd come along (grumbling and snarling to be sure, but without incident). So thereafter, we would explain to our host that we were leaving, and not to worry, our child would follow along. This works 99% of the time, if we have not allowed him too much deterioration before the leaving point. I still tend to overstay a bit ("he's doing so well...maybe just a little bit longer...").

*Laurel '98*

**W**hen my son was young and in preschool (which he loved) he would scream and have very bizarre behavior when I came to pick him up. I felt horrible, sure that everyone else thought he was afraid to go with me. I realize now that his behavior was very typical of many Fragile X children dealing with change (even desired change). One thing that has been shown to help kids with Fragile X is a visual cue. You might try drawing a series of pictures showing you leaving him with the therapist (or whomever) one of him with her, and then another when you pick him up (with a big smile on his face). Stick figures work great and he could even help you draw them. Then show them to him through the week before the appointment, again before you leave home. Have them with you when you get him so that if trouble develops you can quietly pull them out as a silent cue.

*Marta '98*

**C**ampbell's book "Say it With Pictures" deals with this approach. Another thing that helped in our home was to set up a chart around difficult events. If the child was successful they were able to put up a sticker, which could later be redeemed for an ice cream, pizza, etc. I know it sounds like bribery, but I'd rather deal with positive reinforcements than negative cycles. My son is now

a young adult and though he still has occasional mild problems with change, he has made tremendous growth in this area.

*Jeannie '98*

**I** am a Speech Pathologist and I work with a lot of children. It sounds to me like your little guy doesn't like transitions. In my experience there are two ways to deal with it:

1. You can say "it's time to go" and pick him up and leave. The advantage of this is that you have the control and (hopefully) eventually he will realize that fussing won't make a difference - you are still going to go.
2. The therapist (or you) could give him a job to do. For example, the therapist could say "I need you to give this letter to your mom in the waiting room. It's time for you to go." Children often really enjoy performing tasks like this, and it allows you to direct his behavior without him feeling like he has lost control. My favorite is the approach of you (mom) giving him the keys to the door and saying "It's time to go now. Go open the door." This makes him feel important (of course, you lay on the praise as you help him unlock the door) and it also allows for a transition that does not make him feel like he has lost control. Good Luck!

*Anonymous '98*

## **Transition Planning**

Transition to middle school years is a difficult time for many families. Here are some thoughts on the subject:

**Circle of Friends for support:**

When my son Brian was transitioning from elementary to middle school I knew it would be a huge change for him, a much larger school with many more kids. I decided to put together a more formal form of support, a circle of friends for him. He had five friends he knew well in school and socialized with. I wrote them each a letter asking if they would consider being part of this circle, hoping maybe 2 or 3 would say yes. They all agreed! We also had the wonderful support of these kids' parents, who were 100% behind their kids being involved. We met once a month and talked about the move to the middle school. We had a sibling who was in 7th grade come and talk to them about what middle school was like. We talked about what they were all nervous about. Then we discussed and brainstormed ideas on how they could support Brian in middle school. They came up with wonderful ideas, such as: making sure they were in his lunch room; one of them should be in each of his classes so that they can help "translate" for the teacher; one of the boys should be in his gym class to help him in the locker room, etc. We sent these ideas to the principal of the middle school. In addition, the school had the kids go for monthly visits to the middle school to help Brian get acclimated to the building. By June, he was very comfortable in there. His friends provided an incredible amount of support for Brian during his school day. Halfway through the first year in middle school, his circle grew to 7 students. They continued to meet, but more for socializing than anything else.

Friendships cannot be forced, however they may often need to be facilitated a little. The circle of friends is a way to provide support to individuals who may need a little help! You can get more information on circle of friends at <http://www.inclusion.com/circlesoffriends.html>

*See Orah's '98 entry on this under "Inclusion"*

*Orah Raia, New Jersey '05*

**W**e had our doubts about transitioning. When Eric started Middle School (after his first year of complete mainstreaming in 6<sup>th</sup> grade) all the teachers fought us and said he belonged back in self-contained classes. We decided against it, since he had such a good experience in 6<sup>th</sup> grade, and continued to mainstream him, with modifications. He had a 45-minute period of study skills each day where the resource teachers worked with his regular teachers to modify his work, tests and assignments to his capabilities. Yes, it was a struggle for all involved but I think it worked out for us. We did have to drop math because it was becoming too involved and went to a special education math class, which dealt with more of the fundamentals such as time, money, etc. as opposed to algebra (which he will never use).

However, now that two years have passed and we have moved on to High School we have decided to pull back a little as some of the regular classes, even with modifications, are not appropriate. He is in special math class with 8 children and an "interactive reading" class which is not specifically for special education since there are 30 children in the class but the literature is at a lower level. They watch movies and discuss them as well as doing a lot of writing. They are required to read at home every night and do oral book reports. Eric is probably at about a 5<sup>th</sup> or 6<sup>th</sup> grade reading level. He does also have a Directed Studies class where they again help modify his program as well as tests. He's mainstreamed into regular classes for gym, ceramics, and horticulture. There is a floating aide who helps him as well as other children in the class.

I guess the point I am trying to make is that it **is** possible. But you need to work very closely with the teachers to get the appropriate support and pull back from regular education when necessary to get these adolescents the best possible courses that will help them as they transition further into the adult world.

*Sali '98*

**H**ow well we know how you feel! Our son, now aged 17 and in 10<sup>th</sup> grade, was 13-15 going through 6-8 grades. It was a roller coaster ride for all of us. He functions in the low-normal ranges but exhibits varying behavior problems. It's his behaviors that are the real problem. If he liked the teacher and classroom and perceived it to be "user friendly" then he did well. If not, well, be ready to intervene -- and fast. It will only get worse. Looking back, let me offer a few suggestions that might help.

Determine as best as you can where he wants/can be as an adult. Middle school might not be the best place, but it can be OK for now. Try shooting for that, but be flexible in how to get there. The first thing we had to address in ourselves was not to take this situation or his disability as a personal affront. The place where he functions best and is HAPPY is of the utmost importance. How we help HIM achieve this will take unique dimensions. Unfortunately, those charged with getting him there are as much in the dark as we are. In my opinion this type of disability is far worse for our kids than one much more physical and readily seen. People don't view them as disabled, just rebellious, etc., as if it were some sort of willful thing on their part. Remind them as often as you need to, **YOU ARE DEALING WITH A DISABILITY, NOT A WILLFUL**

ACT. Treat it like it is! (I'm sure you've encountered this already and know it quite well; I just needed to vent for a moment because of a situation that happened today.)

Some practical things we learned too late were:

- Be very involved and have daily contact through assignment sheets, etc. on his progress.
- Most of our kids get "confused" in a busy atmosphere like changing classes. Being late for the next class is usually a punishable offense. Ask for help before the school year starts. Sometime the teachers will help but we found a peer helped best. What they need is a reminder in all the confusion.
- The worst times were lunch and PE. There were too many people and too much freedom of movement. Suggest a peer lunch arrangement or that he sit within eyesight of a teacher INFORMED of his condition. We found most teachers, etc. were more than willing to help BUT most were NEVER informed of his disabilities.
- Keep a close eye on emotional cues that signal an eruption is near. If your son is like mine, he has learned to handle most immediate problems without exhibiting bad behavior, but behaviors out of nowhere are usually a result of something that happened just a few days ago. It stays with them like peanut butter on the roof of your mouth. Eventually it gets real ugly. There is no immediate cause to this present outburst. At these times, I give him a PM (preventative maintenance) day at home. Unwind with TV, Nintendo, etc. They just have to purge, so do we. We know how to handle it most times. They don't see it coming.
- Be very involved; get with the school psychologist and begin transition discussions. It's not too early.

Again, I apologize for the length of this. But these are things I wish I'd known 5 years ago. We wouldn't be just now asking about transition and appropriate placement. Best wishes on your decision. There may not be any right or wrong, just what works.

*Bob '98*

## **Additional resources for Transition Planning**

### **Guide for Transition Planning**

[www.ed.uiuc.edu/sped/tri/GuideTP.html](http://www.ed.uiuc.edu/sped/tri/GuideTP.html)

Excellent chart for transition planning broken down into four main categories:: Entry, Intermediate, Advanced, Exit for twelve specific areas, such as: Classroom Instruction, Career Exploration, Personal Hygiene, Transportation, etc.

### **Reed Martin, J.D.**

[www.reedmartin.com](http://www.reedmartin.com)

Special Education Law & Advocacy Strategies, weekly free chat room and e-mail newsletter, a good resource for transition planning, see specifically

[www.reedmartin.com/transitionresources.htm](http://www.reedmartin.com/transitionresources.htm)

### **National Center on Secondary Education and Transition (NCSET)**

[www.ncset.org/](http://www.ncset.org/)

The National Center on Secondary Education and Transition (NCSET) coordinates national resources, offers technical assistance, and disseminates information related to secondary

education and transition for youth with disabilities in order to create opportunities for youth to achieve successful futures.

National Center on Secondary Education and Transition  
Institute on Community Integration  
University of Minnesota  
6 Pattee Hall  
150 Pillsbury Drive SE  
Minneapolis MN 55455  
Phone: 612-624-2097  
Fax: 612-624-9344

## Travel

Stephanie and I took our 3 kids - including our two sons with FXS - to Disneyland, and we were able to obtain special needs passes at the office which enabled us to skip all lines. We had one of our brochures with us that explains Fragile X and just showed the person that, but it was hardly necessary as she was warm, supportive, and not 'questioning' at all as to the assertion of the condition. We did find that some of the staff at particular rides were less than attentive to our coming up to the gate with the pass, so we had to be somewhat assertive at times - actually Sam and Ben took care of that - but, all in all, it was a wonderful family experience. Especially after I went back to the car in the 10,000 acre parking lot to get Sam's Elmo doll!

*John '98*

As I recall it is at City Hall on Main Street in the Magic Kingdom (DisneyWorld) that you get the pass. My in-laws took David. I got a note from the pediatrician saying he had ADHD and had great difficulty waiting in line and would they please accommodate our family. The special pass was good for 6 people! David was the most popular guy in the family because those who chose to go with him got in without waiting!

*Anita '98*

As our kids seem to love videos for the most part, we had our relatives from out of state make a video of themselves doing everyday activities and talking to Brandon. He watched it so many times that he started to know their names and was familiar with them when we did get to see them. It also helped getting him ready to go visit as they also videotaped their houses, inside and out and it helped him get prepared for where we were going to stay during our visit. We also made a little book having each relative stand in front of a back-drop that was solid so as not to detract and putting only one person per page of the book. He learned all their names and faces by reading this book again and again. Something that has helped us in almost all travel situations or new situations is to bring along Brandon's portable tape recorder and let him play his favorite music during otherwise stressful times...seems to help comfort him a great deal... Another tip for travel is to bring as many familiar things from home as you can. I even bring Brandon's sheets to put on the bed he will sleep in at Grandma's to help things seem as familiar as possible. Something as simple as the sheets made a huge difference in his sleep while we are away visiting.

We used to have a terrible time on airplanes, but several things have helped for us. We always go to the airport before the trip to watch the planes and talk about that we are going to do. We bring lots of snacks that we usually don't have: candy, pop, etc. I go the Dollar Store in advance and buy several new little distraction items to pack for the plane, and I have heard of someone who wraps them all up so the kids have something to open every 15 minutes or so. We made a tape of our little one's favorite songs repeated over and over and brought along some headphones. We first had to get used to wearing the headphones, so we started practicing several weeks in advance. Finally, he was able to listen for about an hour on the plane... what a life-saver!

Angie '98

I have tried exposing my son to as many new experiences as possible while he was young. This went a long way. He transitions well, loves to go to new places and has learned a lot. He can now find his way to restrooms, open hotel door rooms, handle luggage, pack, money, speech (he can practically check in - he just can't sign a credit card) and read basic signs. A hotel with a pool and/or hot tub is a great idea.

When we found out the diagnosis, and heard how some kids couldn't handle open spaces, like the beach, we made sure that was where we were going. Make as much effort as possible to attend free concerts, shows, restaurants, ride a train, get on a bus, a plane, go to a museum, or stay at a hotel. Just be sure to have a back out plan - you may need to leave a show or just stand outside for a few minutes. You'll need to talk about expectations before and give reassurances during. If it fails, wait a while and try again. While it's acceptable for a young child to have a meltdown, it's not so acceptable when they get older. Desensitizing to sounds, new experiences and new places will go a long way to a calmer child and later adult.

One warning: take it in steps. A free or local concert before going to a big one. A small amusement park before Disney. A plane flight to a fun place before a plane flight to a doctor.

*Pattie Devlin, Burlington, New Jersey '05*

### **'Wings' earned by flying with little children**

PUBLISHED: May 2, 2004, The News Herald and November 2004 Exceptional Parent Magazine.

Whoever invented the title "stay-at-home mom" was definitely not a "stay-at-home mom."

In an ordinary week, I can easily travel over 200 miles and that's not venturing more than five miles from Wyandotte. Many of those miles are spent driving in circles between home and schools.

Even during break periods from school, we are often on the go. Mom-sponsored field trips are frequently scheduled, sometimes to have fun, sometimes to accomplish something specific.

One of our most extraordinary trips recently was to Detroit Metropolitan Airport.

It was a trial run. Austin will be participating in a speech and language research study at the Waisman Center in the University of Wisconsin-Madison, and we'll be flying there.

This is the first time we have done anything like this, so there are many unknowns.

I've had visions of Bill Cosby's old skit of the mother who traveled with her young child who traumatized everyone on the plane, including the mother, and it's something I don't want to mirror.

So I devised a plan. The first part of the plan involved going to the airport, walking through the steps we'd have to take for our trip and taking away some of the strangeness.

Austin, 12, Natalie, 10, Genevieve, 5, and mom, 46, (or pushing 50, according to my husband) began the adventure at U.S. Park.

Everyone enjoyed the extra bounce in the airport shuttle's seats and the fact that every seat was a window seat.

The next form of excitement came with the journey on the escalators to the ticket counter. Isn't it amazing how fascinated kids are with escalators?

Well, we made it that far, so my next step was to determine if it was possible to go through security.

We waited in the check-in line and explained to the Northwest ticket agent what we wanted to accomplish and why.

I explained that Austin had Fragile X syndrome and autism (I always add the autism because people understand it better than FXS).

She contacted a supervisor. The supervisor arrived and contacted a manager.

Austin walked in continuous circles as we waited for the different levels of management to arrive. He made me dizzy just watching him.

I let him pace. I realize he does this when he is anxious; it helps him remain calm. I responded to stares from other travelers with a smile, hopefully relaying the message that, yes, he is "different," but it is OK.

When the manager arrived, I again explained what I wanted to accomplish. He provided us with a special pass so we could go through security.

The supervisor escorted us to first-class security check in, where we proceeded to remove our shoes and coats and place all of our belongings in bins to go through the X-ray machine.

We all walked through the security gates without a problem. Next, each of us had to stand on mats with footprints while they used the metal-detecting wands on us.

Austin went first; I was so proud of the way he followed instructions. Genevieve made Natalie and me laugh; I wish I had brought a camera.

Her little legs were spread so wide and her arms were out like airplane wings.

Then it was time to gather our belongings, put our shoes on, and begin the next phase of our adventure.

Watching the children's faces light up when we rounded the corner from security made all the waiting worthwhile.

Another escalator to ride, stores everywhere, a train inside the building, the fountain randomly spouting water, and sidewalks that moved.

We tried to experience as much as we could with me trying to teach a little airport etiquette while riding the moving sidewalks and trains.

It was a wonderful adventure and Austin's success on our trip will be possible because of our journey. Everyone couldn't wait to return home to show their friends the pilot's "wings" they received from the kind ticket agent.

As for me, this isn't the first time I've earned my wings traveling with children.

A very long time ago, I took my oldest son, Jon, now 24, on a vacation to Las Vegas to visit my sister.

This trip had a purpose, as well. It was a practice run to prepare Jon for a flight he would be taking alone.

On the flight from Chicago to Las Vegas, we intentionally didn't sit together. We were both in aisle seats and he sat in front of me.

During landing he was airsick and there was nothing I could do. A kind gentleman heading to Vegas with adults to have a little fun without children was one of the best unexpected caregivers I have ever encountered.

I'll never forget his understanding, his compassion. He, on a different level, truly earned his wings that day.

*Sally Nantais, Wyandotte, Michigan '05*

### **Fly High; redefine 'normal'**

Published April 3, 2005, The News-Herald

This stay-at-home mom has once again been flying high.

My son and I recently participated in another research study for Fragile X (FX) syndrome at the Waisman Center in Madison, Wisconsin.

We departed on a Sunday in the middle of a February snowstorm. It's one of those experiences when you ask yourself "What was I thinking? Traveling in February, in Michigan?" We left home late knowing our flight was delayed only to arrive at the airport to find the flight was delayed again. What a fine start for a trip with a child with anxiety problems.

Austin did well waiting because he could see that the plane wasn't there at the end of the gate. Once the plane arrived the Austin pace began (three steps, two spins - always to the left). Luckily, we were able to board first on a very full flight.

The next true challenge was soon to begin; after taxiing to the runway, we sat for two hours, waiting to be de-iced. Austin managed well but occasionally expressed verbally what every other person on that plane was probably thinking. Mom kept his anxiety in check by keeping her anxiety in check. He is very intuitive; I call it his sixth sense.

With all the waiting we spent on the plane I figured he'd had his fill for the day so once we got there we caught a cab to the hotel along with another rider on this snowy Wisconsin day. When we arrived at the hotel, I was barely out of the cab and Austin was already in the hotel lobby. Just as I was passing through the entrance doors, he was in the elevator with the doors closing. I bolted and quickly pressed the button. For a moment, I wondered where I would find him next. After about 10 seconds (which felt like an eternity), the doors opened and there was Austin.

Austin has an extraordinary memory that can sometimes be an advantage but at others a disadvantage. He remembered that during our last visit in May we were on the second floor. The kind gentleman behind the desk offered to give us the same room again if we could remember the number. I couldn't so I told him thanks but it didn't matter.

During dinner all the anxiety caught up with Austin. He started gagging so we ran to the nearest restroom. Not a typical dinner out but mom understood how difficult it was for Austin to keep his anxiety in check. I knew how hard he was working to keep it together.



On Monday, we were extremely busy. When I wasn't working separately on my part of the study, I was entertained by watching Austin perform his various study tasks from the observation room.

On Tuesday, we were running well ahead of schedule but with a new challenge. Austin had a blood draw scheduled. I did all that I could to prepare him. He seemed willing to comply after mom told him this might help others with FX.

This is an unusual study because they will compare biological factors to determine if they can identify anything that makes a difference or correlates in a FX child's communication ability.

As part of the standard procedure before drawing blood, the research team read from a script to Austin that ended with "if you don't want to do it, you don't have to". Yet, he once again surprised me. Austin and his entourage (mom and two staff members) left the building for the lab. He was a professional only saying "ouch" once while they filled three tubes with blood.

We finished before lunch and decided to gamble by trying to catch an earlier flight home. Once again, my motherly inner voice was saying, "What are you nuts? Standby with an FX'er". FX'ers typically struggle with change or transitions, so I knew I was taking a chance but it was something that I thought I could handle.

For our return flight, we were randomly flagged for an additional security check. At least I'd like to think it was random and not that we look as if we pose a threat to national security. I coached Austin through what to do, place your feet on the footprints on the floor and stretch our arms out like airplanes. In the end, I counted it as another opportunity to introduce a couple more people to a child with fragile X and autism.

We managed to get on the earlier flight and the trip home was as smooth as silk.

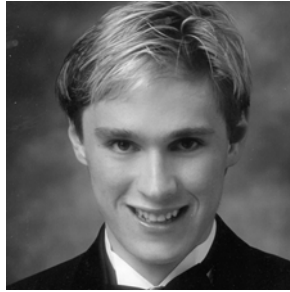
Our feet are physically back on the ground and there is no place like home. Now that I've had the opportunity to reflect on what we've accomplished, I'm still in awe by our success.

If you had asked me five years ago if I would be traveling, by plane, alone with my son, I would've thought you were insane. Yet, during the last five years we've redefined our "normal." It took time for us to realize that our "old normal" wasn't working because we weren't living life to its fullest, and it wasn't productive, for any of us.

Moving on, embracing a "new normal" has made numerous things possible. I wonder how many opportunities would've been missed without the change. How is your normal working for you? I wonder what are you missing?

*Sally Nantais, Wyandotte, Michigan '05*

## *U is for ...*



# Understanding

I went to the drugstore many years ago when my son Aaron, who has Fragile X, was 5 and his brother David was 9, and that experience still has an impact on my life today.

The line was long at the register and although Aaron started out next to me in line, within seconds “escaped” to the candy counter. As I was about to get out of the line to bring him back, I decided instead to give him some freedom as a learning experience. I watched him like a hawk ready to grab him for any “inappropriate” action. I was pleased that he had finally progressed to being comfortable enough in the store to explore like any ordinary toddler would. Previously, because stores were over-stimulating, he had no interest in exploring and I often needed to carry him in order for him to be comfortable. Although he was 5 at the time, he was at an earlier stage in the development of object exploration.

There was a woman first in line and Aaron, who is non-verbal, patted her on the chest several times to say hello. She smiled back and said hello. When the cashier handed the woman her change, she good-naturedly laughed when Aaron took it, realizing his innocence in thinking it was being handed to him. The line was now one customer shorter, but still long enough. Next Aaron went to greet the man in front of us. He tapped him on the chest and the man stared ahead, ignoring Aaron. Aaron tapped him again and the man still ignored him. I told Aaron not to tap the man’s chest, but to wave to say hello, but Aaron had given up and went back to the candy, this time making a little mess. As I went to get him to get back in line with me, the man finally spoke and nastily said, “If that were my 3-year-old, and he behaved that way, I would leave him home.” I am usually calm in these situations, but I lost my cool and retorted in a loud nasty tone, “But your 3-year-old wouldn’t be developmentally delayed and have Fragile X Syndrome and he is 5!”

After we had made our purchases, when we were walking out of the store, David, who had been silent until now, was very upset. He said, “Mom, why were you so mad at that man? You know he just didn’t know about Fragile X Syndrome. He didn’t understand so you have to educate people”. (You can see how hard I work when I am calm to help David cope with comments and stares.)

After that episode, I saw the symbolism of the two people in line. Throughout our lives, we will encounter two basic types of people, the woman and the man. I will always be grateful for understanding and accepting people like the woman and I will struggle when encountering people like the man.

*Robin, Massachusetts ‘05*

# Unique

Each child with Fragile X is unique and we must try to understand what our child needs. There are a lot of similarities between children with Fragile X but there are many differences, even between brothers.

My son is unique because he is mine. His smile is unique and his laugh is contagious. He loves to play with his little sister rolling on the floor or bed, kissing her belly. The way he says “I love you” is unique, especially when he goes to bed, he hugs me so strong and so sweet. Sometimes he can be annoying when he wants something and he repeats, repeats and repeats, but that’s not unique, that’s Fragile X.

*Filomena , Portugal, '05*

To answer the question, “what makes a person with Fragile X Syndrome unique?” I thought I should have a good understanding of what unique means. Being an English teacher, I am a big proponent of the dictionary and the thesaurus, and use them regularly. And although I was already brainstorming which of the quirky, lovable qualities of my two young sons I could describe, I became dismayed to read the definition and synonyms of this word that previously conjured up pride at the idea that my child was special.

According to the Merriam-Webster Thesaurus, unique means: *the quality or state of standing alone and without a peer*. Great. Every parent’s worst fear: my sons will have no friends. It also includes the synonyms *curiousness, oddity, peculiarity, strangeness, and unusualness*. Perfect. Just how I want my sons to be remembered.

But the more I thought about it, the more I realized that the unique thing about my Fragile X sons is that they must be appreciated. Like a work of art, a fine wine, the autumn leaves; things are treasured when we take the time and effort to enjoy them.

Having two children with a genetic disorder is by no means easy, but it surely simplifies our life. There are people who appreciate my sons’ uniqueness and those who don’t. We don’t worry too much about the latter. As the cliché goes: it is their loss, not yours. We now cherish our Fragile X family; those people who appreciate every last unique detail of Braden and Keaton. And while we try to educate others about FXS, we often have to take a breather and admire how many lives we have touched. Because of Fragile X, there are better people in the world. And that is because my FX sons are smart, comical, lovable, and, yes, truly unique.

*Nichole Tooz, Dickinson, North Dakota '05*

## *V is for ...*



## **Verbal Perseveration**

When our son Brad gets excited, he will often ask the same question over and over. For example, when we are driving to Grandma and Grandpa's house he will ask "where are we going?" over and over again regardless if we just answered him that we are going to Grandma and Grandpa's. What works for us is to turn the question around that he is asking us and ask him "I don't know, where are we going?" Most of the time he answers correctly and stops asking the question. It seems at times he is trying to tell us that he knows something and doesn't know how to phrase it correctly, so he asks the question instead. Yet, when the question is asked of him he is able to answer it correctly.

*Dawn Cook, Illinois '05*

This is my two cents on the lighter side of perseveration. I know there is a wrong side to it but we seldom take the time to see the good in it. When Alex was younger (he is now 17) he also perseverated and because the "experts" told me this was a bad thing I kept trying to get him to stop. He perseverated on a certain word or a specific phrase in a video constantly hitting the rewind then play button (VCRs and tapes did not have a long life expectancy in our house) and on CDs (he figured out how to use the search button to get where he needed to.)

Well, after a bit I came to realize that he was practicing certain words/phrases, rehearsing them and eventually using them to communicate. For awhile we joked that he talked in Dr. Seuss language. Our favorite was when toilet training he would have wet pants and would come to me and say "two dogs are wet" a phrase from "Go, Dog, Go" by Dr. Seuss. He would use "C is for Cookie" when he wanted cookies, etc.

As he got older he would watch Bear in the Big Blue House video and then run to get the CD, find the exact song that was playing on the video and compare it to the CD version. He discovered that the Beatles and Roy Orbison both sang "Chains" and would somehow be able to put the CD in and get to the exact phrase he liked and then put in the other CD to hear the same phrase. My husband noticed that he would go through a CD and find the same note in different songs.

I also noticed that he loved how certain words felt in his mouth. He would break into a big grin and repeat it over and over and over.

Words with three syllables are hard for Alex. We found this out with the "Sesame Street ABCs" CD. They sing words for each letter and one of the words for "L" was linoleum. Well, you

wouldn't believe how many ways you can mispronounce linoleum but he finally got it and was so proud of himself. It was maddening to keep hearing that same part of the song but once he got it he didn't persevere on it anymore. Unfortunately it's now the song "Daisy, Daisy, I'm so in Love with You" on the Disney CD. "I'm so in love with you" is his favorite phrase right now to use with his dad and me.

So, please try to remember that while it may be maddening to you, consider that maybe your child has discovered how to teach himself, without anyone's instruction. They are so darned cute, can you really stay mad at them?

*Julie, Wisconsin '05*

## Videos

**W**illiam loves to rewind the same few seconds of video over and over for hours, or until the VCR motor burns out. We solved this by buying Sansui TVs with built in VCR. There is NO rewind on the set! Only on the remote (the set has on/off, play, stop/eject, volume up/down and channel up/down--all you need for day to day, if you have a separate rewinder). I have observed William, in search of the TV remote, work through his mental checklist, in order, of all the places we have ever hidden the remote control... I think we are up to about 35 locations. We used to pull and hide the batteries, too, but one time when William found and loaded them in backwards, he blew up one remote, and it never worked again.

*Greg '98*

**T**alking about "picking" the labels and jackets of video tapes....

William 'picks' too, but fortunately he is slowing down as he gets older (he's 16 now). He also gradually tears the boxes up, a little bit at a time starting around the edges.

- 1) We buy cases for our tapes at the local county library cooperative when they are having a used video sale, usually for about a nickel a piece. Open up the box, slide it in the pocket and tape the top shut with packaging tape, and watch the packaging tape for signs of 'picking.'
- 2) The tapes themselves: clean any remaining label and adhesive off the 'spine' of the tape cassette with a little rubbing alcohol, ethyl alcohol, or soap and warm water on a damp cloth, whatever works.....Once the tape cassette is cleaned, use a permanent laundry marker to label the tape. You can read black laundry marker on a black cassette if you hold the tape at an angle to the light, and for some reason, it seems to work better than red, green or blue, though try them all.
- 3) When the tapes are new try putting clear packaging tape over the labels and watch the tape! (bad pun)

*Greg '98*

# W is for ...



## Waiting

We use a "Wait card" which is simply a card that has the word wait on it with a small picture of a clock in the corner. They use the wait card in school all the time. I simply let her hold the wait card until it is time for the desired activity, i.e., waiting until all siblings have their shoes on to go outside, waiting in line at the store. That being said the wait card only works if the time increment for waiting is short. I also have a card with a big stop sign on it for when I want her to stop something she is doing. Both cards are discreet visual reminders of what she needs to do.

*Deborah Parker, Pennsylvania '05*

With our Nate, who is now 6.5, waiting has been a big deal too! It has gotten better over time because he has learned games to do while waiting. We play I Spy a lot, he actually asks to play it. We bring a "bag of tricks" everywhere we go. It has changed over time from mostly snacks to games like memory games, I Spy, and coloring in what he wants me to draw for him. Lollipops are not given a lot in my home but are a great waiting tool. Books for my son are great, but I need a lot ready to go. I try to have the thin paperbacks with me and a lot of them! Puzzles work well too. My son does not understand the "why" behind waiting. If I tried to explain to him it is because other people are eating, or got here before us, or even that we ordered and the man is making our supper for us...he really wouldn't understand. So we keep him as busy as possible. It really takes a lot of effort to find things that can be used in line waiting, but it is possible. The outcome for our son is great. We have gone out to eat recently with no problems at all and we had to wait 20 min. for food. I think he broke a personal best.

If life was easy it wouldn't be so worth it!

*Cheryl, Maine '05*

Waiting was a goal we had written into my son's IEP many years ago. It's a social skill, and he practiced waiting in line for lunch, waiting his turn on the playground, waiting for his turn in gym. Successful waiting was rewarded. It was an all day every day part of his school program. Social stories were written to reinforce everyone's need to wait and take turns--even if it's hard.

A few years ago he "got it" and waiting is now something he can usually do with a verbal reminder. He's 17 and a pretty good waiter.

*Mary Lou Supple, Newburyport, Massachusetts '05*

# Websites

[www.bestbuddies.org/home.asp](http://www.bestbuddies.org/home.asp) - **Best Buddies International.** Best Buddies is a non-profit organization dedicated to enhancing the lives of people with intellectual disabilities by providing opportunities for one-to-one friendships and integrated employment. In addition to the traditional campus-based volunteer activities, and for those with limited personal time, Best Buddies helps people with intellectual disabilities connect with others through technology with its online friendship program, e-Buddies

[www.congress.org](http://www.congress.org) - Our Congress and Senate. For things to change our elected officials should be aware of the challenges we face day in and day out that only make our job as a parent with a child with special needs more difficult. It's another way to advocate for our children. The easiest way to do this is use the web site: [www.congress.org](http://www.congress.org)

[www.enchantedlearning.com](http://www.enchantedlearning.com) - **Enchanted Learning.** Enchanted Learning produces children's educational web sites and games which are designed to capture the imagination while maximizing creativity, learning, and enjoyment. Ease of use is a hallmark of our software. Children need the clearest, simplest computer interface, and our material is created so that the navigation and controls are intuitive. Our mission is to produce the best educational material, emphasizing creativity and the pure enjoyment of learning.

[www.kidzone.ws](http://www.kidzone.ws) - **Kidzone – Fun Facts for Kids.** Excellent site to supplement your child's education. Many online activities as well as printable worksheets. Tracer pages can be customized in different formats. Fun crafts to make as well

[www.tash.org](http://www.tash.org) - **TASH.** TASH is an international association of people with disabilities, their family members, other advocates, and professionals fighting for a society in which inclusion of all people in all aspects of society is the norm.

[www.primaryschool.com.au](http://www.primaryschool.com.au) - has free lesson plans and links to other website which offer free lesson plans in a range of topics, such as; English, Math, Reading etc. Well worth looking at.

# Wisdom

There is one thing we all share, whether expressed or not: we all have dreams for our children. Fragile X Syndrome has forced us to view those dreams through a kaleidoscope of its own, making simple things difficult, and many difficult things impossible. This dark lens shadows my world, making every gain, every acquired skill John achieves, another step out of my fear for his future. And every loss both frightens and enrages me.

If I do all the right things ... and what if I don't? I have kept these fears, this anger close to my heart, because John can't be responsible for my feelings, my husband doesn't share them, and until now, no one else I knew *had* them.

I have to risk sharing these feelings. I am no professional, but I am determined to learn from every one of you. From some, I gain understanding of why my son is as he is. From others, I gain strength, knowing I am not alone. But, if there is a hesitation to express anything other than facts, then we are simply playing an intellectual version of "keep up with the Jones."

*Tonii '98*

Today was Kyle's *Moments with Mom* day at school. I brought Christopher (4) also. We had donuts and juice etc....One of the other students in special education can be very aggressive when he hugs. He could squeeze the stuffing out of you! Well, Christopher saw this and says, "Mom, he pinches, I'll pinch him back!" I told him, "No you don't want to do that he is just trying to show he likes you when he does that and doesn't realize it may be too hard." I proceeded to explain to him that this child was different, just like Kyle is different from other children and that is how he tells you he likes you. Christopher's reply: "They're not different, I am!" I guess it just goes to show, it's how you look at it. My four-year-old enlightened me today with his profound words of wisdom.

*Gail '98*

My friends and community know about my children, how we run here and there for therapy, school, trying to fill our children's lives. (I have two Fragile X sons.) Everyone comments about how much my husband and I do with our kids, how hectic our lives are. Recently, a good friend of mine gave me some advice about parenting that I'd like to share. She stated that parents and children are like a glass of water. Parents are the glass of water and children drink from the glass. The parents like the children also need water to live and are responsible for keeping the glass full so that the children have something to drink. To keep the glass full, the parents must do things which fill the glass with water. Things include exercising, socializing with other adults without children present, going to the movies, spending time alone with your spouse, doing something you love to do which energizes you and makes YOU happy. When a parent doesn't do these things then they dry up, the glass dries up, and everyone starts to get thirsty and eventually may die. SO! KEEP YOUR GLASS FULL i.e. TAKE CARE OF YOURSELF! AS WELL AS YOUR CHILD(REN)."

*Anonymous '98*

This is a biggie, and as somebody already has suggested ... it's likely that all of us on the list have encountered it, especially at the beginning. What brought me around was a friend I bumped into at the market, as I was a crying wreck. At that moment, a group of disabled adults arrived at the store to shop. They were happy, greeted all with smiles and hello's, were thrilled to be at the market. My friend said to me "Look, Tyler is fine. You're the one with the problem." It hit me like a ton of bricks and I knew she was right. Tyler is himself, and he is perfect as he is. I was the one attempting to hold on to an idea of Tyler as somebody else. It was that attempt that was causing my suffering. What also helped was keeping in mind that all the therapies being suggested were what he really needed, regardless of how I was coping with my own suffering. It's hard to see our children not as extensions of our own egos, but as fully enlightened beings in their own right. The fact that he has certain disabilities is no reflection on my worth as a human being. My worth as a human being is measured by how well I serve Tyler and everybody else in the great drama I call my life.

*Sarah '98*



## **The Veil of Their Disability - A Positive Perspective for Advocacy, Networking, and Self Esteem**

For people close to Fragile X syndrome, the phrase “more than meets the eye” could have been coined specifically with this complex condition in mind. How often while observing my own son I have caught glimpses of a capability or an understanding that is not his norm. I have heard and read parents and others echo this experience. Doesn't this phenomenon substantiate something very significant to us? Namely that the abilities of those with Fragile X are in place, but are prevented by the sensory, behavioral, and attentional “shackles” of their condition from being fully utilized.

The effect of these “shackles” becomes highly focused when we venture into the world of standardized intelligence/achievement testing. A neuropsychologist administering this test will tell you that these instruments are needed to compare the tested child to a baseline of prior results and other cases. (But what of these “shackles?”) It is at this point that a phrase comes to mind that I hope will paint a graphic verbal illustration of something we can all feel, and that phrase is “the veil of their disability.” Has the neuropsychologist done enough to lift this veil? If not, then the result of standardized testing is woefully inadequate. As research continues, support appears to be growing for a more positive outlook toward the abilities and thus the futures of those with Fragile X. As advocates for this population, we (parents and concerned professionals) face the ongoing challenge of enlightening both the public and, very importantly, our academic institutions about this outlook. In addition, especially as regards our younger children, we must constantly be wary of the placement of limitations on their potential. These limitations are a result of stereotypical misconceptions and can be counteracted only by a campaign of positive, productive information outlining successful techniques.

For our children's sake, we must help develop methods by which “the veil of their disability” can be lifted as frequently and as thoroughly as possible, by their teachers, therapists, and indeed ourselves as well.

*Joe Gerardi, Fragile X Association of New York '98*

***X is for ...***



**X Chromosome**

(see Genetics)

# X-Rays

Nicholas was getting his teeth X-Rayed, which of course is a total sensory malfunction for him. The dental tech told him, "I'm going to take pictures of your teeth." The tech put the funky little films in Nicholas' mouth; goes behind the lead wall and tells Nicholas to hold still. Nicholas then proceeds to spit out the little films and said "Cheese" with a huge grin! It was really tricky to get him to understand that those little films needed to stay in for his picture of his teeth. We all had a good laugh during that visit.

*Lexi, Michigan '05*

*Y is for ...*



# Y Chromosome

(see Genetics)

## Z is for ...



## Zany Tales

**K**enny's story of his son sometimes playing in the toilet reminded me of an incident that happened at Burger King. Matthew, my X-man at age 5, loved an old harmonica that had belonged to my husband as a boy. While waiting in line for our order, Matthew started doing the bathroom dance. Stephen, my oldest and not Fragile X, took him to the bathroom that was located within about 10 feet from where I was waiting for the food. I did not know it, but Matthew had the harmonica with him. When he got in the bathroom it was too much to hold the harmonica, pull down the pants, and take care of his business, so something had to give. The harmonica fell into the toilet! UGH! I would have left it, but Stephen (being the wonderful big brother that he is) fished it out and washed it off. When we got home, it was bleached and by the next day, Matthew was playing it again.

Sue '98

**J**osh has very little fine motor control. I usually tie his shoes for him every morning in double bows. On Thursday morning, we were running late and Alicia tied Josh's shoes. She didn't double the loops. At school Josh's shoes came untied. He asked his teacher to please tie them. Well, for whatever reason they didn't get tied. Josh started down the hallway and his favorite teacher followed him into the resource room, and said "*Josh your shoes are untied, better tie them.*" Josh, with his quick grin and sparkling eyes, looked at the teacher and said: "*HELLO! FRAGILE X, NO FINE MOTOR SKILLS!*" Well I guess everyone who heard Josh say it thought it was just sooo funny! At any rate, the teacher sat down with Josh and worked with him on tying. So far we've got loops! We have worked on this for years, and never made any progress!

Eileen '98

**W**e too celebrate Hanukkah. Every year I have to explain why we don't have a Christmas tree. "We're Jewish" I tell Simon. Last Friday, I met with Simon's teacher. He is doing well this year, she said, but lately they're having some compliance issues. They'll ask him to do something he doesn't particularly want to do - like math - and his response is, "I can't, I'm Jewish."

Nancy '98

In my last response...I mentioned that Brent participates in modified Grade 4 work with his class and that we have often talked with him about having Fragile X. Recently he was working on a social studies project about ancestry. He had to make an oral presentation, as did all his classmates. His was modified to make it shorter and we settled on about 5 sentences. His ancestry includes Japan...his dad is third generation. I helped him write 5 sentences on cards to say to his class. It included "I am part Japanese" along with something about rice etc. (He wrote it...it talked of his likes). Anyway...he practiced it for us in the kitchen and at the end stopped for a minute and said to us "Am I Japanese or am I Fragile X?" We roared and told him that he was many things...including those two. My point...he will absorb what he can and be who he is. Our responsibility is to be sure he feels good about all of it.

*Kim '98*

At an IEP for Kindergarten, I tried to get the school to write that he would learn his address, phone number and town, as well as how to call for help (911). They told me no, it was not appropriate for him yet. Well as it turns out the class was working on it anyway. Kristopher wouldn't participate in the lesson. He was wandering around the class. The next day the OT came to class and picked him up and they made a pit stop at the office on their way to the OT room. Can you guess where this is going? Well, the school got a call from 911 and wanted to know who had called from the school, and they were upset... No one knew who had done it even though Kristopher was by the phone. Of course they thought he wasn't capable of doing it...the OT told me the story...Well, it didn't take me long to figure out who did it. Never underestimate what these guys are taking in and what they can do!!

*Suzzane '98*

