

Empowering and informing families and professionals caring for children with special health care needs and disabilities from birth to adulthood for over 20 years.

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Fighting HARD

Two girls transform their battle with chronic conditions and rare diseases by encouraging others like them to fight HARD.

At 13, Allie is many things... student, friend, sister, illustrator, painter, teen with chronic health conditions, activist and change maker. Above all, Allie is a fighter. She battles many chronic health conditions, medications and their side effects on a daily basis and she helps other young people do the same each and every day.

"Allie has had many diagnoses over the past several years, including but not limited to Crohn's Disease, Juvenile Rheumatoid Arthritis, Vesicoureteral Reflux (post bilateral ureteral re-implantation), Fibromyalgia, chronic inflammation, Patellafemoral Syndrome, Tendonitis, Osgood Schlatters, chronic migraines, vasculitis, costochondritis and the list goes on and on. She is in a great deal of pain most days, but manages to do the very best she can. She is currently on many medications, including chemotherapy drugs and steroids to help with the inflammation, and although they come with their own sets of side effects, she continues to Fight HARD every day!" says her mom, Tara Crocker.

It's no secret that the tween and teen years are challenging. Add several chronic conditions, constant doctors' appointments and hospitalizations into the mix and imagine what Allie's day to day looks like. When she was 11 years old, her parents began to notice some signs of depression with Allie.

"After having thoughts of suicide, as it seemingly became all too much to deal with, we immediately brought her to therapy. With the help of a wonderful therapist, it was recommended that we join a foundation that would help Allie to know that she wasn't alone in her journey." Said Tara.

They began researching and quickly realized there weren't many foundations to help kids like Allie who had multiple chronic illnesses or rare diseases. The family discussed several options and Allie brought up the idea to start their own foundation to help other kids who were in similar situations. Allie, with the help of her family started the Fighting HARD foundation.

The mission of Fighting HARD is to help other children who have rare diseases or chronic illness by letting them know they are not alone. Allie knew firsthand how difficult things could get when multiple specialists, hospital stays, medications, side effects, and missing lots of school becomes the norm. She wanted other kids like her to see that there are people out there who "get it" and that Fighting HARD is there to help them through the difficult days. "That is really what Fighting HARD is all about!" Says Allie.

Just under a year after Allie started the Fighting HARD foundation, her younger sister Jonna was diagnosed with a rare stomach disorder called



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

nhfamilyvoices@nhfv.org



www.nhfv.org

Letter from our NHFV Team



Jen Pinneo, ASD Project Coordinator & Liaison to the NH Council on Autism Spectrum Disorders

Dear Readers,

On April 19th, 2016 we officially launched the NH State Plan to Improve Supports and Services for Individuals on the Autism Spectrum with other Related Developmental Disabilities and their Families, referred to as the NH State Plan for ASD/DD. In the acknowledgements of this plan, Elizabeth Collins (NH Title V CYSHCN Director & NH Autism Planning Grant Director) noted that this was the culmination of the vision, passion, and effort of a committed group of planners and stakeholders. It was a true collaboration of partners who worked together from creating the application funding, planning the project and bringing the plan to fruition. Liz also gave special thanks to recognize the many families, professionals, service providers, community members, and NH Council on ASD members who provided information, input and support to the NH State Plan for ASD/DD. Because of these efforts the plan is actionable, comprehensive and relevant to NH's system of care.

NH Stakeholders were engaged in a variety of initiatives that served as a solid ground work for this development of the state plan. In 2014 NH completed a comprehensive needs assessment that systematically analyzed data from the existing data sets and collected additional information from families, young adults, self advocates, providers and other stakeholders regarding their needs. The needs assessment can be found at <http://nhfv.org/wp-content/uploads/2013/09/ASD-Needs-Assessment-2014-Final.pdf>.

Following the completion of the Needs Assessment, work was begun on developing the NH State Plan for ASD/DD.

The state plan focused on the following areas:

- Early Identification, Screening, Referral, and Diagnosis
- Family Support
- Early Intervention/FCESS
- Education
- Therapeutic Services
- Health Care
- Community Supports and Services
- Transition
- Infrastructure



The state plan can be found at <http://nhfv.org/wp-content/uploads/2013/09/State-Plan-Final.pdf>

From now until the end of August, when the grant ends, we will be working on action plans to address the recommendations in each of the focus areas. These will be fluid plans that can be worked on by stakeholders beyond the end of the grant.

It has been a privilege for me to work with such a dedicated group of people to complete this process. As a mom of two children on the Autism Spectrum I am excited about this work and the positive impacts it will make in NH.

If you would like to take part in the action planning please contact me at jsp@nhfv.org.

Note: This work was completed utilizing the State Planning Grants for Improving Supports and Services for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities, US Department of Health and Human Services/Health Resources and Services Administration (HRSA Grant # H6MMc26245)

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

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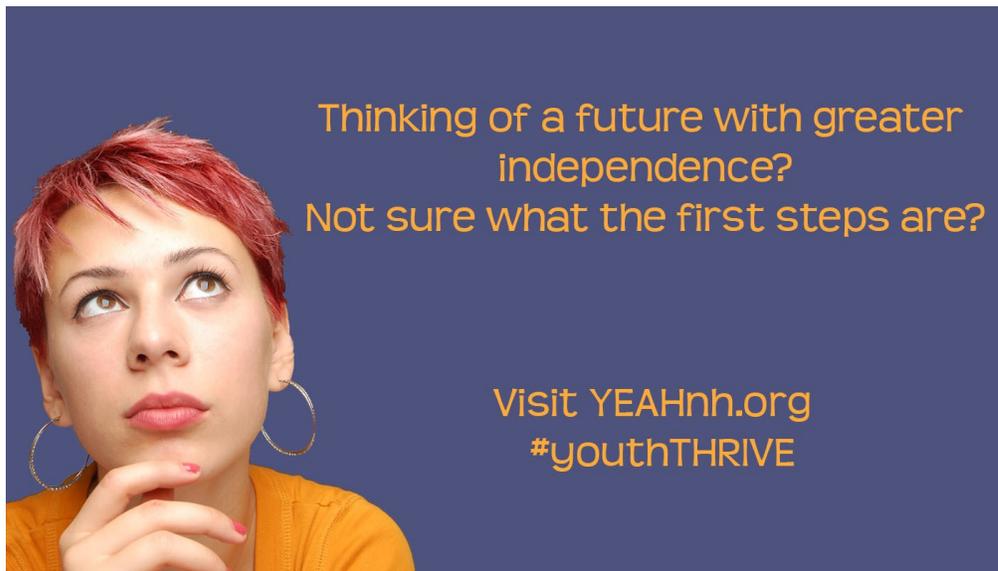
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YEAHnh.org is LIVE!

Online resources to help young people to navigate educational, social, physical and mental health issues



Parent Information Center of NH and NH Family Voices recently launched an online resource for teens and young adults in NH ages 14-26. YEAHnh.org is an interactive, content rich website geared towards granite state youth who

fulfilling lives. Those areas are advocacy, education, employment, finances, healthcare, leadership and life skills. There is a resource page for each of these categories with information on everything from how to write a

“YEAHnh.org is a first of its kind resource in NH because it was created exclusively for teens and young adults. The beauty of this website is that it’s a place for young people to access information, resources and inspiration as they begin to take the necessary steps to the life they dream of for themselves.”

*– Robin deAlmeida, Marketing & Outreach
New Hampshire Family Voices*

are experiencing challenges in school, socially, or with physical or mental health. It also serves as a resource for any young person looking to gain independence and knowledge about personal finances, employment, living on their own and planning for life after high school.

YEAHnh.org addresses six main areas that teens and young adults need to know about to live independent,

resume and manage a personal budget to communicating effectively and transitioning from pediatric to adult healthcare.

The website also has a variety of different ways in which young people can engage with each other. There are galleries where visitors can submit and share artwork, music and stories about their journey to independence or anything going on in their lives. The “Ask a

Youth” feature allows visitors to submit questions about growing up with a disability, challenge or health condition that is answered by a team of NH teens and young adults. There are also news feeds featuring headlines that pertain specifically to the youth population. There are also live Twitter and Instagram feeds, a necessity for this age group. And a calendar of youth focused events such as camps, workshops, webinars and local entertainment.

YEAHnh.org is also the online hub for YEAH Council, a group of young leaders doing important work throughout NH in the areas of advocacy, education and healthcare.

Check out YEAHnh.org and let us know what you think!



Have We All Gone Nuts?

Teaching others: A sandwich is not more important than a child's life, it's just not.



Last year at Annabel's Pre-K orientation, a dad asked if kids would be allowed to have peanut butter in their lunches. I watched a mom in front of me stiffen as the teachers replied, "We're asking you not to. We have a child in one of the pre-k classes with a severe nut allergy."

As the dad made a face, the mom in front of me stood up. "My daughter is in the Tuesday/Thursday class, and she has the nut allergy. Even peanut dust could kill her. She's only four. Please, I'm begging you, don't send peanut butter to school. It's only two-and-a-half hours. Please."

She sat back down, and the dad said, "My child is in the Monday/Wednesday/Friday class, does that mean I can send peanut butter?"

I will never forget the look on that mom's face.

I see similar conversations play out again and again. Scared moms and dads beg their fellow parents to leave the peanut butter at home, while other parents refuse, saying, "It's my right to feed my child what I want – your child's health is not more important than mine." As if the risk of hunger-induced crankiness is the same as the risk of death.

Of course, there are a lot of airborne food allergies, and it isn't real-

istic to ban everything. But I just don't understand the parent who, upon hearing about an allergy in their child's class, continues to send the allergen to school. Why would you willingly risk a child's life? Why would you risk *your child* being the reason a classmate gets sick or dies?

My kids don't have allergies, but Annabel is a picky enough eater that her packed lunch is exactly the same very single day. But if there were a kid in her class with a milk or strawberry allergy, we'd figure out some new foods to put in her lunchbox. There are thousands of options at all different price points for [dairy-free](#), [nut-free](#), and [allergen-free](#) snacks (and [protein alternatives](#)) just on Pinterest. And – *she could still eat yogurt and strawberries at home!*

Last week, Annabel came home and told me about the peanut-free table at her school. "I can sit at it, because I don't have peanut butter!" When I explained to her that the table was started for kids who are allergic to peanuts, she asked, "Why does *anyone* bring peanuts, then?" When I told her it's because some parents still want their kids to eat peanut butter, she was appalled. "But grown ups are supposed to keep kids safe!"

And that's the rub. Kids should know that the adults in their schools *will* keep them safe. I shouldn't have to worry that you'll speed through a crosswalk while we're in it (because your child has the right to be on time to school just like mine, right?), and another mom shouldn't have to worry that your child might accidentally kill hers at lunch. What has happened to empathy? What has happened to our village?

A sandwich is not more important than a child's life. It's just not.

Several of us here at NHFV recently read this editorial in the Huffington Post and exclaimed, "FINALLY!". Many of our children have food allergies and we know many of our reader's children do as well. We know the constant battle of trying to convince others just how real and sometimes lethal certain foods are to our children. We are so very thankful to Heather Spohr, the author, for allowing us to re-print her work here. If you have children with food allergies, share a copy of this post with schools, family members, friends or anyone that needs to know the power that just one little sandwich or snack can have.

This post originally ran on Heather Spohr's blog, *The Spohrs Are Multiplying*. Read more at: <http://thespohrsaremultiplying.com/family-and-friends/weve-all-gone-nuts/#ixzz49ISeugHV>.

Follow them : [@mamaspohr on Twitter](#) | [TheSpohrsAreMultiplying on Facebook](#).

Special Healthcare Needs: Food Allergies

Blogs with news you can use



It's an Itchy Little World

Extensive resources and expert interviews on allergies, eczema and asthma.
<https://itchylittleworld.com>

OneSpot Allergy

Written by a lawyer and mom to inform people with all types of allergies about relevant legal and safety concerns. Includes many product warnings and recommendations. <http://blog.onespotallergy.com>

Lexie's Kitchen

Tons and tons of allergy free recipes! www.lexieskitchen.com

Kids With Food Allergies Blog

Written by the Asthma & Allergy Foundation of America to spread awareness and provide information to families with children coping with food allergies. Tons of tips and trick and live events such as webinars and live chats.
<http://community.kidswithfoodallergies.org/blog>

Allergy Eats

A blog dedicated to helping people find allergy-friendly restaurants across the nation. <https://www.allergyeats.com/blog/>



Join our community!
We post the latest events, opportunities and news.
This online community is a great way to connect with other families like yours!

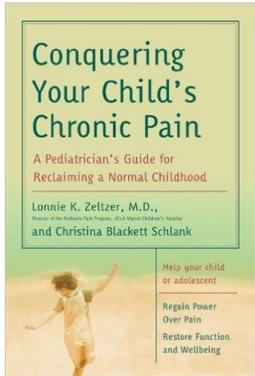
Be sure to click the "get notifications" option so that you receive all updated information.

We also host a private Facebook group so that our families can connect with one another in a more private setting. Our staff and group members exchange information, resources and support around the clock. <http://www.facebook.com/groups/nhfamilyvoices/>





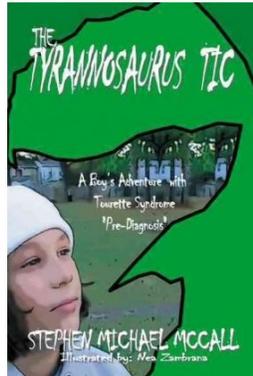
Summer book recommendations....



**Conquering Your Child's Chronic Pain:
A Pediatrician's Guide for Reclaiming a
Normal Childhood**
By Lonnie K., M.D. Zeltzer

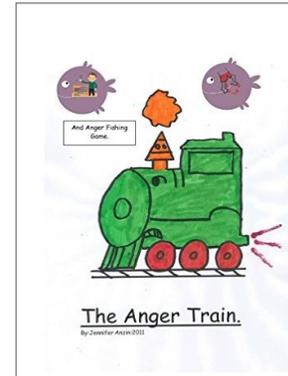
A child's chronic pain undermines school performance and social and emotional health, erodes finances, and can be devastating to families.

Dr. Zeltzer's clinic is renowned for treatment of pediatric pain stemming from headaches, arthritis, irritable bowel syndrome; fibromyalgia, and more, via a multi-disciplinary approach. Based on more than 30 years study, Dr. Zeltzer offers ways to take control of the pain and explains how to soothe the nervous system, reactivate the body's natural pain control mechanisms, which medications are most effective, how to reduce parents' guilt and much more.



**The Tyrannosaurus Tic: A Boy's Adventure
with Tourette Syndrome**
By Stephen Michael McCall

Michael's story unfolds with a new hurdle and difficult situation in each chapter. Told through this brave 12yr olds eyes, each problem and embarrassing tic is dealt with in his own original way, with excuses and humor. The reader will have a better understanding of what young children go through with the on-set of involuntary body movements, also known as tic's. Children with Tourette Syndrome (TS) or other disorders will be able to identify with Michael's challenges with his classmates and teachers. It informs and engages the reader on facing dilemmas one step at a time. It will increase awareness of TS and gain respect for children that face TS and other problems that are bigger than dinosaurs!



The Anger Train
By Jennifer Anzin

Author Jennifer Anzin, an early childhood consultant and parent with over twenty years experience has found that children enjoy learning and practicing strategies while listening to a story. The Anger Train is a children's book which includes practical strategies to help children deal with anger and self-regulation issues. The book is for young children from 3-7 years of age, their parents, and teachers. Practical strategies are woven into the story and additional recommendations are added at the end of the book. An anger, self-regulation game is also included.

Our lending library is expanding!

The Family Resource Connection (previously housed at the NH State Library) will now be held at our lending library. 500 new titles will be added to our selection over the summer. If you are looking for resources on a particular subject, give us a call as new titles may not yet be catalogued.

Books are sent free of charge through the mail with a postage paid return envelope. To borrow a book call 603-271-4525 or visit www.nhfv.org



A Parent's Guide to Developmental Delays: Recognizing and Coping with Missed Milestones in Speech, Movement, Learning, and Other Areas
By Laurie Fivozinsky LeComer

Developmental delays affect millions of children each year, and often go undetected until an alert and caring parent recognizes there's a problem. In this book, special education expert and consultant Laurie LeComer, M.Ed., provides essential information for any parent with a child who might have cognitive, physical, or emotional delays. Easy to understand, reassuring, and up-to-date, the book covers everything concerned parents need to know.

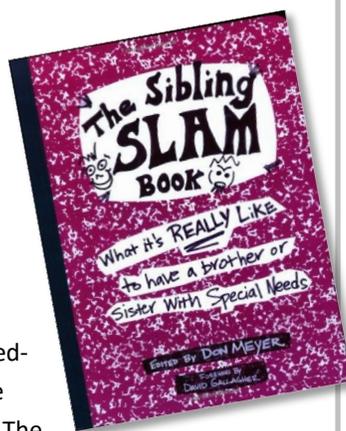
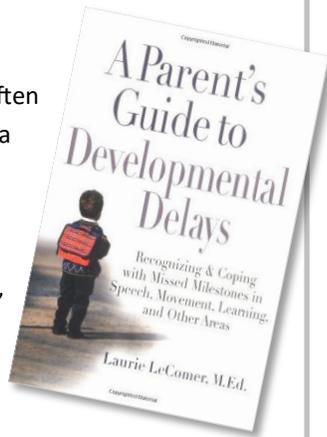
Using real-life examples and case studies along with checklists, exercises, and other hands-on advice, the book covers a range of delays and disorders that include autism, ADHD, learning disabilities, Sensory Processing Disorder, aggressive behavior, and motor-control problems.

Topics include:

- Spotting the "red flags" of delayed development for every age group.
- Identifying your child's specific challenges.
- Acting swiftly in order to gain the advantages of early intervention.
- Getting a diagnosis and treatment plan that fits your child's needs.
- Working with teachers, health professionals, and specialists for maximum results.
- Tracking your child's progress.
- Understanding your rights and making the most of every available resource.
- Trusting your instincts in order to help your child learn, develop, and thrive.

The Sibling Slam Book: What It's Really Like To Have A Brother Or Sister With Special Needs
By Don Meyer

Give teenagers a chance to say what's on their minds, and you might be surprised by what you hear. That's exactly what Don Meyer, did when he invited together a group of 80 teenagers, from all over the United States and abroad, to talk about what it's like to have a brother or sister with special needs. Their unedited words are found in this brutally honest, non-PC look at the lives, experiences, and opinions of siblings without disabilities. The Sibling Slam Book doesn't slam in the traditional sense of the word. The tone and point-of-view of the answers are all over the map. Some answers are assuredly positive, a few are strikingly negative, but most reflect the complex and conflicted mix of emotions that come with the territory. Whether they read it cover to cover or sample it at random, teenagers will surely find common ground among these pages and reassurance that they are not alone. It is a book that parents, friends, and counselors can feel confident recommending to any teenager with a brother or sister with a disability. (2006 Independent Publishers Book Awards: Finalist in Juvenile-Teen-Y/A Non-Fiction category)



Call us or log on to www.nhfv.org and click on "how we can help, then choose Lending Library



Search thousands of books by subject



Add the book you like to your cart and fill out the delivery form



Books will be delivered to your home/office with a prepaid postage envelope for you to return them



National Parks & Wildlife Refuges

Enjoy free access this summer to 2000 federal recreation sites across the U.S.



Free Passes to U.S. National Parks and Wildlife Refuges

Did you know that there are 2,000 federal recreation sites throughout the U.S. including national parks and wildlife refuges? If someone in your family has a permanent disability or your child is in 4th grade, you could enjoy free access to these amazing places this summer!

The Access Pass

If you are a U.S. Citizen with a permanent disability or have a child that fits this description, you could be eligible for the *Access Pass*. This pass is free, and is valid throughout the pass holder's lifetime. The benefits of having the *Access Pass* are that the pass holder and whoever is in their car, will be allowed entry free of charge. At many sites, the *Access Pass* provides the pass owner a discount on Expanded Amenity Fees (such as camping, swimming, boat launching, and guided tours). You can obtain a pass in person at certain sites, but the best bet may be to mail order it. Either way, you will have to supply documentation of the permanent disability, this could be a letter from a physician or proof of social security disability income. Some restrictions apply so see <http://1.usa.gov/1ZJKfua> for more information.

The 4th Grade Pass

If you have a child in 4th grade (home-schooled and free-choice learners 10 years of age are also eligible), you can download your own voucher to gain unlimited, free access to any federal lands or water from the start of the child's fourth grade year to August 31 of his/her fourth grade year. Visit www.everykidinapark.gov to learn more about how to use the pass, obtain help planning your trip, to locate educational materials and more!

With free access to over 2000 destinations, it's time to start checking out what adventures you can plan close to home or far away.

TSA Cares

Disability helpline for airline travel

If you are heading to the airport this summer, you may want to give **TSA Cares** a call before you go. TSA Cares is a helpline number designed to assist travelers with disabilities and medical conditions, prior to getting to the airport. Travelers may call TSA Cares toll free at 1-855-787-2227 prior to traveling with questions about screening policies, procedures and what to expect at the security checkpoint.

When a passenger with a disability or medical condition calls TSA Cares, a representative will provide assistance, either with information about screening that is relevant to the passenger's specific disability or medical condition, or the passenger may be referred to disability experts at TSA. TSA recommends that passengers call approximately 72 hours ahead of travel so that TSA Cares has the opportunity to coordinate checkpoint support with a TSA Customer Service Manager located at the airport when necessary.

Every person and item must be screened before entering the secure area of an airport and the manner in which the screening is conducted will depend on the passenger's abilities and any specific equipment brought to the security checkpoint. The agency works regularly with a broad coalition of disability and medical condition advocacy groups to help understand their needs and adapt screening procedures accordingly.

TSA also has a **notification card** that travelers can fill out and bring with them to discreetly let security personnel know about conditions that might present challenges at security checkpoints such as titanium plates or urostomy bags. These cards can be found at www.tsa.gov/sites/default/files/disability_notification_card_508.pdf

Explore, Experience, Enjoy!

Travel agencies that specialize in making vacation easy and fun for those with chronic conditions and disabilities



When you have a child with special needs, the idea of traveling and sightseeing can seem daunting. All of the extra planning that goes into ensuring accessibility and individual needs being met can be overwhelming. These amazing companies understand that and are dedicated to making travel possible and enjoyable whatever your child's need may be.

Hammer Travel offers a variety of travel opportunities for individuals with developmental disabilities. They provide unique and enjoyable experiences for everyone. Their mission is to "meet the needs of each of our travelers to make your dreams come true!" Their experienced team works with families in all aspects of the travel process; ensuring a safe, fun and memorable trip. <http://hammertravel.org>

Autism on the Seas partnered with Royal Caribbean in 2007 to develop cruise vacation services to accommodate adults and families living with children with Special Needs, including, but not limited to, Autism, Asperger Syndrome, Down Syndrome, Tourette Syndrome, Cerebral Palsy and all Cognitive, Intellectual and Developmental Disabilities. They provide cruise lines with their Staff (selected from regular cruises throughout the year) that assist adults and families in accommodating the typical cruise services, as well as providing specialized respite and Private Activities/Sessions that allow guests the use of the ships entertainment venues in an accommodated and assisted manner. This professional Staff (educated, experienced, background checked and sanctioned by the cruise lines) accompanies families on their cruise to provide amazing vacation and travel experiences. They now offer services on board Royal Caribbean, Celebrity, Disney and Carnival Cruise Lines as well. www.autismontheseas.com

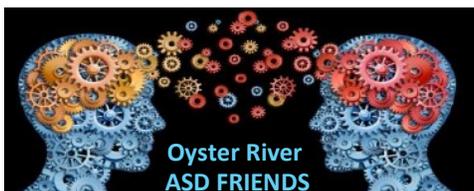
DisabledTravelers.org is another resource to check out. The website is dedicated to accessible travel information. It provides information on businesses from around the world that specialize in disability travel, products to assist travelers with disabilities, access guides, airline information and more. www.disabledtravelers.org

NH Support Groups

Connecting with others creates community & compassion

The Spina Bifida Awareness & Support Group, provides support for families in and around NH. The primary goal of the group is to work with families who are expecting a baby to be born with spina bifida. Having a baby with spina bifida can be extremely overwhelming; however, as a volunteer at DHMC and the mother of a child with spina bifida, group organizer, Michelle Drago, can help. The second mission of the group is to provide a relaxed atmosphere in which families can share experiences, support, and advice. For more information, please contact Michelle Drago at (603) 783-4685 or by email at moofns@comcast.net.

Oyster River ASD Friends is open to all parents from any town or school district who are interested in connecting and learning to support themselves and their teens/young adults on the Autism Spectrum. Please join us on the 2nd Tuesdays of the month at the Durham Public Library. For more information, contact Julie Smith at jsmithnh@icloud.com or 603-767-4190.



SIBS NH is currently available to run Sibling Support programs for central and southern NH. Contact us to find out more about this fun way to support children and youth who have a brother or sister with a disability or special healthcare need. For more information contact Karin at Karin@sibs-nh.com or Kaleigh at Kaleigh@sibs-nh.com. You can also find us on Facebook!!



Project Spotlight: Hollis Brookline High School ***A Collaborative Approach to Improving*** ***Special Education in New Hampshire***

In early 2015, our YEAH Council Youth Coordinator, Karin Harvey-Olson and Youth Leader, Zachary Hastings visited Hollis Brookline High School (HBHS). The purpose of their visit was to share with the students in the HBHS Life Skills Transition Program (LTSP) the great work YEAH Council has done around the state and expose them to opportunities within the council that the students might be interested in. What came out of that day was an incredible partnership that stimulated self-discovery, growth and opportunity for everyone involved.

“The partnership was a natural fit. We decided to embark on a project to help students better understand their IEPs and began meeting twice a month. LTSP became a satellite YEAH Council and we brought in Parent Information Center (PIC) to help with learning the ins and outs of an IEP” Said Harvey-Olson.

Thomas C. Evans, Special Education Teacher and Case Manager at HBHS explained that there were some unforeseen challenges that became apparent right from the start. “We realized our students didn’t know the names of their disabilities, some did not even acknowledge having a disability. Initially, many students experienced anger, denial, depression, and anxiety. Many refused to enter the classroom during YEAH Council meetings, insisting they were not a person with disabilities. We supported them through these growth and discovery processes with the guidance and help of New Hampshire Family Voices (NHFV). Now, in our second



year, we reflect back on the beginning in awe as we see these kids come out on the other side. They have accomplished what many thought to be impossible”.

Their project, called GAIN (Growing Awareness of the IEP process Now) is now in its final stages.

Together, the three organizations worked

“The partnership between PIC, NHFV, and LSTP was invaluable throughout the process.” said Evans.

on educating and informing each other. The outcomes have been astounding. Nearly all the students in the LTSP are now able to clearly and comfortably verbalize their academic and diagnosed disabilities. They have renamed sections of their IEP to represent youth friendly language so that it is understandable to students, parents and educators. HBHS previously used terms like Super Senior and

Repeating Senior to describe students, who by Federal Law have the right to remain in the least restrictive educational setting until the age of 21, or until they obtain their diploma. LTSP found these terms discouraging and came up with new ways to identify the phases each student goes through to graduate high school. Each LSTP student is described as being in the Ready, Get Set, or the Go Phase (terms derived from YEAH

“Our Ready, Get Set, and Go phase students have been able to display more confidence within the Hollis Brookline High School community when interacting with parents, teachers, pre-employment skills Employers, and their fellow students due to this new language.” Said Evans.



Summer Camps

Community Partners offers fun social experiences and a glimpse into the future for young adults with disabilities

FRIENDS FOR LIFE CAMP

For: Ages 15-21

Dates: June 27th—July 1st

Time: Monday – Thursday 9am – 3pm;

After camp social hour available: 3-4pm

Friday 9am-12pm, no after-camp hour

Location: Grace Community Church,
159 Rochester Hill Road, Rochester

Cost: \$300

\$100 deposit must accompany registration.

Space is limited to 20 campers!

Campers will participate in fun, social & recreational activities allowing them to meet new people, enhance existing friendships and practice skills important to maintaining friends or having social success at places like school and work. Activities will include field trips into the community and also games & activities on site. Campers will practice skills such as communication, reciprocity, teamwork, social coping strategies, greetings, and appropriate use of phone and email while engaging in fun activities together!

Level of supervision: Staffing ratio 1:4. Unfortunately, we do not have the resources to provide 1:1 assistance of any kind. If a camper requires 1:1 assistance for any reason, they are welcome to bring along a support person (camp tuition will not be charged for the support person; however, that person may be required to pay for their own admittance to any recreational activity the group may attend.)

*After-camp social hour: Campers can be picked up at the conclusion of camp programming at 3pm or stay until 4pm for social time. This will be in a specific area and supervised by one staff person. The camp's core staff will use 3-4pm for planning time away from the group.

IT'S MY LIFE! CAMP

For: Ages 18-28

Dates: August 1st—5th

Time: Monday – Thursday 9am – 3pm;

After camp social hour available: 3-4pm

Friday 9am-12pm, no after-camp hour

Location: Grace Community Church,
57 Wakefield St, Rochester

Cost: \$265

\$100 deposit must accompany registration.

Space is limited to 20 campers!

Campers will get a glimpse of what it might be like to someday live independently. They will be exposed to options and will participate in activities to practice independent living skills such as: safety awareness, cooking, money management, shopping, managing healthcare and maintaining a social support network. Campers will meet young adults living in their own apartments and hear from them about their struggles and accomplishments, learn about resources available to help them be successful including Housing Assistance, public transportation, apps & technology, and other community resources.

Level of supervision: Staffing ratio 1:5. Unfortunately, we do not have the resources to provide 1:1 assistance of any kind. If a camper requires 1:1 assistance for any reason, they are welcome to bring along a support person (camp tuition will not be charged for the support person;

however, that person may be required to pay for their own admittance to any recreational activity the group may attend.)

*After-camp social hour: Campers can be picked up at the conclusion of camp programming at 3pm or stay until 4pm for social time. This will be in a specific area and supervised by one staff person. The camp's core staff will use 3-4pm for planning time away from the group.

The Youth Transition Program team at Community Partners serves youth and young adults who are facing transitions in their lives such as transitions into adulthood, employment, a new program or a new apartment. The team provides customized services to individuals on a year-round basis by contracting with school districts, Vocational Rehabilitation, Developmental Services or privately with families.

This summer we are excited to offer many new opportunities to meet a wide range of individual needs!

**To register, contact Amy Cook
603-516-9300**

acook@communitypartnersnh.org

Payment can be accepted from school districts, private families or other funding sources.



Summer Time Family Fun for All!

Adaptive paddling lessons at Crothed Mountain

Announcing the region's first adaptive paddling program, specifically designed to assist people with disabilities. Join us this summer for lessons with recreation therapists trained in paddling techniques and skills. All participants are asked to come with a buddy. This could be a family member, friend or caregiver. You can also request a volunteer paddling buddy upon registration. No experience is required. A lifeguard will be on duty at all times.

Crotched Mountain offers paddling opportunities in a safe and supportive environment with various levels of support and adaptations as needed for individual success. This summer, the Introduction to Kayaking course is offered on three separate days. Lessons

will be held on July 13 from 1-3 p.m., July 30 from 10 a.m. - 12 p.m. and August 13 from 1-3 p.m. Participants will learn boat safety, effective paddling techniques, adapting equipment for success and safe boat entry and exit to meet each individual's specific needs. All equipment is provided. Instruction and facilitation of lessons are in a structured, supportive and in a safe environment with certified therapeutic recreation specialists trained in kayaking skills and techniques. Scholarships are available. More information and registration is available at www.crotchedmountain.org/paddling/ or contact Kristin Harris at cmars@crotchedmountain.org 603.547.3311. ext. 1664.



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If...The game of Emotional Intelligence

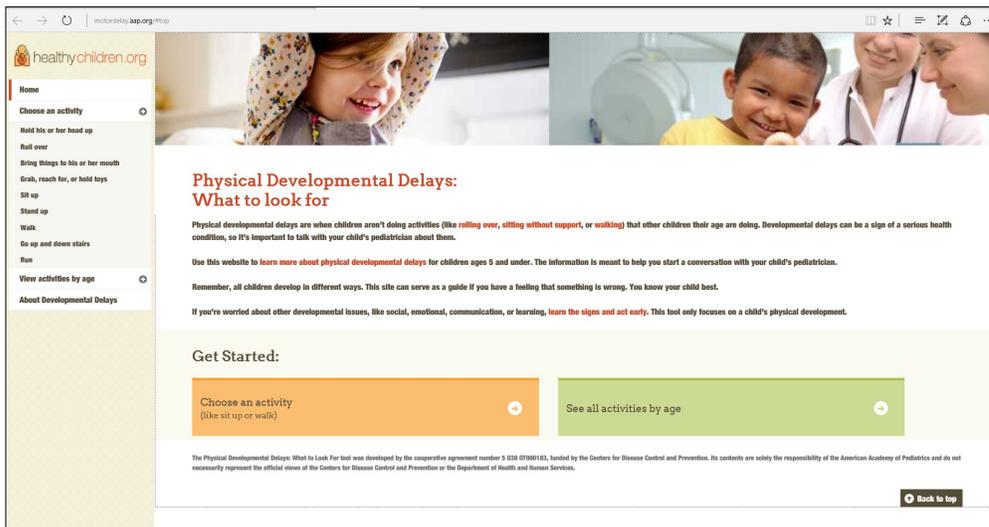


If... The Emotional IQ Game is an adventure game that helps kids age 6 to 12 develop the skills that lead to emotional intelligence. Inspired by the poem "If" by Rudyard Kipling, the app leads kids on a quest that promotes self-awareness and positive social communication. Kids think about and exercise choices related to core social and emotional learning (SEL) skills such as gratitude, helpfulness, and regulation of fear.

As they play, kids get dialogue choices and can choose to say unkind or smart-alecky things; if they make an unkind choice, other characters react with hurt feelings or advice. There characters use language such as "Let's find a win-win" and "This is really frustrating and scary" to help kids learn problem-solving and emotional vocabulary. Parents can view a report on a kid's gameplay and skills practiced for each chapter. This first chapter is free; all chapters thereafter must be purchased. Rated 5 stars by Commonsense Media, recommended by Autism Speaks.

Physical Developmental Delays: What to look for in children under 5

Physical developmental delays are when children aren't doing activities like others their age such as, rolling over, sitting without support, or walking. Developmental delays can be a sign of a serious health condition, so it's important to talk with your child's pediatrician about them. The American Academy of Pediatrics developed a new online tool so that parents and caregivers can learn more about physical developmental delays for children ages 5 and under. The information on this site will help parents and caregivers begin a conversation with their child's pediatrician. It is important to keep in mind that all children develop in different ways. To use this tool, visit <http://motordelay.aap.org/>. For those who have concerns about developmental issues that are not physical, like social, emotional, communication, or learning, visit the Learn the Signs. Act Early website issued by the CDC at <http://www.cdc.gov/ncbddd/actearly/index.html>.



Our Twitter account is growing and we are sharing new information and resources each week!

Here are some great reasons to get on twitter;

1. You can quickly find information by subject just by search #ADHD, #SpinaBifida etc.
2. You will get news from organizations around the world, real time in quick bits.
3. Your inbox won't be over crowded with lengthy announcements and info that you have to sort through, because twitter provides all the headlines you are interested in.
4. Based on the organizations and people you follow, Twitter exposes you to more you may not have known about.
5. The interface is super easy and fast to use.
6. New Hampshire Family Voices is on twitter, so follow us [@NHFamilyVoices!](https://twitter.com/NHFamilyVoices)

Fighting HARD... continued from page 1

gastroparesis. She has been in and out of the hospital for the past 7 months for multiple surgeries and procedures. Jonna was a travel soccer player who loved cooking, but since her diagnosis, her world has been turned upside down. She can no longer eat and now has a feeding tube. Jonna, like Allie, continues to make the best of each day and the Crockers continue to hope for a cure so that she can get back to all of the things she loves to do. Both girls are now Fighting HARD and helping others to do the same.

Every day, children with rare diseases or chronic conditions and their parents reaching out to Fighting HARD. The biggest challenge for these families is that they are feeling alone and overwhelmed. Fighting HARD is on a mission to raise awareness about rare diseases so others have a greater understanding of what life is like for these children and their families..

“A common complaint is ‘No one understands what we are dealing with...’ and it really is a true statement. Many will say things like, ‘At least it’s not cancer...’ and that really minimizes the feelings of these kids and their families. Unless you are in this world, you don’t really comprehend all that a family is enduring if their child is sick, with any illness. We hope to help others understand that even though you can’t necessarily “see” some illnesses, and even if you have never heard of it, they are still very real and can be just as severe. These kids and their families need to know they have support and resources to help them



Allie Crocker, 13

through their journey” Said Tara.

“It is really difficult some days, and the pain is very real. Sometimes it is hard to get through a day, but we do our very best. Some teachers and doctors are so understanding and helpful and others make us feel like it is our fault that we are sick or that it’s not as bad as it really is. We would love for these professionals to be more sympathetic and understand that all we really want is to be able to be a kid and do normal things with our friends.” Say Allie and Jonna.

When it comes to their own healthcare, both girls are very involved. Both have a thorough understanding of their illnesses and are active in the decision-making processes that go along with their care. They research their conditions, talk with others who have similar symptoms, and help each other through the ups and downs. The Crockers have the girls write questions for their doctors in an effort to be independent but also to advocate for themselves and others. Asking questions themselves allows doctors to see that they are kids with very real concerns about their lives and how medications or treatments will affect them on a daily basis. “Some doctors forget that these are kids and the quality of life should be considered. What good does it do to prescribe medication to reduce inflammation so that you can walk, if it makes you vomit all day and become so tired that you can’t get out of bed? The girls really have to fight for their answers and help doctors see that these are very real concerns for them and should be taken seriously.”,

said Tara

Through the foundation, the girls are empowering other kids, tweens and teens to do the same. Fighting HARD works with family members to help them understand the perspective of the patient. Even something as exciting as a family vacation can lead to lots of anxiety for a child with chronic illness. They might be acting out because they are thinking, what if I’m sick? What if my joints hurt and I can’t walk? Am I going to ruin the vacation for the rest of my family? It is crucial that they are able to discuss their real feelings and that everyone in the family and the medical field validate their thoughts and help them to know they are not alone.



Jonna Crocker, 11

“We enjoy talking with the many other children who are Fighting HARD each day through social media, and we look forward to helping more and more families as we grow our organization. We send lots of care packages and help families with things that they need while a child is in the hospital. We have lots of projects and send cards and get well gifts to kids all over the country to help them know that they are not alone!” - Allie & Jonna

For more information on Fighting HARD contact: Tara Crocker
Fighting HARD Foundation
www.fightinghardfoundation.org
908.907.1691
Twitter:@FightingHARD2

Hollis Brookline High School... continued from page 10

Council's Ready, Set, Go! Tool). As a result of this work, student participation in IEP meetings is on the rise.

Those participating in Pre-Employment Skills Internships have told their employers the supports they will need on the jobsite. All 21 Employer Partners have been educated about this population of potential employees and as a result of the great experience they had with students this year, have requested increased hours for LTSP students during the 2016-2017 school year. This is no small accomplishment given that 73.4% of New Hampshire citizens

with disabilities will not enter the workforce after high school, according to the NH Employment Security, Economic and Labor Market Information Bureau.

"The YEAH Council has helped to give our students the confidence and language to face and overcome the barriers that prevent them from participating in the workforce. It has been an absolute privilege to work and learn with NHFV and PIC. Our hope is that what we have "GAINED" together, will one day be shared with all New Hampshire families and schools who have children with disabilities" said Evans.

If you would like more information on YEAH Council activities contact Terry Ohlson Martin, NHFV Co-Director, at tom@nhfv.org.



Online Subscription

NHFV is striving to deliver valuable information and resources to families and the professionals that work with them through a variety of outreach tools. The paper copy of *Pass It On* serves many purposes and is one of our most valued resources. But reality is... many do their reading and sharing online. The electronic version of *Pass It On* contains live links so that readers may click and get to more in depth information in seconds. We would like to encourage those who are receiving a hard copy to think about this new feature and feel free to switch to the electronic newsletter version.

This is easy to do, just follow these steps!

1. go to www.nhfv.org and click on **Membership**.
2. Fill out the form as if you were a new member (please include address information).
3. Add nhfamilyvoices@nhfv.org to your email safe senders list, address book or contact list so that email newsletters are not blocked or filtered into your spam folder.

This free resource is intended for sharing so please continue to "*Pass It On*" to friends, family and professional you think might find it useful.

Supporting Families

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.

Through sharing experiences, it is our hope that these personal stories will help, encourage, and support others.

If you have a story to share or know of someone who does, please contact our editor at nhfamilyvoices@nhfv.org.



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How did you hear about our *Pass It On* newsletter? _____