



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 <mailto:hic@ecacmail.org>

August, 2008

Volume 2, Issue 7

The "Teleconference Tuesday!" Series



With gas prices soaring we want to make it easier for you to get the information you need!

Join us the last Tuesday of each month for training teleconferences on a variety of subjects. Each call will last 1 hour or less. For more information on this exciting opportunity please see page 6.

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We're on the web:

www.ecac-parentcenter.org

The NC Family to Family Health Information Center

907 Barra Row
Suites 102/103
Davidson, NC 28036
1-800-962-6817 ext. 35
Phone: 704-892-1321 ext. 35
Fax: 704-892-5028
E-mail: <mailto:hic@ecacmail.org>

Support Groups Around the State

Please Note: Meetings are listed alphabetically by city.

Asheboro, NC:

Randolph County Support Group for Families of Children with Autism

Meets the 3rd Thursday of each month from 6:30-8:00pm at the Early Childhood Development Center (ECDC) 1738 N. Fayetteville Street, Asheboro. Light refreshments served, child care available with RSVP. Please contact Brooke Juneau at (336) 334-5601 ext. 217 or brooke.juneau@ncmail.net for more info or to RSVP.

Advance NC:

Davie County Autism Society Support Group

Meets the third Tuesday of each month at 6:30 pm at Hillsdale Baptist Church in Advance, NC. Childcare is provided. Contact Stephanie Ashby, Co-Leader at (336) 940-4146.

Burlington, NC:

Circle of Parents of Children with Down Syndrome Support Group in Alamance County

Support group is for families of children with Down Syndrome. The meeting dates and times are to be determined and location is at the Alamance Partnership for Children. For more information contact Ashley Moore at (336) 513-0063 ext. 108 or Brooke Juneau (Family Support Network of Central Carolina) at (336) 334-5601 ext. 217.

Carrboro, NC:

Family Advocacy Network (FAN) Parent Support Group Meetings

Meetings held on the second Tuesday of each month, 11:30am-1:00pm in the conference room of the Mental Health Association in Orange County on 302 W. Weaver Street, Carrboro NC 27510. Meetings are free and geared toward emotional support. Refreshments included. Childcare is not provided. For more information contact a family advocate at the FAN (919) 942-8083 or visit www.fan-mhaorangeco.org

Chapel Hill, NC:

Family Advocacy Network (FAN) "Meet the Experts" Support and Educational Series

Meets on the 4th Saturday of each month, 9:30-11:30 at the Orange United Methodist Church, 1220 Martin Luther King Jr. Blvd. Chapel Hill, NC 27516. Designed for parents of school age children who have emotional and behavioral challenges or other mental health issues. Refreshments available. Childcare provided with advance registration. Contact a family advocate at FAN 919-942-8083 or visit the website at www.fan-mhaorangeco.org for more details.

Charlotte NC:

Parent VOICE Adult and Youth Support Groups

Parent VOICE has an Adult and Youth Support group for families raising youth with emotional, behavioral and mental health concerns. They both meet on the 4th Tuesday of the month at Grace United Methodist Church 737 E. Woodlawn Rd. Charlotte, from 6-8pm. Call or email Nancy at 704-336-7128 parentvoice01@aol.com

Charlotte, NC:

Greater Charlotte Metropolitan Area, Mom's Morning Out "Little Stars"

Empowering families with special children in the Charlotte, Lake Norman, and Statesville areas. Contact Sandra Ringelstein at (704) 877-3751 for more information about meeting locations and times. Children are welcome. Co-sponsored by Family Support Network of Mecklenburg County. www.fsnncc.org (704) 336-7173.

Concord, NC:

Cabarrus County Chapter of the Autism Society of NC

Group support meetings offered every second Thursday of the month at Epworth United Methodist Church in Concord from 6:30-8:00pm. Childcare provided on a limited pre-reserved basis. Please contact Maria Anthony at mariaanthony@asnc-ccc.org for more information.

Support Groups Around the State (Continued)

Please Note: Meetings are listed alphabetically by city.

Greensboro, NC:

Triad Area Hitch-Up Support Group (For Families of Children with Hearing Loss)

The Triad Area Hitch-Up is a support group for parents/guardians of children with hearing impairments. Meetings are held on the last Tuesday of each month from 6:30-8:30pm at Greensboro AHEC at Moses Cone Hospital rooms 31 and 33. Child care is provided. For more information see their website: www.triadhitchup.com or call Pamela Bensimhon at (336) 638-6111 or email her at info@triadhitchup.com

Greensboro/High Point, NC:

Club Social Group-Guilford County

For youth ages 9-14 with social learning disabilities (such as Asperger's, ADHD, NLD and High-Functioning Autism). For more information about the monthly activities contact Deanne O'Connor at (336) 510-4628 or Karen Boggis at Kcboggis@aol.com.

Hickory NC:

Sensory Integration Support Group

Support group meets last Tuesday of each month from 6:30-8:30 at Children's Neurotherapy Services. To register call Angie Stone at (828) 267-1688. Child care available with advance registration.

King NC:

Circle of Parents Support Group Stokes County Family Support Network

Support group meets 1st and 2nd Monday of each month from 6-7:30pm. Child care available with registration. For location and more information contact Donna Wishon at (336) 985-2676 ext. 167.

New Bern, NC:

FSN of the Crystal Coast Presents: Sibshops

Sibshops are meetings for the brothers and sisters (siblings) of children with special needs which provide peer support. Meetings are from 10-2 on Saturdays at the Craven Smart Start 1917 Trent Blvd. in New Bern. There is no fee and lunch is provided with registration. For more information contact Teresa LeRiche at (252) 675-2751.

Raleigh, NC:

Triangle Area Hitch-Up "Hearing Impaired Toddlers and Children Have Unlimited Potential"

The Triangle Area Hitch-Up is a support group for parents/guardians of children with hearing impairments. Meetings are held on the first Tuesday of each month at the Providence Baptist Church 6339 Glenwood Avenue, Raleigh NC in room 219. Child care is available at no charge. For more information contact Alisa Oliver at (919) 271-9142 or alisaoliver@gmail.com

Wilson NC:

Family Support Network of ENC Parent Resource and Support Group in Wilson County

Serves families with children that have special health care needs. Meets the 1st Thursday of every month at Wilson Medical Center 7:00-8:30pm. Contact Mary Brown at (252) 290-0862 for more information.

Wilmington NC:

Sensory Integration Support Group

Support group meets the first Tuesday of every month from 7:00-8:00pm at Coastal Rehabilitation Hospital. To register or receive additional information, contact Kacey Trout at kt trout@nhhn.org.





Lifeline for Parents...

American Academy of Pediatrics

The American Academy of Pediatrics (AAP), founded in 1930, is a not-for-profit membership and child advocacy organization. The AAP's mission is to attain optimal physical, mental, and social health and well being for all infants, children, adolescents, and young adults. It supports the professional needs of its 60,000 members-- including pediatricians and pediatric specialists and sub-specialists -- through continuing education, policy guidance, advocacy and research.

Just as important, the AAP, along with its state chapters across the U.S., advocates for children's health and safety, implements programs at the community level, and serves as an independent resource to the public on a wide range of issues.

The AAP believes that each child should have a "medical home"—a place where care is accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective. The AAP works with government, communities, and other national organizations to help shape this and many other child health and safety issues. For more information go to <http://www.medicalhomeinfo.org/>

Priority issues for the AAP include universal health care coverage for all children; increased efforts to prevent and reduce childhood obesity; expanded education about childhood health issues for parents and pediatricians; greater understanding and research in human genetics; increased efforts to reduce prematurity; and improvements in vaccine efficacy and delivery. Mental health and oral health services are also priorities.

As August is National Immunization Awareness Month, the AAP will participate in various activities to emphasize how important vaccines are to children's health.

These include national and local media outreach, public service announcements, and a Web area dedicated to the month.

For more information, go to www.aap.org (national AAP site) or <http://www.ncpeds.org/> (North Carolina chapter).

Inter'NET' Links

- **Children and Youth with Special Health Care Needs (CYSHCN): Special Needs Families:**

A web site that you can join for free that is bringing special needs families together.
<http://www.specialneedsfamilysupport.com/>

- **Transition: Social Security/Work Incentives/Ticket to Work:**

Social Security has revised its regulations around the "Ticket to Work" Program. Find the information here.
<http://www.pacer.org/tatra/resources/socialsec.asp>

- **Monthly Health Topic: Immunizations**

Childhood immunization support program. Immunization information for parents including frequently asked questions and recommended immunization schedules. <http://www.cispimmunize.org/>

- **Disaster Preparedness/Emergency Planning: State Emergency Planning and Preparedness Recommendations for Maternal and Child Health Populations:**

Scroll down to find Emergency planning for children and youth with special health care needs.
<http://www.amchp.org/topics/a-g/emergency.php>

- **Financial Concerns/Insurance Issues: First Hand Foundation:**

First Hand Foundation is a non profit organization that helps children with health- related needs when insurance and other financial resources have been exhausted. <http://www.cerner.com/firsthand/default.aspx>

- **Parent-Professional Collaboration-Medical Home: Family-Agency Collaboration:**

What is Family-Agency collaboration?, Keys to successful family-agency collaboration, Tips for building a collaborative partnership and much more. http://www.spannj.org/publications/familyagency_pub.htm

- **Advocacy: Parent Advocacy for Children with Special Needs:**

This ComeUnity website has many links you can click on to with advise on how to advocate for your child with special needs. <http://www.comeunity.com/disability/advocacy.html>

- **Record Keeping: Effective Recordkeeping:**

An important part of raising a child or youth with special health care needs is keeping records of the major life events in their life. A tip sheet from Family Voices of North Dakota on effective recordkeeping.
<http://www.fvnd.org/files/REcordKeeping.pdf>

- **Legal Information: Medical News Today**

The latest news on Medicare, Medicaid and SCHIP, published daily. Click on the link for Categories M-O.
<http://www.medicalnewstoday.com/>

- **Provider Issues: Diversity and Culturally Competent Care**

A list of links to see if your health care provider is culturally competent and tips and doctor-patient communication.
<http://orthoinfo.aaos.org/diversity/doctor-comm.cfm>

- **Other Links and Information:**

- **Siblings of Kids with Special Needs:**

How does growing up in an exceptional family affect the siblings? Links are available for that information.
<http://www.med.umich.edu/1libr/yourchild/specneed.htm>



Upcoming Events:



August 26, 2008 10:00am-11:00am Teleconference Tuesday! Medical Home

Join us for a 1 hour training call on the Medical Home concept.

A Medical Home is a partnership between families and medical providers. It is an approach to providing health care services in a high quality, cost effective manner. This relationship is especially important for children and youth with special health care needs as it ensures at least one health care provider is informed about, understands, and respects the family's culture and values.

Register by August 12 to make sure you receive the training materials, call in information and code.

To register call (800) 962-6817 ext. 35 or email Wendy Ward at hic@ecacmail.org



September 12, 2008 1:00pm-4:00pm Public Health Programs 1

Parent Workshop. Christ Methodist Church, 410 N. Holden Road, Greensboro NC.

Public Health Programs 1 is a workshop designed to help parents understand Medicaid, Community Alternative Programs (CAP waivers), Early Periodic Screening Diagnosis and Treatment (EPSDT or Health Check), Supplement Security Income (SSI) and Medicare.

Please register by September 8th by calling (866) 740-4135 ext. 17 or email Shanna Capps at scapps@ecacmail.org

September 30, 2008 10:am-11:00am Teleconference Tuesday! How to be an Effective Health Care Advocate.

Join us for a 1 hour call on how to an effective health care advocate for your child.

Register by September 16 to make sure you receive the training materials, call in information and code.

To register call (800) 962-6817 ext. 35 or email Wendy Ward at hic@ecacmail.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:

- *How to Talk to Your Child's Doctor* by Christopher M. Johnson, MD
- *Fitness Nutrition for Special Dietary Needs* by Stella Lucia Volpe, Sara Bernier Sabelawski, Christopher R. Mohr

The NC Family to Family Health Information Center
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"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.

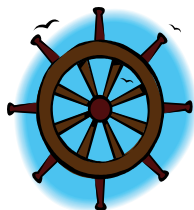
The NC Family to Family Health Information Center (HIC) can help you and your family by providing the information needed so you can make the best choices.

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



907 Barra Row
Suites 206
Davidson, NC 28036

1-800-962-6817 ext. 35
Phone: 704-892-1321 ext. 35
Fax: 704-892-5028
E-mail: hic@ecacmail.org



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.
