

# PASS IT ON

Family to Family  
Health Information  
and Education Center

*"Supporting families  
having children with  
special healthcare needs  
and disabilities."*

(800) 852-3345  
X 4525 (In NH)  
or (603) 271-4525

[nhfamilypoices@nhfv.org](mailto:nhfamilypoices@nhfv.org)

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

## Inside....

YEAH Council

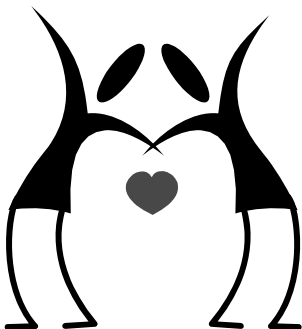
NHFV Conference

Seclusion & Restraint

Spring Activities

Insurance Update

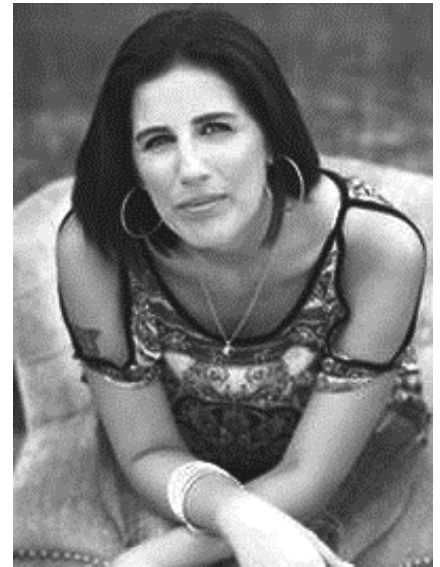
## And Much More ....



Spring/Summer 2014

## Partnering for Strength 2014 Conference

NHFV and Parent Information Center (PIC) co-sponsored the "Partnering for Strength" conference on March 28 and 29. The conference was attended by over 140 people. This year the YEAH Council planned a concurrent conference for "youth only" entitled, *Finding Your Voice* sponsored by the Council for Youth with Chronic Conditions. These sessions for ages 14-25 were focused on advocacy, finding your voice, healthcare and independence. Friday evening's keynote speaker Michelle Oaks, 18, of Bedford NH spoke about the long term effects that children and youth who have experienced cancer and other medical conditions encounter. Michelle captivated the audience with her humor, insight and intellect while providing attendees with a unique view into the challenges children and youth with chronic conditions experience. Saturday morning opened up with keynote speaker Rae Hoffman, CEO of PushFire Communications. Rae inspired audience members to approach challenges with courage, optimism and attitude in her presentation, "11 Things I Learned Along the Way". She told the



Rae Hoffman, keynote speaker ,  
on facing challenges with  
optimism and attitude.

story of her son CJ, who suffered a bilateral stroke at two weeks old and how it changed both of them forever.

The day continued with twelve workshops on topics such as learning & cognition, healthcare, social success for children and many more.

Continued on page 2

Partnering for Strength 2014 Conference.. Continued from page 1



YEAH Council members (from left to right) John Jackson, Sarah Fostier, Nicole Tucker, Karen Steele and Zach Hastings

Nicole Tucker, YEAH Council Member said of the *Finding Your Voice* youth track, "We set out on wanting to empower youth to show participants that they have a voice, they can use it and this is how. We began by getting to know each other and talking about what brought them to the conference. Then reviewed the history of disability which got a little scary because of how recent some of the things that had happened. Our next subject was how everyone has a voice no matter how they communicate and that everyone and their voice matters. Next how to use your voice respectfully and effectively and knowing where you can use your voice. This is very important because you need to start off small then build off of it. I think that the conference was a great success and look forward to doing more events for youth in the future"

Special thanks to Erika Downie of NHFV and Jen Cunha of PIC for their efforts in organizing this wonderful event and to our NHFV community, your valuable feedback on our Facebook page, online surveys and post conference evaluations help us meet and exceed your expectations each year!

♥ Keynote presentations can be seen on  
The NHFV's YouTube channel  
at [www.youtube.com/channel/  
UCFJLKDHjX4YqFv5jgRf7ahA](http://www.youtube.com/channel/UCFJLKDHjX4YqFv5jgRf7ahA)



♥ Or search by typing "New Hampshire Family Voices"



## New Hampshire Family Voices

*Pass It On* is a free quarterly newsletter for parents of children with special health care needs and the professionals that support them.

This publication is made possible by funding from NH Department of Health and Human Services, Special Medical Services (Title V, Social Security Act). Opinions, activities, products and publications mentioned are for informational purposes only and do not imply endorsement by NHDHHS or Special Medical Services. The NH Department of Health and Human Services does not discriminate in its activities on the basis of race, color, national origin, sex, religion, age or disability.

This publication is not intended to provide medical advice on personal health matters. All health concerns should be discussed directly with your physician.

Permission is granted to quote from this publication, while giving credit to Pass It On, a publication of NH Family Voices (and original author, if appropriate). Some material may carry other copyrights as well (noted where appropriate) and cannot be reprinted.

### For correspondence:

Robin deAlmeida

New Hampshire Family Voices  
129 Pleasant St. Thayer Bldg.  
Concord, NH 03301

In state toll free: 1-800-852-3345  
Ext. 4653 or (603) 271-4653

E-mail: [nhfamilyvoices@nhfv.org](mailto:nhfamilyvoices@nhfv.org)  
Web site: [www.nhfv.org](http://www.nhfv.org)

## PIO Policy Updates

### SB396 Seclusion & Restraint, Our Voices Matter!

Last year, ABLE NH leaders organized and established a task force in response to growing concern around the state about the use of dangerous restraint and seclusion practices on children in schools and treatment facilities, particularly on those who experience a disability. Southern ABLE NH chapter leaders began collaborating with Disabilities Rights Center (DRC) attorneys Mike Skibbie, Karen Rosenberg, and Becky Whitley in July 2013 on Senate Bill 396, which would revise the current restraint statute RSA Chapter 126-U. The proposed Senate Bill 396 seeks to ensure the following:

- Parents are promptly notified whenever physical intervention is used with a child in response to behavior in a school or treatment facility.
- The confinement of children in locked seclusion rooms is limited to circumstances where it is necessary to prevent harm to a child or others.
- Minimum requirements for lighting, ventilation, and visual observation of children are followed when seclusion is used.
- Definitions of the types of physical intervention are clarified so that proper record-keeping and parental notification occurs whenever physical contact in response to behavior or confinement is used on children.
- Special education programs are reviewed whenever restraint or seclusion is used for the first time on a child with disabilities.
- Procedures are in place at the Departments of Education and Health and Human Services to investigate complaints of improper seclusion and restraint.

SB 396 is a well-crafted, thoughtful bill that balances the need to keep dedicated teachers/support staff and children safe in schools and other youth environments while ensuring restraint and seclusion are used only when absolutely necessary and with appropriate safeguards in place at all times.

This bill is the result of DRC Mike Skibbie's extensive collaboration with child and disability advocates, treatment providers, and educators" said Jennifer Bertrand, Southern ABLE NH Chapter Leader and NH Council on Developmental Disabilities Policy Chair who played

Continued on page 10

## TRAINING

### Apps to Supplement Executive Functioning

July 29, 9:00 AM-3:00 PM  
ATECH Services, Concord

Many children and adults struggle with executive functioning. Tasks such as initiation and completion can be a daily challenge. Organization of ideas and prioritizing the to-do list can be overwhelming.

Participants will discover what the different categories of executive functioning are and explore apps to help support each function. Feature matching of apps will also be analyzed and participants will leave with an understanding of how to evaluate an executive functioning app for its potential usefulness. Participants will have a hands on experience to explore the benefits of particular executive functioning apps.

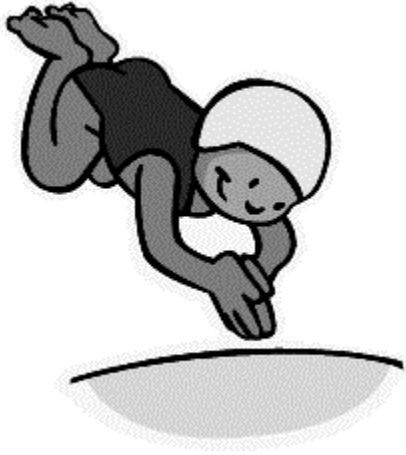
#### Who Should Attend:

Teachers, parents, paraprofessionals, direct support professionals, caregivers, those with executive functioning deficits and other service providers.

**Cost:** \$129.00 - includes a continental breakfast and lunch

For more information call ATECH at (603) 226-2900.

[www.crotchedmountain.org/Programs-and-Services/ATECH-Services/ATECH-Services/](http://www.crotchedmountain.org/Programs-and-Services/ATECH-Services/ATECH-Services/)



## Summer Sun & Fun ... Swimming & Biking Safely for Children with Epilepsy

Swimming is a terrific form of exercise, and one many children look forward to in the summer. It is always safest to swim with someone, regardless of age or health condition. This is particularly important for children and youth with epilepsy, due to the risk of a seizure occurring

in the water. In general, supervision should be provided by someone familiar with both the child's condition, and life saving techniques. Children whose seizures are more frequent, or impact consciousness or motor control should be even more closely supervised. If your child is swimming where a lifeguard is available, tell them about your child's health condition. If your child is a long range or competitive swimmer, please be sure to speak to your child's physician and coaches about safety measures appropriate for your child. Remember, if you plan to enjoy the water from a boat, life jackets are recommended for all!

Many YMCA chapters throughout New Hampshire offer adaptive swim classes for children who experience disabilities. Check out your local YMCA by visiting [www.ymca.net](http://www.ymca.net) and entering your zip code.

In NH it is the law for all children under the age of 16 yrs. to wear a helmet while riding a bicycle. Like the safety recommendation regarding swimming alone, riding with a friend is more fun, and for a child with epilepsy, riding with a friend who knows how to get help if needed, is recommended. Additionally, if a child's seizures impact consciousness or motor control, consider riding in a park, or other location free of car traffic or other dangers if a child were to swerve or lose control of their bicycle due to a seizure.



## ADVENTURELORE SUMMER CAMP

A safe coed outdoor living experience for kids and adolescents ages 8 to 17. Experienced counselors structure trips focused on building self-confidence, taking on healthy challenges, building trust and having fun with peers. Trips range from 5 to 8 days and include activities such as rock climbing, white water kayaking and rafting, biking, hiking, and sailing.

For more information visit:

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

or call (603) 382-4661

Life is like riding a  
bicycle.  
In order to keep  
your balance,  
you must keep  
moving.

— Albert Einstein

## Granite State Insurance Update

### Medicaid Expansion

The state legislature recently approved the NH Health Protection Program (Medicaid Expansion), a pathway for insurance coverage for those 18 and older with low-income status. This new pathway eliminates the previous requirements for individuals to have a child or have a disability themselves in order to obtain coverage. Anybody who meets the financial criteria could be eligible.

The NH HPP is being offered to people between 19 and 65 years old. To be eligible, a household of one would have a monthly income limit of \$1,294; a household of two, \$1,744 or less per month; a household of three monthly income limit of \$2,194; or a household of four with a monthly income limit of \$2,644 or less.

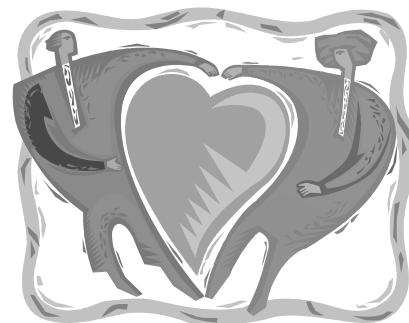
For example, under the new guidelines, individuals 18 and older with mental health or other disabilities who do not meet the criteria for APTD (Aid to the Permanently and Totally Disabled) could now be eligible for coverage. For more information call NHFV at 271-4525.

The New Hampshire Department of Health and Human Services (DHHS) is announcing 12 Statewide information sessions about the implementation of the New Hampshire Health Protection Program (NH HPP). All 12 sessions will cover the same information, so people need to attend only once. Registration is not required, but is appreciated. For meetings schedule and registration go to DHHS website at:

[www.dhhs.nh.gov](http://www.dhhs.nh.gov)

### Medicaid Managed Care

The Disabilities Rights Center (DRC) recently reported Medicaid recipients and providers have raised questions about access to care and the availability of services through NH's new Medicaid managed care program. With the implementation of managed care, it is critical that recipients understand their rights to Medicaid services and the procedures available to them if they disagree with a decision or action taken by the MCOs, or if they have a complaint or grievance. The DRC has prepared an informational sheet, *New Hampshire Medicaid Managed Care Health Plans: Your Right To Appeal Or File A Grievance*, available on the Medicaid Page of the NHFV website or for more information call NHFV at 603-271-4525.



## Supporting Parents

There are many different ways parent support and information opportunities are available to parents. Some are directed by professionals and others are directed by parents; sometimes the support is provided in a group setting and sometimes the support is provided individually.

Sharing the family experience with others in similar circumstances is an important source of social support.

NH Family Voices is proud to offer parents an opportunity to support each other by writing articles for our newsletter, participating in our Facebook group and through NH Parent to Parent at NHFV.

We hope you will join us.





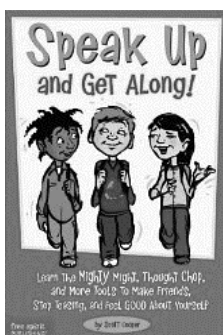
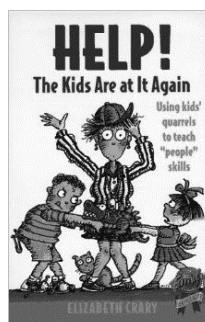
## NH Family Voices Lending Library

### Summer Reading Ideas...

Summer vacation is almost upon us! A break from harried morning routines, no nighttime homework battles, a lemonade in your hand and hot dogs on the grill... you can't believe it's finally here. And then, a few weeks -or let's face it, a few days- into summer vacation, parents begin to lament over that familiar sound.... their children bickering! At the NHFV lending library we have some books that will help transform those teeth clenching moments in to teachable moments.....

***HELP! The Kids Are at It Again! Using kids' quarrels to teach "people skills"* By Elizabeth Crary**

Learn how to use sibling quarrels to teach and reinforce social skills. Teach children ways to get attention without hitting or whining, deal with feelings without blowing up or giving up, establish and respect boundaries, and solve problems without resorting to yelling or hurting. Easy-to-understand examples and insight into ways we unknowingly encourage sibling struggles. Winner 1997 Family Channel Seal of Quality Award.



***Speak Up and Get Along!: Learn the Mighty Might, Thought Chop, and More Tools to Make Friends, Stop Teasing, and Feel Good About Yourself* By Scott Cooper**

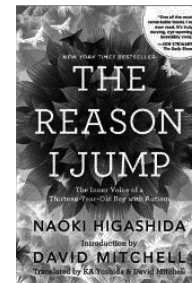
What if every kid had a handy toolbox of ways to get along with others? That's just what this book is: a collection of 21 concrete strategies kids can pull out and use to express themselves, build relationships, end arguments and fights, halt bullying, and beat unhappy feelings. Each tool is clearly described, illustrated with true-to-life examples, and accompanied by dialogue and lines kids can practice and use. A terrific resource for any young person and any adult committed to teaching social skills.

## Just Arrived...

***The Reason I Jump*  
By Naoki Higashida**

Written by a very smart, self-aware, and charming thirteen-year-old boy with autism.

This is a unique memoir that demonstrates how one autistic mind thinks, feels, perceives, and responds in ways few of us can imagine.



♥ Check out the Lending Library's Bibliography list on our website

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

📖 Books are sent through the mail with a postage paid return envelope.

To borrow a book call 1-800-852-3345 Ext 4525 or online @ [www.nhfv.org](http://www.nhfv.org)

♥ We would like to thank our patrons for quick returns. Books highlighted in the newsletter are frequently requested by many others who wait patiently.

♥ If you are looking for something in a specific topic, please feel free to call us... we may be able to suggest a book we have available.

## Spring into Occupational Therapy This Spring and Plant Some Seeds for Growth

As the weather warms up outside (finally!) and we all gear up for spring, don't forget the excellent outdoor sensory activities and games you can play with your sensational child!

Planting a garden is a favorite springtime activity of many families, but did you know that this seasonal activity also helps children work on their proprioception abilities? Proprioception is our ability to tell where our body is in space. There are proprioception receptors located on our joints, muscles, and tendons. When our proprioceptive system is working correctly, our body automatically adjusts to the different situations we are in. For example, if you are walking across an uneven lawn to get to a playground, your body will correctly fire the right muscles at the right force for you to successfully make it to your destination, without even thinking about it! When our proprioceptive systems are not working correctly, it is easy to lose balance when taking a step off a curb, or fall off a swing because our body does not adjust automatically. Some excellent outdoor activities to improve this system are moving rocks, digging and planting and shoveling mulch. Your family garden doesn't have to be large, it could be a few containers in a sunny area, but think of the opportunities for children of all ages to learn about nature and get a free and fun OT experience at the same time!

Other spring and summer activities that give children the opportunity to strengthen their proprioceptive abilities are wheelbarrow races, jumping on a trampoline, hipity hop, or pogo stick, hanging clothes outside using a clothes pin and using sidewalk chalk.

So go out and have fun with your sensational child in the beautiful, warm weather! If you think of another activity not mentioned on my suggestion, go for it! Giving your child an occupational opportunity while having a blast at the same time is what everyone is aiming for.



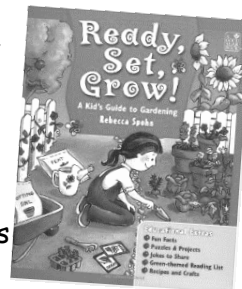
Libby DeAmicis, M.S. OTR/L is a pediatric occupational therapist currently working in Early Intervention (ages Birth to 3) in Brockton, MA.

A recent graduate of UNH, Libby is passionate about adapting everyday activities children do so they are more meaningful. She wants every child to be successful in their daily occupations.

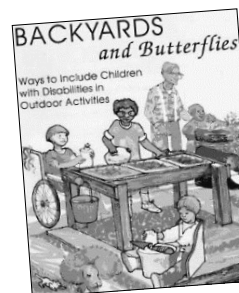
## Also in the NHFV Lending Library...

**Ready, Set, Grow! A Kid's Guide to Gardening** By Rebecca Spohn

Practical advice equips children to grow fruits, vegetables, and flowers outdoors or indoors in a milk carton



or even a paper cup. Readers learn how a seed grows, what tools to use, and how to prepare seed-beds. Growing instructions are accompanied by glossary terms that build knowledge, "Did You Know" sidebars introducing fascinating facts, "Try This" activity ideas that foster active engagement and Garden Giggles" to lighten the mood. Grades 1-5.



**Backyards and Butterflies: Ways to Include Children with Disabilities in Outdoor Activities**

By Doreen Greenstein

Dozens of imaginative ideas for making outdoor activities accessible to children with physical disabilities. Lots of ideas for gardening, nature, swings, and slides for parents and professionals.



## PIC Offers One on One Consulting Through Their Fee Based AFC Program

Spring is often referred to as "IEP Season" and having a consultation with the Parent Information Center's Advocates For Children with Disabilities program (AFC) could make IEP Season a lot smoother for many families. The Parent Information Center (PIC) of NH offers this fee-based service families wanting an in depth analysis of their child's IEP and assurance that this document is addressing their child's educational needs in a comprehensive manner. Families meet one on one with a staff member at the PIC office in Concord where a consultant will thoroughly review all records included in the child's case history. From there, PIC will provide guidance in identifying needs and obtaining appropriate services. They will also educate families on the options and resources that may be available to them.

This service is particularly helpful to families who may be approaching a new diagnosis or want to explore the most effective way to communicate with their child's school while ensuring they are accurately addressing the unique needs of their child. AFC is also useful for families who may have an upcoming IEP or 504 meeting for their child with an already established IEP. Parents will be guided in techniques such letter writing and other documentation that are tailored specifically to their child's situation. In addition, AFC can assist families at special education mediation sessions.

To prepare for a consultation, families are advised to compile their child's entire educational file. This may include an IEP or 504 plan, evaluations (school and private), team meeting minutes, progress reports, report cards, work samples and other written documentation. Because AFC is a fee for service program and payment will be due on the day of service, having records organized by date and a list of questions or concerns assembled in advance will promote the most effective use of time.

If you are interested in what AFC has to offer, please call PIC at 224-7005 or toll-free at 1-800-947-7005 and let the receptionist know you are interested in scheduling an AFC consultation or visit [www.afcnh.org](http://www.afcnh.org)

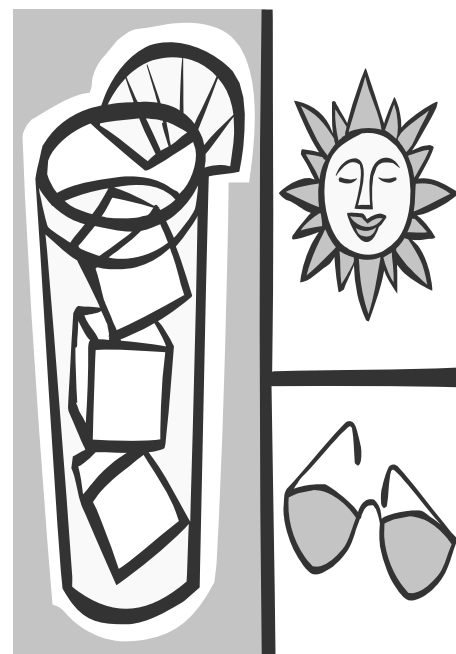


Would you like to help another parent that is walking the same parenting role you are?

NH Parent to Parent at NH Family Voices will be offering a basic Parent to Parent Training.

Mark your calendars and save the date November 8, 2014

More details coming soon.





## BLOG SPOT



**C**arrie Cariello lives in Southern NH with her husband and five children. Her son Jack experiences autism. One would think this would be enough to keep Carrie busy, but clearly Ms. Cariello is a woman who knows she has something special to share with the world.

In her free time, Carrie pens the blog *Exploring the Colorful World of Autism* and recently wrote a book *What Color is Monday?*

Published by Riddle Brook Publishing. Both about her family's unique journey through the world of autism. Carrie's writing is candid, real and astoundingly beautiful. Her blog stands out among the countless number of autism blogs out there. You can find Carrie's blog at <http://carriecariello.com> and check out her book at Amazon.com.

### *A Family Voices Interview:*

**NHFV:** What motivated you to start a blog and tell your stories?

**CC:** Every year our family goes to an indoor water park in North Conway, then we stay at the Hampton Inn right in town. Three years ago we walked into the hotel lobby and a family was sitting there with their dog. Jack had been terrified of dogs for quite a while at that point, and would sometimes start screaming when one walked by him on the street. As Jack began anxiously circling the perimeter of the room, the owner of the dog sat beside her on the floor and started to call out softly, "Jack, this is Gracie. Her name is Gracie and we're waiting for you. Gracie and I are waiting for you." Jack circled closer and closer, eventually reaching out his hand and petting the man's hair, and then extending his fingers to brush them against Gracie's fur. Eventually we went up to our room and put the kids to bed. As I was about to fall asleep, I realized I was ready to tell the story of our family and Jack and autism. I wanted to spread the message about how great he is and how much autism has added to our lives, but even more, I wanted to show people how kind the world can be to a little boy who is afraid of dogs.

**NHFV:** Did you always have such a frank and open take on the world?

**CC:** I would have to say yes, I have pretty much always been an open book. As you can imagine, my husband just loves this about me.

**NHFV:** Tell us about the license plates...

**CC:** Jack has a tendency to become fixated on things; people's birthdays, cars, spiders. For over a year now he's been obsessed with license plates. I mentioned it a few times on the blog, and people from all over the country started sending them to Jack. They almost always send them with a personal note addressed to him. One of my favorites is from a father in Ohio who has an adult son with autism. He sent it a few days after the bombings at the Boston marathon with a note that simply said, "I hope this makes Jack smile." We have over a hundred plates at this point, from every state in the US and even a few international ones. We've hung them all on a wall in the playroom, and every time I look at them they remind me how tolerant

Continued on page 14

## A Youth Perspective on Cancer

by Michelle Oaks

It has been said that the biggest changes in one's life occur over time. I would disagree with that. The biggest, most unexpected changes in life happen in a matter of seconds. It only takes a few words to change your life forever, such as "you won the lottery". In my case it only took three words: "You have cancer". Those three words packed a harder punch than any professional boxer. At the age of ten I didn't fully understand what it meant. My biggest concern at the time was that I was going to lose my hair. I begged the doctors to postpone treatment until after my soccer season was over. Luckily for my health, I lost that battle. My treatment started on Halloween, thus permanently ruining candy for me. After five rounds of chemo cocktails being pumped into my veins, I was finally ready for the next step. I had the honor of having a fantastic surgeon gut me like a fish and remove the mass. After that, localized radiation lasted a few days. It was relatively uneventful other than the new tattoos I received. They had to make little dots on me to aim the radiation. I thought they would mark me with a sharpie but they were afraid I would wash it off. Do they not know how hard it is to wash sharpie off your skin? I received 8 blue dot tattoos, or what I now call Smurf freckles. To finish off the treatment I underwent a stem cell transplant. I was given a nearly lethal Long Island Ice Tea mixture of chemotherapy and was then infused with my own stem cells that had been taken out earlier. I made the mistake of doing some internet research on the treatment, which made walking into the situation even more terrifying.

The room was bare: white walls accented by white machines. It was cold and uninviting, completely void of life. It wasn't where a little kid should be, yet there I was. I remember entering that unit on a sunny day in mid April. Heavy steel doors opened automatically as I walked in. They slammed behind me as I stopped in front of another set of doors. My hands being drowned in Purell brought back the all too familiar smell of the hospital. My head spinning, I walked through the second set of doors and they slammed behind me. The hall was empty except for a few nurses. I realized there weren't any little bald kids walking down the hall, IV poles in tow.

Continued on page 12



Michelle Oaks was a keynote speaker at Partnering for Strength

## SB396 Seclusion & Restraint . .

continued from page 3

a major role coordinating hearing testimony on behalf of parents and mobilizing many stakeholders across the state to contact their representatives in favor of this legislation.

The power of those phone calls, emails, and outreach was evident as this bill has met little opposition on its way to the House. In March, the Senate Health, Education and Human Services committee voted unanimously to recommend SB 396, followed by a unanimous full Senate vote to pass the bill later that month. In April, the House Children and Family Law Committee showed their support with a 16-2 vote recommending that it pass and then again received overwhelming support of the full House, but due to the fact that the bill has rule-making provisions it was sent to a 2nd House committee, the Executive Departments & Administrative Rules Committee (ED&A). Concerned parents and constituents continued the momentum by flooding the phone lines of Representatives on the ED&A, and on May 6, the committee voted unanimously in favor of SB 396 with an amendment that further clarified some language within the bill. SB 396 was then placed in the House and passed. It will now go to the Governor, a longtime supporter of disability rights and if signed will become law.

## Speech & Hearing

Do you know how to identify the signs of speech/hearing disorders in children?

The American Speech Language Hearing Association has put together an online resource guide that identifies signs for Language, speech and voice disorders and stuttering and ways to help. Check it out at:

<http://identifythesigns.org/the-signs>

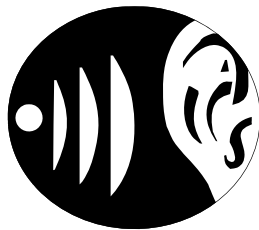
### Noised Induced Hearing Loss

You can also learn if your children or someone you know may be at risk for noise-induced hearing loss by listening to Dr. Jessica Rossi-Katz as she discusses just how prevalent noise induced hearing loss really is in children and what you can do to help prevent it at:

<http://podcast.asha.org>

To find out more information and facts about hearing loss, or help if you or someone you know is experiencing symptoms of hearing loss, visit

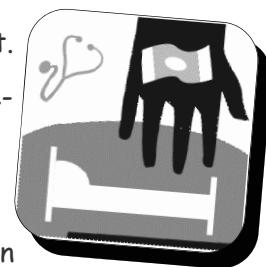
<http://identifythesigns.org>



## Taking an Active Role on Your Healthcare Team

The Agency for Healthcare Research and Quality (AHRQ) has a great website dedicated to improving communication between patients and medical professionals. The site is in English and Spanish and contains videos of patients and clinicians sharing why it's important to ask questions and offer ways that you can ask questions and get your health care needs met.

In these short, compelling videos, doctors and nurses talk about how your questions help them take better care of you and offer advice on how you can be an active member of your health care team and get your most pressing questions answered. This is a great resource for youth in transition to independence and serves as a general resource for all of us who are looking to foster great working relationships with the medical professionals in our lives!



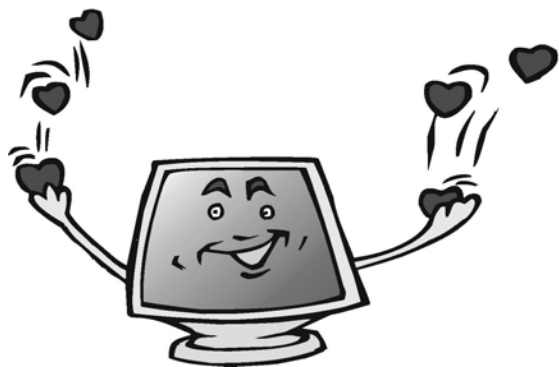
You can check it out at:

[www.ahrq.gov/patients-consumers/patient-involvement/index.html](http://www.ahrq.gov/patients-consumers/patient-involvement/index.html)

## Support Groups for Parents in Derry & Surrounding Communities

**The Autism Parent Support Group in Derry, NH and Surrounding Areas:** This parent led group meets on the first Wednesday of every month in the downstairs meeting room at the Derry Public Library from 9:30 AM to 11 AM. We encourage parents from Derry and all surrounding towns to attend. Our group was formed in collaboration with Easter Seals after a great need was expressed by families to find support and locate resources in their local areas. We will be expanding our meeting days and times to include an evening support group and adding a new meeting location in Londonderry in the coming months. For more information about this group or to be added to our Facebook group page, please contact Marla at: [Marla.Soucy@gmail.com](mailto:Marla.Soucy@gmail.com) or (603) 724-0790. We look forward to meeting you!

**Single Parents of Children with Special Needs Support Group:** This group is new, and is currently seeking interested parents to join our online Facebook community. We will be expanding to include group meetings and outings in the next few months. Our goal is to provide the much needed support and social needs of single parents who have children that experience any disability. For more information or to be added to our Facebook group, please contact Marla at: [Marla.Soucy@gmail.com](mailto:Marla.Soucy@gmail.com) or at (603) 724-0790. We look forward to hearing from you!



## Accessing WEB RESOURCES

More and more we have been including web resources in our newsletter.

Please remember if you DO NOT have access to these web based resources and information, NH Family Voices would be pleased to send you whatever information you would like printed out.

Just call us at:

1-800-852-3345 X 4525  
or (603) 271-4525



## JOIN

## NHFV-Talk List serve

NHFV is an affiliate of national "Family Voices". This organization supports its own through a great network and communication stream. NHFV would like to share local, state, and national resources on parent leadership, legislation, trainings, workshops, support groups and families connecting.

To do this we have established a *NHFV-Talk List-Serve*.

We would like to invite you to join us and receive up-dated information and resources.

To sign on go to:

<http://groups.yahoo.com/group/nhfvtalk>

**Michelle Oaks...** Continued from page 11

That's when I was shown the room: *my* room. I walked in, and the smell of cleaning chemicals filled the air. It didn't help that as a crime show addict, the smell of bleach signaled death to me. What's worse is that it was probably true.

As the nurse left she shut the door. And then it hit me: this was an isolation room. I'm back, and this time I'm trapped. I walked over to the window, sat on the bench, and pulled back the blinds. The glass was unusually thick. It was made impenetrable as if someone had tried to escape that way. I wouldn't blame them if they had. Outside the window was the world, and more importantly freedom. The first few days along with my birthday went by as a flash of puke bins and a constant gag reflex. I was lying in bed feeling particularly green in the face when the nurse came in with the stem cells. The bag of deep, rich, red fluid contrasted against the white walls. It seemed ironic that my cells were being given a new life in a room that seemed so void of it. The rest of my stay became a blur of morphine induced dreams and hallucinations as I faced complication after complication. It was in that room that I was told my best friend had died. I'm writing this exactly eight years since the day he died.

This part of my life has created so many memories. Some I wish I could remember more about and others I wish would be permanently erased from memory. I survived, but it is not over. There is no such thing as "you survived, it's over". It never ends. Life never returns to normal. A worry-free mindset ceases to exist. Every unusual lump has the potential to be another life altering tumor. It becomes a paranoia that your cells are conspiring against you. Survival doesn't give you any new-found freedoms. It's a reminder of all the new limitations put on you by long term side effects of treatment. I cringe every time a stranger comes up to me and says "well you are just so lucky to be alive". Do you know what that means? Lucky is winning the lottery or getting the last parking space.

Lucky is not surviving a living hell in order to realize that your life will never be the same again. Would you go up to a returning soldier and say that to them?

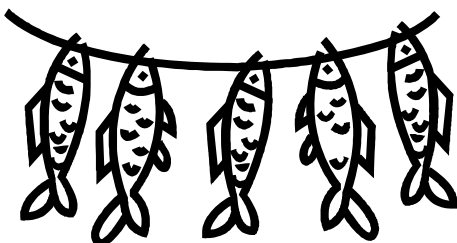
Continued on page 13

## The Great Accessible Outdoors!

Looking to plan an outdoor excursion now that the weather is warming up? Look no further than NH Fish & Game! NH Fish & Game has identified many trail routes, hunting and fishing opportunities that are accessible to all on their website.



If your family enjoys fishing, NH Fish and Game's "Let's Go Fishing!" Program works with many groups to enable those with varying abilities to engage in this fun sport. They have all the necessary equipment including a pontoon boat and ramp for getting wheelchairs onto the boat.



NH Fish & Game also publishes a map of fishing and boating locations around the state which includes accessibility ratings.

The free maps are distributed at official N.H. Visitor Centers, or can be requested by calling Fish and Game at (603) 271-3211.

[www.wildnh.com/Inside\\_FandG/ADA.html](http://www.wildnh.com/Inside_FandG/ADA.html)

### *Check out these trails...*

Dutton Brook and Gregg trails at Crotched Mountain in the Monadnock region are completely wheelchair accessible from beginning to end. So many details of this trail experience are well thought out from being able to pick blueberries from the comfort of a wheelchair to the interpretive signs along the way detailing natural treasures and wildlife habitats. The beauty of nature extends from the trails to a fully accessible observation deck where more interpretive signs give names to the many hills on the horizon. While no trails have a grade higher than eight percent, some parts were intentionally designed to be a challenge for those going up and down in a wheelchair, all part of the authenticity of this very special place. For more information visit

[www.crotchedmountain.org/Programs-and-Services/Accessible-Trails/Accessible-Trails](http://www.crotchedmountain.org/Programs-and-Services/Accessible-Trails/Accessible-Trails)

## Michelle Oaks...

Continued from page 12

I am glad I'm alive, but I wouldn't call myself lucky. If I was truly lucky, I wouldn't have gotten cancer in the first place. However, I am lucky to have met some amazing people along the way. These people have helped me overcome challenges I never thought I would be able to overcome.

They helped me grow as a person and taught me lessons that no level of education could even grasp.

High school has been an incredible struggle of perseverance. There were times when I had missed so much school that I questioned whether I would be able to last all four years. It took a lot of hard work and resulted in a lot of mental and emotional breakdowns, but as I prepare to graduate in a month I know I will make it. I am even getting ready to go off to college in New York in the fall.

I am excited to start such a big journey in a new place. In a way, it is a fresh start. I still worry about getting sick and dealing with all of my resulting health issues, but that has become the new normal. Some things I have to accommodate to and plan around, but I have also decided that there are some medical things that I simply will not let get in my way.

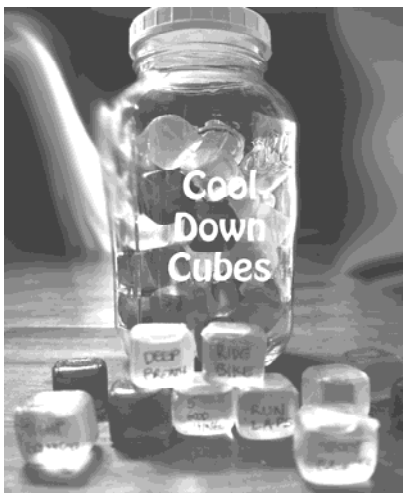
I may have to work harder than other people to achieve what I want and I may not live quite as many years, but how I live those years will be dictated by me only. Cancer will always be a part of my life, and survival is not just a state of being. Survivorship is a journey to regain power and control over your life. ♥

## Summertime Strategy: Cool Down Cubes

Looking for a new way to inspire emotional regulation strategies in children this summer? Try Cool Down Cubes! Make these with your children so they can have fun coming up with ways to cool down when tough emotions get the best of them.

### *Supplies Needed:*

- ♦ Plastic reusable ice cubes (can be bought at Bed, Bath & Beyond or Walmart)
- ♦ Container
- ♦ Permanent marker



Talk to your children about anger and frustration and let them know we all experience these feelings at times, it is normal and healthy. Anger is our body's way of telling us we don't like what is happening at that moment. The problem with anger is that sometimes it grows out of control and that may make us do or say things we are not so proud of later. The key is to find ways to be in control of angry feelings, so that we can express ourselves clearly and be understood. There's a bunch of ways to do this such as taking a break in another room, take a few deep breaths, running outside, different things work for different people. Spend some time together brainstorming ways that work for you and your family and write one on each cube with a permanent marker.

Next, place the cubes in the freezer and when anger strikes, grab hold of a cube, try out the strategy until it turns to liquid and see how it works. Sometimes you may need more than one cube! The idea is to have reminders in place so that when kids are overwhelmed by strong feelings they can quickly access the methods that you created together. This also opens the door for discussion later of what works and what doesn't and fosters problem solving skills.

♥ This idea came from The Crafty Counselor Chick blog:

<http://craftycounselorchick.blogspot.com/2012/09/cool-down-cubes.html>

and the Entirely Elementary blog

<http://entirelyelementary.blogspot.com/>.

## BLOG Spot..

continued from page 9

and accepting and willing people are. How, for the most part, people are eager to bridge the autism gap and connect with my son.

**NHFV:** Where does the book go that the blog does not?

**CC:** My blog posts are essays about something current in our life; my husband Joe's back surgery, my oldest son losing the spelling bee, Jack's tantrum about wearing glasses. I think it kind of provides an inside glimpse into our marriage and day-to-day life with the kids. The book, on the other hand, starts at the very beginning with Joe and I and tells the story of our life together as newlyweds and eventually with kids. I go into a lot more detail about our journey with Jack as a baby; our red flags, his symptoms, and his diagnosis.

**NHFV:** If you had one piece of wisdom to share today regarding anything, not Jack or family specifically, what would it be?

**CC:** People ask me where I find the time to write. The truth is, I don't know. I read an article by one of my favorite writers, Mary Beth Danielson, called *Seventeen Minutes of Kayaking*. Danielson talks about our need to honor our inconvenient passions; to pursue what lights us up from the inside out, and to chase what is rightfully ours.

Continued on page 15

**Blog Spot...** continued from page 14

Writing helps me somehow fit the puzzle pieces of Jack, autism and my family together. To write about my son, first I have to really see him. And once I really see him, I want to write about him. And then I want to tell you about him. I guess my advice would be to chase what is rightfully yours, and the rest will fall into place.

<http://carriecariello.com>

**facebook**

Join us on Facebook - We post learning opportunities for families and encourage contributions and conversations between members

<http://www.facebook.com/groups/nhfamilypoices/>

**Thank-you for the book donations.**

We would like to thank those who have donated books to our Lending Library  
Lynn Murray, Christina Whitaker  
And Beth Theisen



**BOOK DONATIONS**



Do you have books gathering dust on your bookshelf?

Are any of them on a specific diagnosis, educational issue, or children's book that address a life issue such as friendship, divorce, or illness?

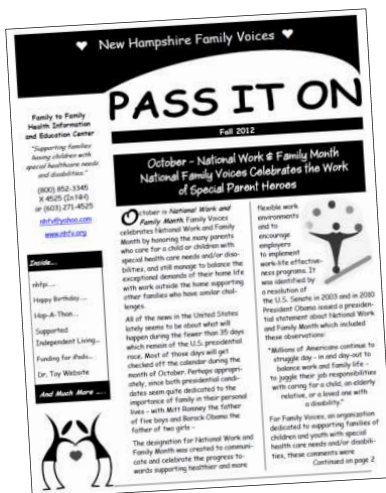
If you no longer have use for these books but are not sure what to do with them, NH Family Voices will take them and share them with other families, professionals, and children.

Call: 1-800-852-3345 X 4525

**Become a "Pass It On" Contributor**

Years ago, as a stay at home mom, I would find tidbits of information or resources that I slipped into a three ring binder for future use. My beginning days of being a resource hound! Do you have a knack for finding interesting resources? Do you have an experience you would like to share with other parents? Are you involved in activities you wish you could tell others about? Have you found something that works with your child that you would like to share?

NHFV is looking for submissions that can be included in the newsletter to share with other parents around the state. Pass It On is published three times a year. Help us fill it... family to family.... Contact Martha-Jean Madison at [nhfamilypoices@nhfv.org](mailto:nhfamilypoices@nhfv.org)



8282  
NHDHHS/SMS  
NH Family Voices  
129 Pleasant St. Thayer Bldg.  
Concord, NH 03301

Return Service Requested

PRST. STD.  
U.S. Postage  
PAID  
Concord, NH  
PERMIT # 1478



**I WOULD LIKE TO RECEIVE "PASS IT ON"...**  
**This is a FREE publication. Return to** 

NH Family Voices  
129 Pleasant St. Thayer Bldg.  
Concord, NH 03301

Please Print **Clearly**

**NAME:** \_\_\_\_\_

**STREET:** \_\_\_\_\_

**CITY, STATE, ZIP:** \_\_\_\_\_ **Tel. #:** \_\_\_\_\_

**E-MAIL ADDRESS** (If you would like it sent by web page) : \_\_\_\_\_

**I am a**  Parent / Family member of a child/teen/adult (circle) with a:  chronic health condition,  
 physical disability,  learning disability,  developmental disability,  behavioral challenges,  
 I am interested in materials relating to: \_\_\_\_\_

**I am a**  Professional working with families and/or children/adolescents/adults (circle) with a:  
 chronic health condition,  physical disabilities,  learning disabilities,  
 developmental disability,  Behavioral challenges,  
 I am interested in material relating to: \_\_\_\_\_

**I am a Professional in**  Education (circle one), EI, Head-Start, Pre-school, Elementary, Middle, High school, Residential setting.  Health Care Field (circle one), Community clinic, Hospital, VNA, Physician, Family Practitioner, Nurse.  Human Services (explain) \_\_\_\_\_ Other: \_\_\_\_\_