



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**

December, 2008



Volume 2, Issue 11

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 hic@ecacmail.org

We are looking for you...



If you are a parent of a young adult that has made the transition from pediatric to adult health care we would like to talk with you!

**Would you like the opportunity to assist other families with this process?
Would you like to provide workshops in your own community to parents who need your expertise?**

The project is called Carolina Health and Transition (CHAT) and we would like for you to become involved. This is a great opportunity for family leaders to step forward and develop the skills to become effective mentors.

For more information call Wendy Ward at (800) 962-6817 ext. 35

**The NC Family to Family Health
Information Center at ECAC**
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Upcoming Events:



- January 10, 2009 Workshop “How to be an Effective Health Care Advocate”
3:00pm-5:00pm Mecklenburg County Muscular Dystrophy Association.
- January 15, 2009 Workshop “How to be an Effective Health Care Advocate”
6:00pm-8:00pm Sparta NC
- January 21, 2009 Workshop “Health Care Transition: From Pediatric to Adult Health Care” 9:00am-1:00pm Ft. Bragg NC

For more information or to register for any of these events please call
(800) 962-6817 ext. 35.



Other Events...

The National Alliance on Mental Illness (NAMI) is offering Basics Teacher Training Feb 27 - March 1, 2009 in Forest City NC. In order to teach or take the NAMI Basics 6 week course, you must be a parent or direct caregiver of a child/adolescent that was showing symptoms of a mental illness before the age of 13, no matter what age they are now. The weekend teacher training is for those who want to teach the 6 week course to other parents. For more information contact: Lisa Cook, Basics Teacher Trainer (704) 713-3710 or lisareneepoet@yahoo.com



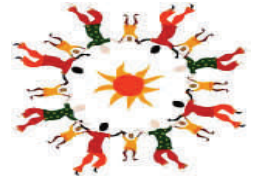
WEB LINKS for **December**

Topic	Link to Web Article Simply click on title to be taken directly to the web page!
Children and Youth with Special Health Care Needs	<u>Birth Defects and Genetic Conditions</u>
Transition	<u>The Forum for Youth Investment</u>
Monthly Health Topic:	<u>For Parents of Children who are Deaf or Hard of Hearing</u>
Disaster Preparedness/ Emergency Planning	<u>Information about seizure first aid</u>
Financial Concerns Insurance Issues	<u>United Healthcare Foundation Grants for Medical Needs</u>
Parent Professional Collaboration: Medical Home	<u>Family-Centered Care Tools</u>
Advocacy	<u>How to be an Effective Health Care Advocate</u>
Record Keeping	<u>Creating a Care Notebook for Your Child</u>
Provider Issues	<u>Provider Tool for Family-Centered Care</u>
Leadership Tips	<u>The National Consortium of Leadership and Disability for Youth</u>



Lifeline for Parents...

TelAbility



TelAbility is an innovative, community oriented, interdisciplinary program that uses telecommunications to improve the lives of children with disabilities. Using real time video conferencing and internet technologies, TelAbility provides comprehensive, coordinated, family-centered care to children with disabilities across North Carolina. TelAbility offers education, training and peer support for people that care for them.

Along with “What’s New” and Case Studies, this site is packed full of information that can be useful such as: education, handouts, clinical trial information, book store, links, a newsletter and an expertise directory. This site also has a trading post. Included in this site is a medication section which features an update on medications and their descriptions.

In the WATCH October 2008 newsletter an Emergency Stress Relief Toolkit was included that may be helpful, especially with the holidays fast approaching. Here are some of the helpful tips:

- Keep stamps on hand.
- Keep a few dollars and spare change somewhere safe in your car.
- Always have a good book or magazine nearby.
- Always put your keys away in the same place each time.
- Make lists.
- Go to bed 30 minutes earlier than usual.
- Don’t wear tight pants or uncomfortable shoes.
- Find ways to laugh at yourself.

Find the complete list and much more on their website.

www.teleability.org

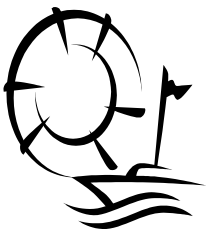
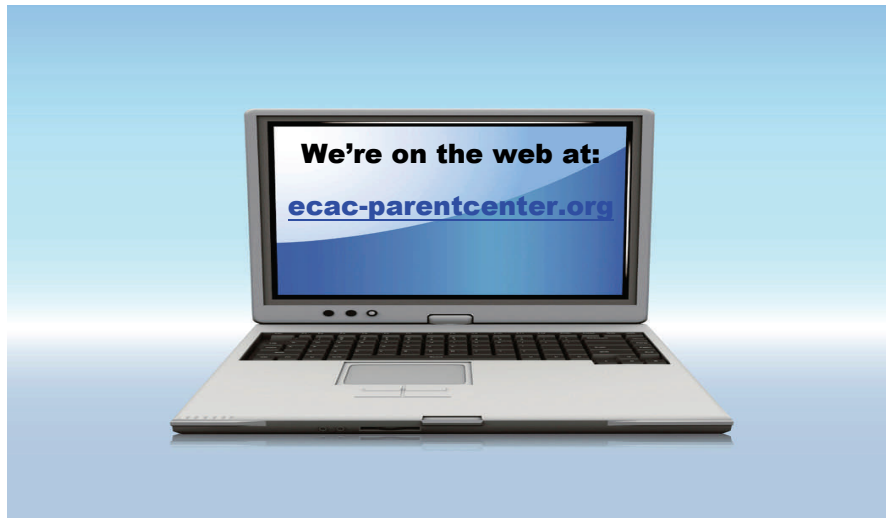


Lending Library

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/materials added this month:

- **A Parent's Guide to Hearing Loss** from the Centers for Disease Control and Prevention (CDC) CD-ROM explaining choices available for families of children with hearing loss.
- **Learn About Life: Sexuality and Social Skills** by Don Bastian (books)



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 the U.S. 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.