



The Beacon



**The NC Family to Family Health Information Center
A project of The Exceptional Children's Assistance Center
Home to Family Voices of NC**

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Welcome from the NC Family to Family Health Information Center (HIC)!

This monthly electronic newsletter is designed to provide parents with links, resources, information and activities of particular interest to the issues of children with special health care needs.

To be added or removed from "The Beacon" mailing list <mailto:hic@ecacmail.org>

Are you ready to "CHAT" about health care transition?

CHAT = Carolina Health and Transition

The CHAT project is up and running and we are scheduling workshops across the state for parents of children and youth with special health care needs. To schedule a workshop in your area please call (800) 962-6817 ext. 35.

We have produced a DVD on health care transition and are working on duplication efforts. To pre-order your copy please call us (above) or write to hic@ecacmail.org. These DVDs will be available at no charge to families in NC.



Previous Editions

Click on the month:

July 2009
June 2009
May 2009
April 2009
March 2009

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Lifeline for Parents: paws4people



How can a dog change the life of a child with disabilities? With the help of **paws4people™** nonprofit organization the possibilities are truly endless. The mission of **paws4people™ foundation** is to enhance the lives of special and regular education students, seniors, and the seriously ill or disabled, by utilizing the "Special Powers" of canine companionship displayed by highly trained Assistance Dogs; including Service, Educational Assistance K-9s, Rehabilitative Assistance Dogs and Social Therapy dogs in specialized educational, private placements and therapeutic visitation programs. In North Carolina **paws4people™** has various ways to help if you have a child with special needs. From an Educational Assistance dog to a Service Dog your child's life can be changed.

NIKKI is a Rehabilitative Assistance dog that works each day with students who receive physical therapy services. Her handler is Sharon Antoszyk, Physical Therapist with Cabarrus County Schools. Sharon takes NIKKI with her daily to visit her students. It is amazing how hard the students will work when NIKKI is involved. She is able to motivate students to do things such as walking, kneeling, or simple head control. Many times teachers will build their lessons around NIKKI coming. Students enjoy making dog biscuits, reading stories to NIKKI, or just brushing her as part of their reward for working hard. Rehabilitative and Educational Assistance Dogs within the school is the key to bridge the gap between students with special needs and their typical developing peers.

CAMDEN is a Service Dog being trained for Alex. Alex was diagnosed with Mitochondria Encephalomyopathy. He has no head control and cannot sit or stand unsupported. Speaking and eating are very difficult for him due to his movement disorder. There are many benefits we see to having a Service Dog for Alex. The main benefit for Alex is the companionship and social improvements, especially on walks around our neighborhood. Alex's dog will also help him cope with hospital visits and different doctor's appointments. We know that CAMDEN will enable Alex to be more independent. The dog could pick things up that Alex drops, intentionally and unintentionally. There are so many possibilities with a **paws4people™** dog for Alex.



CAYLIE is working hard to finish up her training to be ready for Jack. Jack is an intelligent and vibrant six year old who was a victim of Shaken Baby Syndrome. He was shaken when he was nineteen months, had brain surgery to relieve the swelling and suffered several strokes as a result. His prognosis was very poor, but he survived and has improved. Jack needs a Service Dog to help him walk with a special harness that has a handle. His mobility is limited, so he needs a dog to help stabilize him as he goes up and down stairs, help him walk safely in public and most importantly, to assist with seizures. Jack has violent seizures and the dog that has chosen him is sensitive to the sudden change that occurs. Over time we hope to teach Jack's dog to support him and ease him to the ground during a seizure and also to alert his parents of seizure activity.

For more information on **paws4people™** and the services it provides please go to www.paws4people.org.

Internet Links:



Health Reform - Get The President's Message on Health Reform:
www.healthreform.gov

Scholarship Opportunity - American Association on Health and Disability (AAHD) Scholarship Program 2009-2010. For details please visit: www.aahd.us

DisabilityInfo.gov was re-launched as www.disability.gov. In conjunction with the 19th anniversary of the Americans with Disabilities Act, the US Department of Labor has renamed and re-launched the website which provides easy access to comprehensive disability related information and resources.

2009 State Medicaid Rankings - Vermont provides the highest quality Medicaid services to individuals with intellectual and developmental disabilities, while Mississippi provides the worst, according to United Cerebral Palsy's report "[The Case for Inclusion 2009.](#)" Find out where your state stands in the ranking of the 50 states and the District of Columbia (see page 8).

Choosing a Mental Health Professional - article available in English or Spanish
http://www.aboutourkids.org/families/seeking_professional_help/choosing_mental_health_professional

Starbright World - an online social network for teens with chronic and life threatening medical conditions, and their siblings. <http://www.starbrightworld.org/>

Does it run in the family? A family health history tool from Genetic Alliance:
<http://www.familyhealthhistory.org>

Kidde Smoke Alarm Recall - Can fail to warn of a fire:
<http://www.cpsc.gov/cpsc/pub/prere/phtml09/09266.html>

Federally Funded Health Centers- The US Department of Health and Human Services, Health Resources and Services Administration has an online tool to help you find a federally-funded health center. Federally-funded health centers care for you, even if you have no health insurance. You pay what you can afford, based on your income. Health centers provide:

- checkups when you're well
- treatment when you're sick
- complete care when you're pregnant
- immunizations and checkups for your children
- dental care and prescription drugs for your family
- mental health and substance abuse care if you need it

Health centers are in most cities and many rural areas. For more information go to
<http://findahealthcenter.hrsa.gov/>

Upcoming Events:



NC Family to Family Health Information Center Workshops:

- September 8, 2009, Public Health Programs 1
12:00-1:00 Hendersonville, NC
- September 22, 2009, Health Care Transition: From Pediatric to Adult
Health Care 6:30-8:00 New Bern, NC



- October 13, 2009, Public Health Programs 2
12:00-1:00 Hendersonville, NC
- October 22, 2009, Public Health Programs 1
6:30-8:00pm Location: to be determined (Orange County)

**Call us to schedule a workshop in your area!
(800) 962-6817 ext. 35**

Visit our website for a complete list of training and events in your area:

<http://www.ecac-parentcenter.org/training/training.htm>





Announcements

Victory Junction Gang Camp

Victory Junction is still looking for a few great families for their Fall Family Weekends.

Sept 25-27 Crohn's and Colitis
Camper Recruiter-Chris at 336.495.2019

Oct 9-12 Young Adult Camper Weekend (ages 16-21)
Camper Recruiter-Kristin at 336.495.2002

Oct 30-Nov 1 Ventilator/Physical Disabilities (ventilator families get priority)
Camper Recruiter-Kim at 336.495.2017

Please visit their website at www.victoryjunction.org.

If you haven't been to Victory Junction before please know that it is an experience that you and your family will enjoy. The mission of Victory Junction is to enrich the lives of children with chronic medical conditions or serious illnesses by providing life-changing camping experiences that are exciting, fun and empowering, in a safe and medically sound environment.

How to be an Effective Health Care Advocate

During these difficult economic times we are expanding our workshop on Health Care Advocacy to include a section on **“What to do When Services End: Options and Ideas for Families of Children with Special Needs”**. Learn how to advocate for your child and find alternate strategies for covering costs as programs and supports are ending due to budget cuts. If you would like to schedule a workshop in your area please call (800) 962-6817 ext. 35.



Visit our website at:

www.ecac-parentcenter.org



Lending Library

The NC Family to Family Health Information Center is adding health and disability specific books to the lending library at The Exceptional Children's Assistance Center. Our library has over 2,000 books which are available to NC parents at no charge. To borrow a book or other library item, please call Shandra Umazar, ECAC's librarian at **(800) 962-6817 ext. 13**.

Health Related Books Added This Month:

- *Living a Health Life with Chronic Conditions* by Kate Lorig, RN, DrPH, Halsted Holman, MD, David Sobel, MD, Diana Laurent, MPH, Virginia Gonzalez, MPH, & Marian Minor, RPT, PhD
- *Sotos Syndrome A Handbook for Families* by Rebecca Rae Anderson, J.D., M.S., Bruce A. Buehler, M.D., G. Bradley Schaefer, M.D.

The purpose of the e-letter is to assist families and the professionals working with them to better understand issues and resources related to health care for children and youth with special needs so that they may make informed choices. Funding comes in part from grants from CMS and HRSA. The views and opinions herein do not necessarily reflect views or policies of CMS, HRSA, The NC Family to Family Health Information Center, or The Exceptional Children's Assistance Center.
