

# 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

[nhfv@yahoo.com](mailto:nhfv@yahoo.com)

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

Winter 2011

## Family Experiences: Ways to Lead Change Through Telling Your Story

I recently attended a conference about model programs serving children with disabilities and their families. After one parent gave a particularly moving account of her family's struggles, the audience took a break. During the break, I overheard a remark from another audience participant. "I don't know if I can listen to any more tear jerking stories," the person complained. "What's the point?" I was initially startled by the remark, then insulted. How could someone be so callous as to question the experience of a parent? As a parent of two children who receive special education services, I took this comment personally - as if the person were talking about my story, and telling me that it wasn't worth listening to. As I thought more about this situation, however, I realized the problem was not one of insensitivity, but that somehow the story had no impact on some listeners. It did not move them to think and consider using the themes and information as a prompt to change their personal and professional lives. Whether it be to pediatricians, neighbors,

legislators, therapists, conference audiences, teachers, administrators, or peers, parents of children with disabilities are frequently asked to tell all or part of their family's life story. Parents reveal their stories as a way to understand the past in relation to an imagined future for themselves and their children. Stories help us connect. Stories also reveal the details, the impact of systems on the daily lives of families and children. They are a powerful way to develop relationships among parents and professionals.

Continued on page 3



### Inside....

New Epilepsy Support

JRA Scholarships

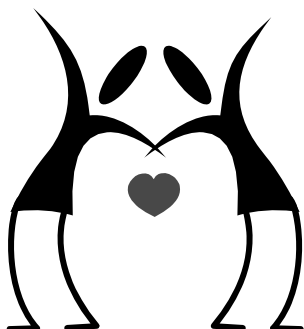
Camp CAYA

Service Dogs

Sensory Benefits of  
Snow

Upcoming Conferences

And Much More ....



## PIO Policy Updates

### Excerpts from the Governor's Executive Budget Summary

Budget for Fiscal Years—June 30, 2012 - 2013

#### Cutting, Consolidating Programs to Focus on Core Responsibilities

*This budget cuts programs across state government in order to meet the state's core responsibilities to ensure public safety and public health, and to educate our children.*

- ♦ Eliminates the catastrophic illness program. Savings: \$500,000
- ♦ Eliminates support to hospitals for medical education costs. Savings: \$5.9 million
- ♦ Eliminates funding for diversion incentive programs. Savings: \$3 million.
- ♦ Asks the Legislative Branch to follow the same rules as the rest of state government and return unused funds to the general fund at the end of each fiscal year. Will result in \$5 million being returned to the general fund at the end of fiscal year 2011.

#### Protecting Health Care, Services for Our Most Vulnerable Citizens

*This budget invests the highest-priority programs to serve New Hampshire's most vulnerable citizens.*

- ♦ Reducing Health and Human Services District Offices:  
The Department of Health and Human Services will build on a pilot project launched this year to use technology to reduce the need for physical offices. More department caseworkers now move around the district, going to where the people are, instead of making citizens come to state offices. As a result the department will eliminate an additional four district offices. Estimated savings: \$1.9 million.
- ♦ Reducing administrative costs to protect services: New Hampshire state government provides more than 90 percent of the funding for the Community Mental Health Centers and the Area Agencies for Developmental Disabilities. To protect the state's ability to provide services within communities, this budget reduces the number of administrative units for the Community Mental Health Centers and the Developmental Disabilities Centers by three each. Estimated savings: \$3.6 million in 2013.

♦ Protecting existing services to people with developmental disabilities and acquired brain disorders: In the past two years, New Hampshire has invested an incremental \$20 million in general funds to provide services to an additional 1,300 people with developmental disabilities and acquired brain disorders, moving them off waitlists. This budget provides \$250 million in general funds to assist people with developmental disabilities and acquired brain disorders, but does not provide separate funding for waitlists.

#### Protecting Health Care, Other Services, for NH's Most Vulnerable Citizens

*Re-directing funds to protect health care and other services for New Hampshire's children, seniors and people with disabilities.*

- ♦ Moving to Lower-Cost Providers: The Department of Health and Human Services will limit out-patient and in-patient access to Children's Hospital in Boston when comparable services are available at New Hampshire hospitals. It will also integrate community mental health treatment in Nashua under the Community Mental Health Center, eliminating a more costly provider. Estimated savings: \$13 million.

To download/read the Governor's Executive Budget Summary log onto:

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



## Telling Your Story..... Continued from page 1

These stories are what connect us to our work and to each other in meaningful ways. They deepen our understanding of individual and shared experiences. Stories often spur change in systems that seem impossible to understand. They can also help clarify disagreements. Storytelling can also be a huge risk. By sharing a story, you can easily make a point; however, you can also be vulnerable to criticism or misinterpretation. Often, the powerful lessons that these stories reveal are not fully appreciated; often parents grow fatigued with revealing private experiences that are frequently painful to recall.

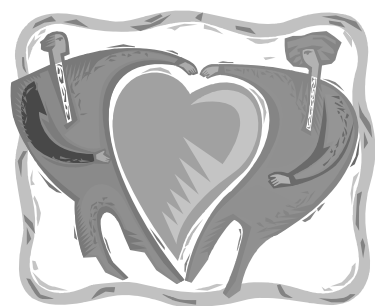
"Stories help us connect. Stories also reveal the details, the impact of systems on the daily lives of families and children." These are some of the key issues to consider in preparing and presenting a story and ways parents can shape their stories so that key themes are emphasized.

### PREPARING THE STORY

#### What's The Purpose?

Parents tell their stories in many situations, sometimes when they are invited, others when they discover the opportunity informally. Parents speak in formal settings, including parent training, professional development, keynote speeches or panels for conferences, legislative hearings, school presentations to teachers and students. A group of parents gathered at a recent conference discussed some of the key purposes for speaking out. They mentioned the importance of using one's own experience to bring change and broaden their experience to apply to others.

Continued on page 12



## 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. In this issue there are articles written by NH parents. They have expressed the hope that their personal stories will help, encourage, or support someone else.



## 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.

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Concord, NH 03301

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

## The Concord Area Regional Expert ASD Consultation Hub

The Concord Area Regional Expert ASD Consultation Hub (REACH) is happy to share with everyone the launch of their new Greater Merrimack County ASD website. The Concord Area ASD Team is comprised of individuals/parents and professionals that come together monthly to increase support for individuals and family members throughout the Greater Merrimack County in regards to autism.

This regional team is initiated from House Bill 1634. This House Bill establishes the NH Council on Autism Spectrum Disorders to coordinate supports and services for individuals and their families. This bill resulted from the commission to study autism spectrum disorders in New Hampshire.



The Concord Area REACH team works on three primary goals and objectives:

- To development of a primary resource bank for individuals, families, and providers who are seeking diagnosticians, behavioral specialists, speech pathologists, occupational therapists, psychologists, and others who have expertise in working with individuals with ASD.
- To promote access to families and individuals with ASD to have information about evidenced-based and promising practices for community-based education, support and treatment.
- To promote training opportunities, policy analysis, and research initiatives.

The above goals and objectives will assist a regional capability by which access to efficient and timely coordination of supports and services for individuals and their families can be achieved.

This website is intended to be interactive, so if you have suggestions or things that you would like to add feel free to contact them. They are always looking for new family members to participate in meetings. See website for the schedule.

<http://concordreach.homestead.com/Home.html>



SAVE THE DATE  
The 5th Annual Statewide  
Caregiver Conference  
Hosted by the Coalition  
of Caring

The conference is for parents, spouses, relatives, adult children and friends in the community who provide the day to day care for another individual.

Wednesday, November 2, 2011  
8:00 am - 4:00 pm  
Castleton Banquet and  
Conference Center  
Windham, New Hampshire

For more information or to  
request a registration brochure  
contact: Ellen Ederly,  
Coalition of Caring  
Phone: 603-332-9891 or email:  
[ellenedge@metrocast.net](mailto:ellenedge@metrocast.net)

Or visit the Coalition of Caring's  
website:  
[www.coalitionofcaring.org](http://www.coalitionofcaring.org)

\*Check out the new Caregiver's  
Blog on the website\*



## A.B.C.'s of Special Education

The A.B.C.'s of Special Education: Sounds like a great title for a book right? A book that would be a primer for teachers and parents alike...

What if A stands for Advocate?

B stands for that five letter word that mom's get called every once and a while... and C stands for Cheerleader? For every parent is the lifelong cheerleader for their kids~ especially our kids who experience disability or special health care needs.

The A.B.C.'s of Special Education, the book that I see in my dreams, will be a collection of your stories. A collection of anecdotes that illuminate what the special education process is like from the other side of the table through stories that touch our hearts, make us burst with pride and make us laugh. The good, the bad and some of the ugly that will show parents that they are not alone fighting the good fight and shares those lessons with the teachers, therapists, doctors, social workers and all the people who make up the teams that help our kids reach their full potential!

My daughter turned 21 last year and our journey through the education system was filled with both joy and trauma. She has just about every possible label in her file and there were days I thought only one of us would survive when she went through adolescence. She had truly awesome teachers and medical professionals in her life and she endured many who couldn't wait for her to go home at the end of the day. As fascinating as our story is (JK) I want this book to be about your stories. For through our collective experience, we will find that no matter what diagnosis our kids have... no matter what the educational setting...no matter where we live... what faith we turn to when we need support... we are all A.dvocates and C.heerleaders for our kids and we all must sometimes become the

B-word to accomplish our goals to help our kids reach for the stars.

So... I need your stories. Not your life history but those anecdotal stories that share your experience: Experiences about diagnosis, testing, friends, recreation, recess, inclusion, segregation, IEP meetings, health management, riding the bus, medical appointments, emotional health, personal care, transition, behavior plans, writing goals, early intervention, bullying, therapy, etc. You get the idea. You could share you stories anonymously if the issues are sensitive.

♥ Author, Laura Miller lives in Concord, NH. When she's not busy selling educational toys and teaching supplies at Imagination Village~ she hangs out with her daughter Jenn, the inspiration for this book!

Interested? Please send an Email to her at: [abcsofspecial@gmail.com](mailto:abcsofspecial@gmail.com)

A.dvocate

B. #\*@\$

C.heerleader!

Stories from MOMs about the  
Special Education Experience...

"It has been shown as proof positive that carefully prepared chocolate is as healthful a food as it is pleasant; that it is nourishing and easily digested... that it is above all helpful to people who must do a great deal of mental work."

Anthelme Brillat-Savarin





# NH Family Voices Lending Library

## Tools For Teaching

- Encourage friendships...
- Teach tolerance...
- Reduce fear...
- Provide correct information....
- Dispel myths and stereotypes....
- Promote understanding....



### Help! The Kids Are At It Again

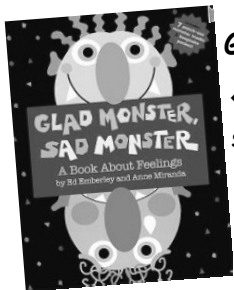
- ♦ Tips to help parents teach children how to get attention without whining. Deals with feelings, respecting boundaries and solving problems. Easy to understand with real life examples.

### Sometimes I Like to Fight, But I Don't Do It Much Anymore:

A Self-Esteem Book for Children with Difficulty in Controlling Their Anger



- ♦ Tells the story of Douglas, whose aggressive play and rough-housing turns into a more serious problem in controlling his anger. Designed to be read by children with similar problems, to help them see that there are ways that they can learn to understand their anger and redirect their need to fight.



### Glad Monster Sad Monster: A Book About Feelings

- ♦ This simple, colorful book helps children to understand and discuss feelings more openly. Feelings addressed are glad, sad, loving, worry, being silly and being angry.

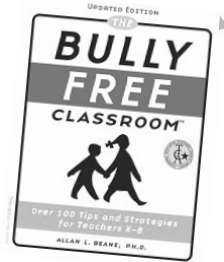
### Secret of the Peaceful Warrior

- ♦ An old man named Socrates shows Danny that the best way of dealing with a bully is the way of the peaceful warrior, through courage and love. An inspirational story that sheds new light on age-old issues faced by all children.



### The Bully Free Classroom:

Over 100 Tips and Strategies for Teachers K-8



- ♦ Offers tips to teachers on establishing a zero tolerance policy on bullying. Identifying and helping potential bullies and victims as well as communicating with parents. Students will learn to treat each other with respect.

♥ 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.



## Parent & Family Support

For Parent of Children, Teens and  
Adults with Epilepsy

The Parent and Family Support Group is the place to discuss and receive support for challenges associated with epilepsy. All individuals with epilepsy, family, and friends are welcome to attend. This is the chance to meet with others and discuss personal and social issues that doctors and family members may find hard to understand.

Meeting Place	Time	Date	Facilitator	Contact
Manchester Community College 1066 Front St Room 107 (in library) Manchester, NH	6:30 - 8:00 PM	3rd Monday March 21, April 18 May 16, June 20 July 18, August 15 Sept 19, Oct 17	Jessica Price	Susan Welby (617) 506-6041 X 19 <a href="mailto:support@efmarinhme.org">support@efmarinhme.org</a>
The Children's Place and Parent Education Center 27 Burns Avenue Concord, NH	9:00 - 11:00 AM	March 19, April 16 May 21, June 25 August 6, September 10, November 12	Jay and Allison Goodwin	<a href="mailto:jayandallison@comcast.net">jayandallison@comcast.net</a>

### 2011 JUVENILE ARTHRITIS COLLEGE SCHOLARSHIPS

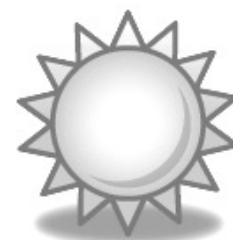
The Arthritis Foundation's scholarships for New England are available for the purpose of assisting deserving students with juvenile arthritis within the chapter service area to continue their education in a post-secondary accredited institution. Students must have juvenile arthritis or another rheumatic disease. Students must be a resident of CT, MA, ME, NH, RI, VT, Clinton, Essex or Franklin County NY.

Application Deadline: April 15, 2011

Applications are available by mail, email or fax from the Arthritis Foundation or available online by visiting [www.arthritis.org](http://www.arthritis.org) and entering your zip code to connect to the local webpage.

Arthritis Foundation  
6 Chenell Drive, Suite 260, Concord NH 03301  
603-224-9322 or 800-639-2113  
[Info.nne@arthritis.org](mailto:Info.nne@arthritis.org)

### DREAM DAY ON CAPE COD



Dream Day on Cape Cod is an organization dedicated to children with life threatening illnesses and their families. This FREE family camp is held at Camp Nan-Ke-Rafe in Brewster, MA. The facility include cabins, a centralized dining hall, and a centralized bathhouse, nature trailer, waterfront, playground, challenge course, and stage. Camp Nan-Ke-Rafe staff members organize and lead numerous family activities throughout the day at various recreational areas. Come and enjoy activities such as archery, hiking, swimming, fishing, and arts n crafts. This year camp will be during the week of July 18-22.

The 2011 application for family summer camp is now available online at:

<http://dreamdayoncapecod.wordpress.com/about/families>

## Help in the Care of Infants with Acid Reflux

In 2004, my son Luke was born and at 6 weeks was diagnosed with Gastro-Esophageal Reflux Disease (GERD). During the first few months of his life, he cried often, especially after eating. Sleeping was particularly difficult for him. Needless to say, his distress was our distress too!

More than half of all newborns suffer from infant acid reflux. Some suffer to the point it interferes with activities of daily living such as feeding and sleeping. It's important for parents to observe closely to determine whether their child may be affected. If new parents suspect their baby suffers from acid reflux, they should monitor the child's spit up behavior, especially after feeding, during bedtime hours and when lying flat. If a parent has a concern they should talk to their pediatrician.

Some of the symptoms may surprise you. Symptoms for infant acid reflux include irritable behavior, crying all hours of the day and night, difficulty falling or staying asleep, bad breath, blood in their stool, wet burp sounds, arching after feedings, frequent feedings and refusing feedings. And while only a trained professional can make a diagnosis, if reflux is confirmed, there are numerous ways to treat the symptoms.

Positioning is key. During and after feeding, keep babies as upright as possible in order to keep food from coming back up. During sleep, raise the head of the crib to let gravity help keep the infant's food down. Wearing your baby in a baby carrier and offering smaller, frequent feedings can help too. As long as they are doctor-recommended, some infants may find relief with medications such as antacids or proton pump inhibitors, which reduce stomach acid.



Once a child is diagnosed, parents must act quickly in order to avoid potential complications such as failure to thrive and long-term food aversions that may lead to refusal to eat. Most of all, take deep breathes, be patient and seek support. Most babies will outgrow this in a year or less.

♥ Beth Jackson-Gagne, MS, OTR/L is a licensed Occupational Therapist and founder of Baby Stay Asleep, an infant reflux sleep system for the crib.

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



**BRIANNA ROSE  
DILLON**

## NH FAMILY COMMUNITY INCLUSION AWARD 2011

Brianna Rose Dillon lived a life that wasn't supposed to be! She was woven into the community for 25 years, wrapped in care and support, challenged to grow and serve in her community. She received so much from people who helped develop and improve systems of care, education, and support in NH. Brie passed away on May 1, 2010, a day she was supposed to be at the 2010 Family Support Conference, a conference she enjoyed for so many years with her family.

In honor of beloved Brie's life and the amazing families of NH, a Leadership award is being established in her name. This award will be given each year to a NH Family who has contributed to their community to help other families facing challenges due to disabilities to become more inspired, stronger advocates, and work to help others have full and meaningful lives in their communities. This family could be viewed as catalysts for change, "nudgers", nurturers, and leaders who have a strong vision.

Continued on page 10



### Free Eye Exam for Baby During the First Year of Life

Cooing, sitting up, and crawling are signs that your baby is growing. Your baby's vision has stages of development too, but the signs marking progress are not so obvious.

For many months to come, those little eyes will be the windows she uses to learn almost everything about her new world.

Many eye conditions have no symptoms that can be identified by a parent or in a well baby check-up. Early detection is the best way to ensure your child has healthy eyes and appropriate development of vision, now and in the future.

**InfantSEE®**, developed by the American Optometric Association and The Vision Care Institute of Johnson & Johnson Vision Care Inc., is a public health program designed to ensure that eye and vision care becomes an integral part of infant wellness care to improve a child's quality of life. Through InfantSEE participating optometrists provide a no-cost comprehensive infant eye and vision assessment within the first year of life.

To find a participating optometrist near you go to:  
[www.infantsee.org](http://www.infantsee.org)



### Recipient of the 2010 Doris Barnes Retired Educator Lifetime Achievement Award

Mary Morse, Ph.D. has more than 40 years of experience in the field of special education, primarily on behalf of students who have multiple disabilities including those who are blind, visually impaired or deaf-blind. She has worked in public and private schools, universities, and medical settings. She developed and, for 12 years, directed New Hampshire's statewide services for infants and young children diagnosed with multi-sensory disabilities. This was one of the first early intervention programs in the United States. Dr. Morse is engaged in a variety of research projects including a longitudinal study of students with cerebral/cortical visual impairment and students with facial recognition problems. Dr. Morse has published numerous articles, and has received many regional and national awards for her work.

### THE GOVERNOR'S COMMISSION ON DISABILITY HAS GONE TO THE DOGS ...

Service dogs, that is. With three members who use either service or guide dogs, the GCD is sensitive to service dog concerns. The GCD even took part in drafting service dog legislation which came before the 2010 legislative session.



The GCD is able to help answer your questions regarding the rights, guaranteed under the Americans with Disabilities Act (ADA), of service dog users and issues concerning ADA non-compliance in regard to these service dog rights. The GCD is also able to help answer questions from the business community concerning the rights they must afford service dogs and their owners.

Governor's Commission on Disability  
Toll-Free NH: 800-852-3405 or (603) 271-2773

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

Click on service animals - lower right

## CAMP CAYA COME AS YOU ARE



Camp Come as You Are is a weekend camp experience for New England families with Dwarfism, children, teens, siblings and parents of all sizes. Held at Camp Allen in Bedford, NH, it is fully accessible with paved pathways, ramped buildings and an accessible swimming pool.

The camp provides a great atmosphere to get to know other families while sharing cabins and s'mores, swimming in the pool, canoeing and doing crafts. The ideal ages are school-aged children, teens and their families, but younger ones are welcome too! The camp offers a nightly campfire, swings, indoor games, puzzle and craft areas, water balloons, whiffle ball, basketball, hiking, boating, swimming, karaoke, and a camp store full of fun stuff. Bring bikes! Camp is a great place for pedaling due to its many paved pathways.

This years camp dates are July 29-31, 2011.

For more information go the LPA Camp CAYA web site at:

[www.lpadistrictone.org/camp-caya.html](http://www.lpadistrictone.org/camp-caya.html) or

e-mail Ruth Ricker at: [rickerruth@aol.com](mailto:rickerruth@aol.com)

## NH FAMILY COMMUNITY INCLUSION AWARD 2011 ... continued from page 8

Do you know of such a family? Please consider them for this award. Think of a NH FAMILY who has worked toward the values of inclusion and full community participation, and who has contributed to other families in the state (and perhaps beyond) so that lives can be richer and woven into the fabric of their communities.



At least two members of a family need to be involved as described above to be considered for the award. Nominations will be reviewed by committee and the award will be presented at the 2011 NH Family Support Conference (April 29 - May 1).

Nominations are due by April 1, 2011. To nominate this family you may contact Ann Dillion at to [dill5@comcast.net](mailto:dill5@comcast.net) for a nomination form or download it from NH Family voices website at [www.nhfv.org](http://www.nhfv.org)

NH Family Support Conference  
Celebrating 25 Years...



SAVE THE DATE

April 29, 30 & May 1, 2011

The Mount Washington Resort  
Bretton Woods, New Hampshire

The 25th Annual New Hampshire

Family Support Conference offers families & caregivers the opportunity to learn about possibilities and choices for their family member with a disability, to meet others, and share experiences.

For updated information visit the

NH Family Support Conference

webpage: <http://nhfsc.com>



## Tax Assistance

Contact the Community Action Program (CAP) in your region of the state.

For a list and link go to:

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

*On tour in New England*

## A Friendship Adventure with Ronald McDonald

More than 160,000 students skip school every day due to bullying or peer pressure. It's time to prevent bullying and teach positive actions to stand up to bullying behaviors. McDonald's® is pleased to announce the arrival of a new elementary school show; "A Friendship Adventure with Ronald McDonald."



This show has been endorsed by noted author and Kids/Parenting expert, Dr. Michele Borba and through audience participation, magic, music and drama "A Friendship Adventure with Ronald McDonald" challenges students to be heroes to each other and experience the positive effects of standing together. The key elements of the show are:

- ♥ Friendship
- ♥ Cooperation/Teamwork/ Mobilizing peer compassion
- ♥ Anti-bullying/Don't let bullies stand in your way.
- ♥ Active Play

In addition, Ronald also uses geography, culture, language, values, and healthy habits to communicate and demonstrate the key elements. The show is a powerful, fun, educational, interactive adventure leading to the discovery that; "We're all good individually but together we're excellent!"

This free performance is written for elementary schools; grades Pre-K through Fourth and is sponsored by your local McDonald's. If you have any questions or would like to schedule the performance for your school, please call:

Laurie Webster,  
Ronald McDonald Show Coordinator  
N.E. Region at Bump-A-Nose Productions  
Telephone: (508) 477-2554  
Email: [bumpnose@comcast.net](mailto:bumpnose@comcast.net)

## Adult Siblings

### Save the Date !!!

Saturday March 19th from 9:30 to 3:30 there will be a one day workshop for adult siblings at Dartmouth Hitchcock Manchester (100 Hitchcock Way).

Come listen to a fantastic keynote John Kramer, Co-Founder and Vice Chair of the Sibling Leadership Network, a growing movement of brothers and sisters of people with disabilities and siblings with disabilities interested in policy, services, and research. He was a speaker at last Summer's International Siblings Conference.

There are also fantastic breakout sessions - a chance to meet with peers of the same age range - lunch and networking!

For more information contact:

Karin Harvey-Olson

Tel: 459-2774

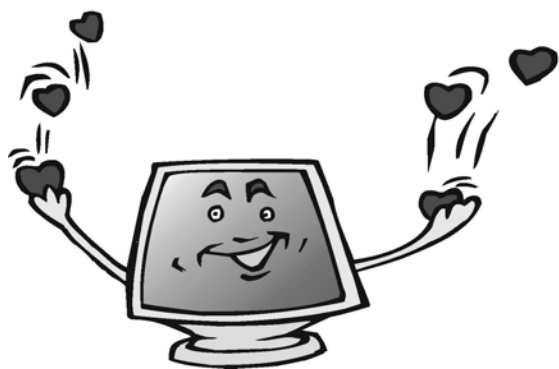
or e-mail:

[kharvey-olson@gatewayscs.org](mailto:kharvey-olson@gatewayscs.org)

Or download the brochure at:

[www.box.net/shared/zc8m4ca9l2](http://www.box.net/shared/zc8m4ca9l2)





## 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>

## Telling Your Story..... Continued from page 3

### *Who's the Audience?*

It is important to think a bit in advance about who will hear your story. A little ground work can help to make the story effective and help you be comfortable in telling it. Who is in the audience can help you to decide which parts to emphasize and, more importantly, why you are telling it. Aspects can change depending on the audience: a story about a wonderful preschool program can emphasize the need for funding with a group of legislators considering the next year's budget; to a group of pre-schoolteachers, it can emphasize the importance of parent/teacher communication and collaboration.

### *How to Organize a Story*

Although most stories have a beginning, middle and an end, they can also vary in length — some are 30 seconds long; others can last over an hour. Engaging stories rely on a beginning that "hooks" the listener who then listens for the details in the middle of the story, and awaits the punch line at the end. The beginning sets the stage, identifies the key characters and location, and gets the listener interested. The middle - where the plot thickens - adds details, examples, and interesting information to understand the key ideas and people. The end usually ties things together and often gives an idea of what can be learned from it - what was the theme or lesson? Sometimes this theme can be stated directly; at other times, it is best to let the listeners draw their own conclusions.

### PRESENTING THE STORY

#### *Finding and Using Your Voice*

The way a story is told is often as important as the story itself. To be an effective storyteller you must have something to tell, someone to tell it to and the ability to make yourself heard. Some suggestions on presenting:

**Relax** - Before you begin to speak, take a few deep breaths and slowly scan the audience for familiar faces.

**Project** - With large audiences, use a microphone. In smaller groups, project your voice with confidence.

Continued on page 15

## There's A Monkey In My Chair

By Amy Cook

As a mother of a child with a chronic health condition, I noticed over the past many months that often times the best advice or guidance came from others who have traveled the road before me. In the journey my family has taken since April 4, 2010 when my 7-year old son was diagnosed with Rhabdomyosarcoma cancer, we have been extremely fortunate to find various organizations, programs and scholarships that helped us in so many wonderful ways.

One of the most creative and heart-warming programs Caleb benefited from has been the 'There's A Monkey In My Chair' program by the Love, Chloe Foundation. Similar to my own son, Chloe was diagnosed with cancer when she was in the 1st grade so her chemotherapy schedule went into her 2nd grade year. She missed many days of school between the two years just as my son Caleb has so far. Chloe's hospital staff gave her a large, stuffed bear that was supposed to sit in her classroom chair while she was away for doctor visits, treatments or when she was too tired or sick to be in the classroom. Chloe's older brother brought the bear back and forth to school which gave him an important role. The bear came with a small backpack that transported notes and pictures from Chloe's classmates. When Chloe's mother started the Love, Chloe Foundation she wanted to help other kids with cancer have the same connection to their classmates and school communities when they could not physically be there. They replaced the bear with a monkey and created a kit which includes a large, stuffed monkey, a duffel bag, journal, photo album, disposable camera for classmates to take pictures, pens & pencils, a small monkey to stay with the ill child, a backpack, a button, a storybook and a teacher's companion. I wish I had known about this program at the outset of our journey!

Caleb received his Monkey Kit just in time for the monkey to go to school and sit in Caleb's seat on Monday, January 3rd when everyone except Caleb returned to school following the holiday vacation. Caleb named his monkey Smarty since he'll be going to school. I've been told by Caleb's 2nd grade teacher that his classmates love Smarty and

he has already helped them think about Caleb more often and look forward to his being there again. The teacher introduced Smarty by reading the accompanying storybook which was written by Chloe's mother and illustrated by Chloe's classmates. The book explains the purpose for the monkey and why Caleb cannot be there himself. The story book encourages classmates to bring the monkey along to various school activities and take pictures. And, that's exactly what Caleb's teacher and classmates have done! I've been told that Mrs. Dooley got many chuckles as she walked with Smarty to gym class! Smarty returned to Caleb at the end of the first week with his backpack filled with cards, pictures and notes from his friends letting him know how much they missed him and looked forward to him coming back to school again!

A great resource that came with the kit that I wish we had received in the beginning of Caleb's journey is the Teacher Companion. This book is filled from cover to cover with resources, ideas on how teachers can communicate about illnesses with children, ways classmates can keep in touch with their absent friend, activities for the classes to

do...and so much more! You can request a free Monkey Kit from the Love, Chloe Foundation or make a donation to sponsor a kit for another child by visiting their website at:

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

♥ Smarty accompanied Caleb to a chemotherapy treatment in Boston before he went to take Caleb's seat at school!



## Tax Benefits for Disabled Taxpayers and Parents of Children with Disabilities

Taxpayers with disabilities and parents of children with disabilities may qualify for a number of IRS tax credits and benefits. Learn about the seven tax credits and other benefits which are available if you or someone else listed on your federal tax return is disabled.

For more information on tax credits and benefits available to disabled taxpayers, see Publication 3966, *Living and Working with Disabilities* or Publication 907, *Tax Highlights for Persons with Disabilities*, available on the IRS website at [www.irs.gov](http://www.irs.gov) or by calling 800-TAX-FORM (800-829-3676).

### IRS Tax Tip 2011-24, February 03, 2011

Taxpayers with disabilities and parents of children with disabilities may qualify for a number of IRS tax credits and benefits. Listed below are five tax credits and other benefits which are available if you or someone else listed on your federal tax return is disabled. Standard Deduction Taxpayers who are legally blind may be entitled to a higher standard deduction on their tax return.

#### Gross Income Certain Disability-Related Payments,

Veterans Administration disability benefits, and Supplemental Security Income are excluded from gross income.

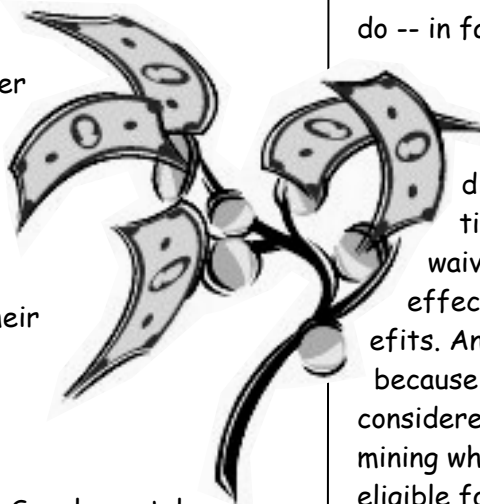
**Impairment-Related Work Expenses** Employees who have a physical or mental disability limiting their employment may be able to claim business expenses in connection with their workplace. The expenses must be necessary for the taxpayer to work.

**Credit for the Elderly or Disabled** This credit is generally available to certain taxpayers who are 65 and older as well as to certain disabled taxpayers who are younger than 65 and are retired on permanent and total disability.

**Medical Expenses** If you itemize your deductions using Form 1040, Schedule A, you may be able to deduct medical expenses. See IRS Publication 502, *Medical and Dental Expenses*.

#### Earned Income Tax Credit

EITC is available to disabled taxpayers as well as to the parents of a child with a disability. If you retired on disability, taxable benefits you receive under your employer's disability retirement plan are considered earned income until you reach minimum retirement age. The EITC is a tax credit that not only reduces a taxpayer's tax liability but may also result in a refund. Many working individuals with a disability who have no qualifying children, but are older than 25 and younger than 65 do -- in fact -- qualify for EITC.



Additionally, if the taxpayer's child is disabled, the age limitation for the EITC is waived. The EITC has no effect on certain public benefits. Any refund you receive because of the EITC will not be considered income when determining whether you are eligible for benefit programs such as Supplemental Security Income and Medicaid. Child or Dependent Care Credit Taxpayers who pay someone to care for their dependent or spouse so they can work or look for work may be entitled to claim this credit. There is no age limit if the taxpayer's spouse or dependent is unable to care for themselves.

[www.irs.gov](http://www.irs.gov)

# 1-800-829-3676

## Telling Your Story..... Continued from page 12

**Pace** - The most frequent problem with nerves is they make us speed up our presentations. Remember to speak calmly and slowly - just a bit slower than normal conversational style. Good listeners require some processing time.

**Eye Contact** - It's always helpful to establish clear and frequent eye contact with your audience. Even in small groups, you will find listeners who appear to be attentive; some folks may nod or smile. It's often useful to consistently look at familiar or sympathetic faces in different parts of the audience. Look around frequently at these groups so that all of the audience feels included.

**Humor** - If appropriate, it may be helpful to use a bit of humor. Test any humorous comments with friends or colleagues to see if it works for them. Avoid making any one group (professional or parent) the butt of humorous comments. Teasing and sarcasm are not a good idea - one person's idea of a sarcastic remark might be another's insult. Give the audience time to ask questions - Allow time at the end of your presentation for audience members to ask questions. If someone asks a personal question that hits a raw nerve simply say, "I find that question difficult for me and I would really rather not answer it." Be comfortable saying, "I don't know, but I can find out for you" if you can't answer a question immediately.

**Working with Props, or Visuals** - Using videotape selections, photographs, and computer-enhanced presentations can be helpful tools. Be sure that your aids are an enhancement of what you are saying and not a distraction.

**What if I Cry?** - For even the most experienced speakers, telling a story that reveals a personal or emotional time can be difficult. Crying is, of course, perfectly acceptable; however, you need to be aware of the audience and their need to understand your emotions and your message. Also, the last audience response you want from telling your story is pity or confusion.

Some tips from parent storytellers:

- ♦ If you start to cry, pause long enough to take three or four deep breaths, and then go on. The audience will appreciate your taking the time and being able to hear the rest of your presentation.
- ♦ Sometimes it is useful to explain to the audience that you need to collect yourself and that you really want



them to understand what you have to tell them, as well as how emotionally difficult it is for you.

- ♦ Mentally focus on something that makes you laugh inside; this sometimes evens out the fear and sadness enough to let you go on.
- ♦ Take a small squeezable rubber toy or some other object that will fit in the palm of your hand. If you start to cry, squeeze the toy to relieve some of the tension.
- ♦ Avoid someone "rescuing" you by interrupting and interpreting what you mean. If you still have a message to convey, take the time to collect yourself and then go on.

### FOLLOW UP

#### How Can I Get Feedback?

Understanding how listeners heard your story is as important as preparing and telling it. If possible, ask trusted colleagues or friends to listen to your presentation and to let you know what they thought of it. Prepare focused questions and listen carefully to their responses. This will help you develop the story and emphasize effective features.

Continued on page 17

## Remember the Mayonnaise Jar

When things in your life seem almost too much to handle, when 24 hours in a day is not enough; remember the mayonnaise jar and 2 cups of coffee.

A professor stood before his philosophy class and had some items in front of him.

When the class began, wordlessly, he picked up a very large and empty mayonnaise jar and start to fill it with golf balls.

He then asked the students if the jar was full. They agreed that it was.

The professor then picked up a box of pebbles and poured it into the jar. He shook the jar lightly. The pebbles rolled into the open areas between the golf balls. He then asked the students again if the jar was full. They agreed it was.

The professor next picked up a box of sand and poured it into the jar. Of course, the sand filled up everything else. He asked once more if the jar was full. The students responded with an unanimous 'yes.'

The professor then produced two cups of coffee from under the table and poured the entire contents into the jar, effectively filling the empty space between the sand. The students laughed.

'Now,' said the professor, as the laughter subsided, 'I want you to recognize that this jar represents your life.

The golf balls are the important things - God, family, children, health, friends, and favorite passions, things that if everything else was lost and only they remained, your life would still be full.

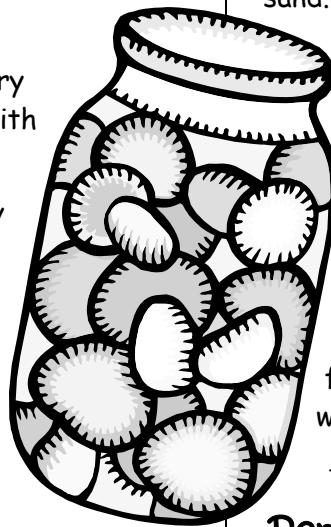
The pebbles are the things that matter like your job, house, and car.

The sand is everything else -- The small stuff. 'If you put the sand into the jar first,' he continued, 'there is no room for the pebbles or the golf balls. The same goes for life.

If you spend all your time and energy on the small stuff, You will never have room for the things that are important to you.

So...

Pay attention to the things that are critical to your happiness.



Play with your children. Take time to get medical checkups. Take your partner out to dinner. There will always be time to clean the house and fix the dripping tap.

'Take care of the golf balls first -- The things that really matter. Set your priorities. The rest is just sand.'

One of the students raised her hand and inquired what the coffee represented.

The professor smiled. 'I'm glad you asked'.

It just goes to show you that no matter how full your life may seem, there's always room for a couple of cups of coffee with a friend.' ♥

## Personal Care Attendant Certificate Course

The new Personal Care Attendant Certificate Course at Great Bay Community College has been deemed eligible by NSCITE (NH Works Source for Consumer Information on Training and Education). This means individuals who are unemployed or under-employed may be able to access Workforce Investment Act funds to pay for the course. Individuals should contact a counselors at their area NH Works office or for more information contact Mickey Pike at 427-7654 or [mpike@ccsnh.edu](mailto:mpike@ccsnh.edu)



Great Bay  
Community College

## Telling Your Story.....

Continued from page 15

Some questions to get feedback:

- ♦ What were the major themes?
- ♦ How did the audience respond?
- ♦ What about volume? Pace?
- ♦ Did I use humor effectively?
- ♦ Did the story make logical sense?

If there is an evaluation form for the activity in which you were speaking, ask to review it.

If you are speaking in an informal setting, ask someone to observe how the audience responds. This can be useful in meetings, training sessions, or even small groups in which stories are told. In some school or hospital settings, families ask a friend to act as an informal advocate; this individual can give you feedback about the interaction if it seems appropriate.

Author: Glenn Gabbard. Reprinted in part with permission. Early Childhood Bulletin, Federation for Children with Special Needs, Boston, MA. Spring 1998.

### **An Important Reminder**

As children grow older and more independent, it is important to consult them about the story details and, sometimes, whether or not the story should be told at all. It's important to remember that as children mature, some will be asked to tell their stories and should understand the importance as well as their right to keep details that they deem private to themselves.

## Keeping It All Together: Balancing Family, Systems and Life

### *Or How to Do It All Without Losing It!*

*NH Family Voices* and *NH Partners In Health* are co-sponsoring a conference for parents of children with special healthcare needs and disabilities.

April 15th & 16th

Waterville Valley Conference & Events Center

Please join us Friday for a special evening of friendship and relaxation. Special guests will be *Ryen Blackey* who will share with us his experiences of being his own advocate, even as a young child, and his mother *Tammy Shaw* and how she supports him.

Saturday's program includes breakouts on "Working with Health Care Providers"; Systems of Care: Who Pays for What, When and Why?"; "Section 504 & IDEA" and "Finding YOUR Voice".

Keynote Presentation

***"There's No Such Thing as Running on Empty:  
Caring for Children While Caring for Yourself"***

Lynn Lyons, LICSW

For more information about registering for this opportunity contact:

Erika at NH Family Voices

Tel: (800) 852-3345 X 8179 or (603) 271-8179

E-mail: [ebd@nhfv.org](mailto:ebd@nhfv.org)



## Unlocking Independence Here are the Keys

Saturday April 9th - 9:30 to 4:00  
Red Blazer, Concord, NH

Come join other youth with special health care needs for a day exploring independence!! Hear from Mallory Cyr - an adult with special health care needs who works on issues at the National level - learn about benefits and working - how to work WITH the system - learn all about Personal Care Assistants and spend lunchtime learning about nutrition while eating delicious food and maybe even learning a recipe or two!

For more information contact Karin at [yeahcouncil@yahoo.com](mailto:yeahcouncil@yahoo.com)  
Registration available on website [www.yeah-councilnh.com](http://www.yeah-councilnh.com)

## Sensory Benefits of Playing in the Snow



Playing in the snow is a great way to build sensory and motor skills

**Heavy work** - Trudging through the deep snow, shoveling, scooping snow with a ladle or garden scoop, loading a sled with snow or pulling it up a hill, rolling snowballs or making an igloo are all examples of activities that provide "heavy work" or resistance to our children's muscles and joints. This provides their nervous system with more information about where their bodies are in space.

**Tactile Input** - The temperature outside, the temperature of the snow and the smoothness of ice all provide tactile input. Making snow angels provides full body input helping to develop body awareness.

**Vestibular Input** - Sledding!! Swishing down those hills provides our children's bodies with information about movement. This is important for the development of eye muscles, body awareness and for regulation. Log rolling down a hill will provide a less intense experience.

**Use of both arms (Bilateral Integration) and strengthening** - Rolling snow balls, making snow angels, fill a small squirt bottle with colored water and 'paint' the snow. This will work on hand and strength. Grab a small stick and write letters in the snow. Make it a full body experience and drag your feet to make letters and shapes. Bulls-eye snowballs - throwing snowballs at a target fosters eye-hand coordination as well as upper body strengthening.

Snow play provides a sensory rich experience for your child.  
Get out and play!

♦ Article written by: Lynne Fleming OTR/L, Capital Kids Occupational Therapy at It's Ability Pediatric Therapy Services, Concord, NH



SAVE THE DATE!

### Early Connections: Taking Care of Our Children... Taking Care of Ourselves

Saturday, April 30, 2011  
8:30-3:30 p.m.

Perkins School for the Blind  
Watertown, MA

A conference for parents of children with visual impairments from birth to 7

Workshops on communication, CVI, literacy, independent living skills, sleep, the brain, play, internet resources, technology, and more!

Child care available. Lunch provided. For more information, call Beverly Temple TVI at (603) 228-1028 or email

[bevtemple@myfairpoint.net](mailto:bevtemple@myfairpoint.net)

### Governor's Commission on Disability

#### Volunteers Wanted!

A host of opportunities for people who are interested in, and supportive of, making NH a better place for people with disabilities. What are your interests, what would you like to do?

Please call and - let's figure something out!

John Richards  
(603) 271-6895

## Wanted..... Family Stories

NH Family Voices would like to put together a collection of family stories about how NH's healthcare systems (Healthy Kids Gold, Healthy Kids Silver, Home Care for Children with Severe Disabilities, i.e. Katie Beckett, Partners in Health, Early Intervention, Family Voices, etc. ) have made a positive impact on the health and well being of children with special healthcare needs.

While policy makers on the national and state level look at programs and funding we think it is very important for them to hear how these programs have enhanced children's access, quality and sustainability to care.

If you are interested in sharing your experiences we are looking for one page stories, and if possible a photo of the family or child.

For more information or to send contact:  
NH Family Voices at 1-800- 852-3345 X 4525 or  
e-mail at [nhfv@yahoo.com](mailto:nhfv@yahoo.com)

### *NHFV Thanks You for the Library Donations*

- ♥ The Family Support Council at Community Bridges, Concord
- ♥ Mary Beth Theisen, Jaffrey, NH

## 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**

## Notice A Change to Pass It On?

If you are receiving this in hard copy, you will not see any changes. If you are receiving the newsletter via webpage (pdf) then you will notice that all references to websites/e-mails are hyper linked.

NH Family Voices is striving to reach families and the professionals that work with them through as many convenient forms as possible. The paper copy serves many purposes and is one of our valued outreach tools. But reality is... many do their reading and sharing online. We hope by hyper linking resources the newsletter will become both an enjoyment to read and a way to explore more easily. 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 webpage e-mail newsletter.

♥ To do this, go to the New Hampshire Family Voices website [www.nhfv.org](http://www.nhfv.org) and click on Membership. Make out the form as if you were a new member (please include address information). We will cross reference with the hard copy list and remove you while adding you to the e-mail list.

♥ This change makes it even easier to share, so please continue to "Pass It On"!

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