



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**

August, 2010

FAMILY VOICES[®]

Volume 4, Issue 7

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 please email hic@ecacmail.org

2010 Advisory Committee on Immunization Practices Influenza Recommendations

The Advisory Committee on Immunization Practices (ACIP) of the Centers for Disease Control and Prevention (CDC) released updated recommendations for the 2010-11 influenza season. The American Academy of Pediatrics is developing its influenza policy statement which will be available shortly. Highlights of the ACIP recommendations include:

1. Routine influenza vaccination is recommended for all persons 6 months of age and older.
2. Children 6 months to 8 years of age should receive 2 doses of a 2010-11 seasonal influenza vaccine (minimum interval: 4 weeks) during the 2010-11 influenza season if they meet the following criteria:
 - vaccination status is unknown
 - never received seasonal influenza vaccine before
 - received seasonal vaccine for the first time in 2009-10 but received only 1 dose in their first year of vaccination
 - did not receive at least 1 dose of an influenza A (H1N1) 2009 monovalent vaccine regardless of previous influenza vaccine history

For the entire report, please visit the [CDC Web site](http://www.cdc.gov).

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Internet Resources



Click on the titles to view the links below:

[Your Health Care Explained](#)

The US government has launched a website to help people learn about health insurance, what they may qualify for and much more! Visit this site to learn about preventive care available after September 23, 2010, at no cost to you. Also learn about programs specific to NC including the pre-existing condition insurance plan, private insurance plans, public programs and community services available to you. Take your health care into your own hands and explore your coverage options are also available on this site.

[Housing](#)

A free housing service that helps people find a room, house or apartment that best suits their needs. Search by rent amount, accessibility features, housing vouchers and more. Also has information about moving costs, assisted living facilities, help for people who are homeless and financial assistance to help pay rent.

[Oral Health](#)

The National Institute of Dental and Craniofacial Research has a section on Developmental Disabilities and Oral Health and includes a section for caregivers. Read their paper on Strategies for Providing Oral Care to People with Developmental Disabilities and review all their resources!

[Health Rights Hotline](#)

Review this four page document for strategies on “How to Appeal a Health Plan or Medical Group Decision”. Health Rights Hotline is for California residents but you may find the information useful.

[How to Start a Support Group or Discussion Group](#)

The National Spinal Cord Injury Association Resource Center offers a Fact Sheet on starting a support group or a discussion group.

[How do you partner with your child’s medical provider?](#)

“Partnering with your Doctor: The Medical Home Approach” was developed by the Region 4 Genetics Collaborative Medical Home Education Workgroup as a guide intended to help families connect with their child's doctor, other medical professionals and caregivers through a medical home. Although it was written for families whose children have genetic conditions, it is useful for all families who seek to achieve accessible, continuous, comprehensive, coordinated, compassionate, culturally effective, and family-centered care for their children.

[Youth Transition](#)

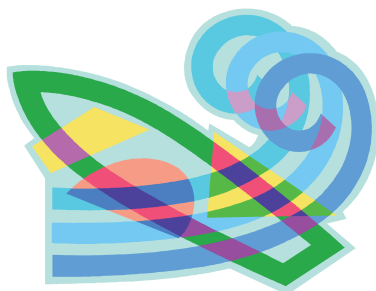
The National Collaborative on Workforce and Disability for Youth has developed a toolkit on “Making the Move to Managing Your Own Personal Assistance Services (PAS): A Toolkit for Youth with Disabilities Transitioning to Adulthood”. The entire toolkit can be downloaded from their site!

Announcements:

NC Assistive Technology Expo

- November 17-19th, 2010
- North Raleigh Hilton, Raleigh, NC
- Registration forms and hotel info available at www.pat.org
- The exhibit hall featuring over 60 vendors is **FREE** and open to the public on November 18th, 2010 only.
- 40 concurrent sessions.
- Keynote speaker: Brian Frasure, Prosthetics Developer and Athlete
- A limited number of scholarships are available for people with disabilities and family members.
- Tracks include communication, education, work, vision, staying independent at home, AT Expo Exhibitor, and a Computer Lab.

For more information please call **(919) 850-2787**.



Your Input is Needed!

The U.S. Department of Health & Human Services' Administration on Developmental Disabilities (ADD) would like input from the public on how they can best meet the needs of individuals with developmental disabilities and their families. ADD is planning future Projects of National Significance (PNS). PNS will create opportunities for people with developmental disabilities to contribute to, and participate in, all types of community life. It will also support national and state policy development to promote self-determination and independence of people with developmental disabilities. ADD is asking for input through an online survey to decide where their next focus should be. The survey can be completed online until **September 1, 2010**.

For more information visit this

link: [http://www.disability.gov/health/disabilities & chronic health conditions/intellectual & developmental disabilities](http://www.disability.gov/health/disabilities%20&%20chronic%20health%20conditions/intellectual%20&%20developmental%20disabilities)

Announcements:

Autism Research Program for Parents

The Autism Research Program at UNC-CH invites you to participate as a volunteer in a research study involving parents of children with autism and parents of typically developing children to see how areas of their brain react when they are doing tasks related to processing social information. We are interested in looking at the brain function of these parents as they perform tasks involving perception of faces and scenes with emotional content. We will be looking at areas of the brain that are thought to be involved with the processing of social cognition. We will be using a scanning device called a Magnetic Resonance Imaging Scanner, or an MRI scanner, to look at brain functioning.

We are looking for parents of people with autism and parents of typically developing children who are less than 56 years old to help us with this study.

Compensation for this study is \$10 an hour up to \$100 for participating in the initial screening and assessment portion of the study and then \$25 an hour for participating in the MRI scans. Participation takes between 10-12 hours over 2-3 sessions.

If you are interested in participating in this study you may contact us by either emailing one of the contacts listed below, or calling us toll-free at 1-800-793-5715 and ask about the "Social Cognition and MRI study". We will then provide further details about the project. No one is expected to pay for travel or other expenses incurred during participation in this study.

We thank you in advance for your interest in this important project.

If you want to pass this information along to others who may qualify for this research study, please do so.

Please contact:

Scott Wallace
scott_wallace@med.unc.edu
1-800-793-5715
UNC IRB #05-2576
IRB Approval: 5/28/2010
IRB expiration: 1/19/2011

Spectrum of Hope Luncheon

Date: Friday, August 27th
Hours: Noon to 1:30pm
Tickets: \$40
Venue: Dilworth UMC
Address: 605 East Blvd. in Charlotte

You're invited to this special event, featuring guest speaker Susan Senator, author of *Making Peace with Autism & The Autism Mom's Survival Guide*. As the parent of a young adult with autism, Mrs. Senator offers the hard-won, in-the-trenches wisdom of someone who's been there and still is today. She demonstrates how families can find encouragement, contentment and connection in the shadow of autism. Lunch will be prepared by Passion8 Bistro. Proceeds will benefit Autism Services of Mecklenburg County.

Need more information? Please click [HERE](#) or call 704.392.9220 x107

Information and Education:

September 2010

Care Notebook

September 21, 2010 6:30-8:30pm

Lenoir Community College 231 Hwy 58 S. Kinston NC
Administration Building Brown Room 121



Please join us for a fun filled evening designed to help you organize your child's medical information. Bring as much of your paperwork as you would like and we will show you to make it easier to access. Refreshments provided. Registration required.

To register please contact: **Wendy Ward (800) 962-6817 ext. 335** or hic@ecacmail.org
or **April Houston at (252) 560-9584** or april@fsncrystalcoast.org

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“Family Perspectives” Transitioning from Pediatric to Adult Health Care DVD Presentation

September 23, 2010 12:00-1:00pm

Space is limited.

Reserve your Webinar seat now at:

<https://www2.gotomeeting.com/register/148169346>

Join us as we follow three families in their quest to transition their youth with special health care needs from pediatric to adult physician practices. Learn strategies to make the transition easier and discover ways to include your teen in the decision making process. We will briefly discuss some of the key concepts immediately following the DVD presentation.

After registering you will receive a confirmation email containing information about joining the Webinar.

System Requirements

PC-based attendees

Required: Windows® 7, Vista, XP, 2003 Server or 2000

Macintosh®-based attendees

Required: Mac OS® X 10.4.11 (Tiger®) or newer

For more information please contact **Wendy Ward at (800) 962-6817 ext. 335** or hic@ecacmail.org



Lifeline for Parents... Prevent Blindness North Carolina

Prevent Blindness North Carolina is a nonprofit health agency dedicated to preventing blindness, preserving and restoring sight, and promoting healthy vision for all. PBNC provides direct service screening programs, public and professional awareness campaigns, and community vision education to carry out its mission throughout the state.

Your vision is priceless! Did you know?

- 1 in 4 school aged children has a vision problem significant enough to affect their learning.
- Approximately 1 in 20 preschool aged children suffers from amblyopia, a condition that can lead to permanent vision loss if not detected and treated at an early age.
- Vision disorders are the fourth most common disorder in the US and the most prevalent handicapping condition in childhood.

North Carolina law requires that all children entering Kindergarten receive a vision screening. Children who fail the vision screening must receive a comprehensive eye examination.

PBNC operates two children's programs in an effort to ensure healthy vision for NC kids.

Kenneth C. Royall, Jr. Children's Vision Screening Improvement Program

This program is based on a three-hour curriculum endorsed by members of the Pediatric Vision Screening Task Force and the Children and Youth Section of the Department of Health and Human Services. Workshop participants are trained in the fundamentals of vision screening techniques. Participants passing performance criteria and a written test are awarded a certificate which qualifies them to perform vision screening in their representative schools. Through this program, PBNC hopes to ensure that all persons conducting school vision screenings in grades K-6 are doing so in a consistent and uniform manner. Trainings and screenings are available in all 100 North Carolina counties.

Preschool Photorefractive Vision Screenings

PBNC currently offers photorefractive vision screenings to preschoolers in 28 North Carolina counties. Screenings are conducted on-site at childcare centers. A screening with this type of technology is very quick, easy, and non-invasive. Nearsightedness, farsightedness, astigmatism, strabismus, opacities, and conditions leading to amblyopia (lazy eye) are some of the vision problems that can be detected. It is important to screen preschoolers in order to detect problems that could lead to permanent vision loss if not treated at an early age.

Prevent Blindness North Carolina (cont.)

As detection of an eye problem is only the first stage to ensuring good vision, Prevent Blindness believes in offering follow-up resources to all children referred for possible problems. The following resource programs provide families the opportunity to get the follow-up care that is needed.

Sight For Students Voucher Program (VSP)

This program targets children whose families earn up to 200% of the federal poverty level and do not have Medicaid or other insurance. Services include a free eye exam from one of our participating doctors, as well as glasses if prescribed by a participating VSP doctor.

Donor Docs Program

Donor Docs is an all-volunteer program of optometrists and ophthalmologists across the state of North Carolina. Vision exams and in some cases, glasses are provided for uninsured children who are referred for a comprehensive eye exam. During the 2009-10 year, 183 doctors volunteered to donate eye exams and glasses to help school children and adults in North Carolina.

Healthy Eyes Program

The recently-initiated Healthy Eyes Program provides free prescription eyeglasses to children and adults whose families earn up to 250% above poverty level and who have exhausted all other vision hardware benefits. This program is offered by PBNC in partnership with Luxottica, LensCrafters, Target Optical, Sears Optical and select Pearle Vision stores.

To find out more about programs and services at **Prevent Blindness North Carolina**, please call **919.755.5044** or **800.543.7839** or visit our website www.preventblindness.org/nc.



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The purpose of this electronic newsletter 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 a grant from the Health Resources and Services Administration (HRSA). The views and opinions herein do not necessarily reflect views or policies of HRSA, The NC Family to Family Health Information Center, or The Exceptional Children's Assistance Center.