



# 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**

May, 2009



Volume 3, Issue 4

## 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 us at: [hic@ecacmail.org](mailto:hic@ecacmail.org)

## National Mental Health Month



For 20 tips on how to make sure that high school students get the support they need, please see the "Thriving in the Community" themed document co-sponsored by the American Academy of Pediatrics and the Substance Abuse and Mental Health Services Administration (link is below).

### 20 Tips

For additional information and resources, please click link below:

### [National Children's Mental Health Awareness Resources](#)

#### Previous Editions

Click on the month:

<a href="#">April, 2009</a>
<a href="#">March 2009</a>
<a href="#">February 2009</a>
<a href="#">January 2009</a>
<a href="#">December 2008</a>

#### The NC Family to Family Health Information Center

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## Internet Links:

### 1. H1N1 Flu Resources:

- One of the most effective ways to prevent illness is through hand washing. Visit the website below for FREE and FUN ways to educate children. You will find songs, movies, posters, coloring books and international translations! [www.henrythehand.com](http://www.henrythehand.com)
- For clear and concise information about “Swine Flu” please visit the website below for videos created in American Sign Language for the deaf community. [www.deafmd.org](http://www.deafmd.org)

### 2. Autism Resources:

- Children’s Health Topic at the American Academy of Pediatrics website. Includes family and community resources including patient education, professional resources and general information. [www.aap.org/healthtopics/autism.cfm](http://www.aap.org/healthtopics/autism.cfm)
- A study released by the American Occupational Therapy Association states that parent interviews may provide key information about autism. Occupational based research finds difference in the sensory experiences of children with autism compared to typically developing children. This study was conducted by University of NC at Chapel Hill and published in the American Journal of Occupational Medicine. To read the complete article please click on the link: [Autism Study](#)

### 3. National Family Caregivers

- There are volunteer representatives in each state for the National Family Caregivers Association. To find the representatives in NC please visit their website: [National Family Caregivers Association](#)

### 4. Multi-Lingual Resources

- A new website provides links, in a variety of languages, on multiple conditions as well as local, national, and international resources for families. [Multi-Lingual Resources on Disabilities](#)

### 5. Financial Assistance Program

- The Kya’s Krusade Financial Assistance Program provides grants to children with physical disabilities for the purchase of adaptive equipment, hippotherapy and additional physical/occupational therapy sessions not covered by insurance. The application deadline is **June 12, 2009**. Applications available at: [www.kyaskrusade.org](http://www.kyaskrusade.org) or call (614) 750-2198.

### 6. Minority Health

- Interactive “Jeopardy” style online game show. Creative way to learn! [“So you think you know minority health”](#)

### 7. Compassionate Allowances Initiative

- The Social Security Administration has compiled a list of 50 illnesses, which qualify for the Compassionate Allowances Initiative, which expedites the approval process for applicants with the most significant disabilities and illnesses who file for disability benefits. The list currently includes 25 rare diseases and 25 cancers which can be reviewed at the SSA's web site at <http://www.socialsecurity.gov/compassionateallowances/>

## 8. \$250 Economic Recovery Payments

- Social Security has announced that the federal government will send out \$250 economic recovery payments to people who receive Social Security and Supplemental Security Income (SSI) benefits beginning in early May 2009 and continuing throughout the month. No action is required to get the payment, which will be sent separately from the person's regular monthly payment. The American Recovery and Reinvestment Act of 2009 provides for a one-time payment of \$250 to adult Social Security beneficiaries, and to SSI recipients, except those receiving Medicaid in care facilities. To receive the payment the individual must be eligible for Social Security or SSI during the months of November 2008, December 2008 or January 2009. For more detailed information about the \$250 one-time economic recovery payments, go to [www.socialsecurity.gov/payment](http://www.socialsecurity.gov/payment).

## 9. Easy Access to Digital Books Online

- The website Bookshare.org has announced exciting news! Book scans can now be shared through a special exemption in the U.S. copyright law that permits the reproduction of publications into specialized formats for persons with print disabilities. The website provides access to books that are stored online as well as add books to the collection. Free memberships for qualified students with disabilities are currently being funded by the U.S. Dept. of Education Office of Special Education Programs. Bookshare also offers more than 45,000 digital books, textbooks, teacher-recommended reading, periodicals and assistive technology tools. For additional information, visit: <http://www.bookshare.org>

## 10. Is *Parents* magazine looking for you?

- A writer for *Parents* magazine is doing an article on access to pediatric sub specialists. If you have children age 12 and under and have had problems finding and/or paying for pediatric sub specialists (such as pediatric neurologists, pediatric cardiologists etc.) please contact Polly Arango at [polly@algodonesassociates.com](mailto:polly@algodonesassociates.com)

## Family Leaders Section

### 1. The Secret Language of Leadership - [Why Storytelling is Important](#)

### 2. Town Hall Discussions Across NC

- North Carolina's state government faces the largest budget shortfall since the Great Depression. It is critical that elected officials hear from folks in their communities about **the importance of public programs and services** so they can make budget decisions that support communities and families and do not undermine the state's economic recovery. The institutions North Carolina families rely on -- education, health care, unemployment insurance, housing assistance, just to name a few -- are in jeopardy this year. **Make Your Voice Heard!** Attend a town hall discussion in your community - locations are Asheville, Fayetteville, Elizabeth City, Charlotte, and Pittsboro. For more information please visit: [www.togethernc.org](http://www.togethernc.org)

## **Disaster Preparedness and Emergency Planning**

We are creating a new packet of information for parents of children with special health care needs and would love your input! If you are involved in an emergency registration program in your community or if you are interested in providing your expertise on this important subject, please contact us.

**(800) 962-6817 ext. 35**

[hic@ecacmail.org](mailto:hic@ecacmail.org)

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**To order any of our packets of information or to schedule a workshop please visit our website:**

[Resource Materials Brochure](#)



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### **Join our mailing list!**

If you have been receiving this monthly electronic newsletter because it was forwarded to you, **now** it the time to sign up for our mailing list! For more information please email or call:

[hic@ecacmail.org](mailto:hic@ecacmail.org)

or **(800) 962-6817 ext. 35**





**Visit us online!**

**[www.ecac-parentcenter.org](http://www.ecac-parentcenter.org)**

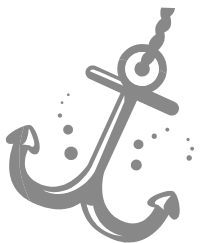
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## *Lending Library*

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:

- *A Special Needs Handbook for Health and Social Care* by Carolyn Meggitt (Book)
- *We Just Happen to Be Deaf* by Tom Lipscomb and Anne McNally (DVD)



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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 provided by a grant from 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.

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