



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**



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

October, 2008

Volume 2, Issue 9

Survey for Parents of Children with Special Health Care Needs

Please take a moment to answer **anonymously** four quick survey questions which are going to be used in a "Best Practice" paper by students from NC State University in the Family Life Education Program.

Please click below to participate:

[SURVEY](#)

Thank you!

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We're on the web:

www.ecac-parentcenter.org



The NC Family to Family Health Information Center

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Davidson, NC 28036
1-800-962-6817 ext. 35
Phone: 704-892-1321 ext. 35
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Support Group Information

You may now find support group information on our website by clicking here: [SUPPORT GROUPS](#)

If you would like for us to include details about a group that is not listed please email the meeting information to:

hic@ecacmail.org

Fact Sheets

Fact Sheets, which cover a variety of topics, are available on our website. Please give us a call at (800) 962-6817 ext. 35 if you have any questions about any of the information provided.

Click here to view all of our fact sheets:

[FACT SHEETS](#)

Packets

The NC Family to Family Health Information Center has a variety of packets **FREE** to NC parents. For more details please click:

[RESOURCE MATERIALS BROCHURE](#).



Upcoming Events:

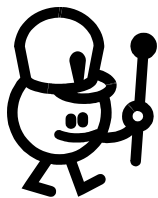


Date	Time	Location	Workshop Title
10/11/2008	9am-4pm	Wilmington, NC	Family Leadership Institute (See page 5 for more details)
10/13/2008	6pm-8pm	Shelby, NC	How to be An Effective Health Care Advocate
10/18/2008	10:30am-12:30pm	Carrboro, NC	Public Health Programs 1 & Consumer Rights and Related Laws
10/23/2008	6:30pm-8:30pm	Hickory, NC	Navigating and Negotiating Developmental Disabilities Services
10/27/2008	10am-12pm	Cherryville NC	How to be An Effective Health Care Advocate
10/28/2008	10am-11am	Teleconference	Care Notebook
10/30/2008	6pm-8pm	Bessemer City NC	How to be An Effective Health Care Advocate
11-10-08	6-8pm	Shelby NC	Navigating and Negotiating Mental Health Services
11-12-08	5:30-7:30pm	Elizabeth City NC	Your Child's Medical Home
11-15-08	8am-4:30pm	Greensboro NC	Outgrowing your Pediatrician: Medical Care in Emerging Adulthood
11-20-08	10am-12pm	Bessemer City NC	How to be An Effective Health Care Advocate

For more information about these workshops and others that are available please see our [Resource Materials Brochure](#).

To register for our workshops please call **(800) 962-6817 ext. 35**.

Conferences



Family Leadership Institute: Parents as Leaders Impacting Health Care Policy

Saturday October 11, 2008 9:00am-4:00pm

Courtyard by Marriott 151 Van Campen Blvd. Wilmington NC 28403

Parents of children and youth with special health care needs that are interested in learning how to develop the skills necessary to become an effective leader are invited to attend .

This training will provide emerging leaders with advocacy skills, information on how to serve on boards and committees, resources to locate leadership opportunities on a local, state and national level and helpful tips to present and utilize your skills.

Registration is free and includes all materials, a continental breakfast, lunch and snacks. A certificate of participation will be provided for each participant. Be prepared to stay for the entire workshop. A small stipend may be available. Please contact us for more information.

Seating is limited - register early! You don't want to miss this!

To register call **(800) 962-6817 ext. 35** and speak with Wendy Ward.



CAROLINA
Health & Transition
PROGRAM

Outgrowing your Pediatrician: Medical Care in Emerging Adulthood

Saturday November 15, 2008 8:00am-4:30pm

**Sheraton Four Seasons/Joseph S. Koury Convention Center 3121
High Point Road Greensboro NC 27407**

The Carolina Health and Transition project (CHAT) is hosting a day long conference on growing up with special needs in the health care system. The project brings youth, parents, and medical providers together to discuss the transition from pediatric to adult health care. Each of the three initiatives will have educational opportunities collectively and break out sessions specific to each perspective.

The NC Family to Family Health Information Center is providing education through the family initiative and will provide the entire workshop in a break out session during the conference. Other training opportunities include "Taking Care of Yourself" specifically for parents/caregivers.

There is no fee for families and youth to attend. Register early by calling **(800) 962-6817 ext. 35** and speaking with Wendy Ward.



Lifeline for Parents... Health Literacy



October is Health Literacy Month

Health Literacy is the ability to read, understand, and act on health information. It is appropriately being able to access and navigate the health care system.

Every time you talk with or visit a doctor, nurse or a pharmacist you should ask questions to help you better understand your health or your child's health. You can build a healthier relationship and get the most from every visit by using some simple tips.

- Make sure you give complete and accurate information.
- Write down your questions beforehand so that you can go over them with the doctor, nurse or pharmacist.
- If you do not understand the answers, tell them you do not understand.
- Let the doctor or nurse know about other doctors or health providers that you or your child are currently seeing.
- Talk about what is important to you and your child-even if you are not asked.
- Keep track of your history or your child's history.
- Make and keep all your appointments, even when you are feeling well.
- Work with your doctor and other health care professionals as a team.
- Follow the treatment plan agreed upon by you and the doctor.

By becoming a more informed health care consumer you can have a safer experience with the health care experience.

For more information on health literacy you can access the following websites:

- National Patient Safety Information: www.npsf.org
- Massachusetts Health Quality Partners: www.mhqp.org

Inter'NET' Links

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>Friday's Child</u>
Transition	<u>Children's Medical Services: Health Transition Workbook</u>
Monthly Health Topic: Health Literacy	<u>Ask Me 3</u>
Disaster Preparedness/ Emergency Planning	<u>Children's Health Topics: Disaster Preparedness</u>
Financial Concerns Insurance Issues	<u>Hill-Burton Free and Reduced Cost Health Care</u>
Parent Professional Collaboration: Medical Home	<u>Parent Partners</u>
Advocacy	<u>Parental Advocacy</u>
Record Keeping	<u>Bright Futures Health Record</u>
Legal Information	<u>Benefits for Children with Disabilities</u>
Provider Issues	<u>20 Tips to Help Prevent Medical Errors in Children: A Patient Fact Sheet</u>
Leadership Tips	<u>Leadership Tips by KASA (Kids as Self Advocates)</u>





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:

- The First Years Last Forever (DVD) hosted by Rob Reiner
- Children with Cerebral Palsy: A Parent's Guide by Elaine Geralis

The NC Family to Family Health Information Center
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Home to Family Voices of NC

"A beacon for families of children with special health care needs."

Parents and families with children that have special health care needs often need help navigating the complicated issues surrounding health care.

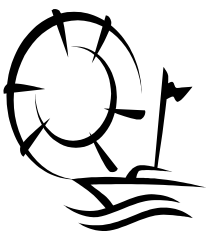
The NC Family to Family Health Information Center (HIC) can help you and your family by providing the information needed so you can make the best choices.

We provide information, education, referrals, workshops and training classes to families, support groups and providers on a variety of topics **at no charge!**



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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 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.