



# 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>

July, 2008

Volume 2, Issue 6

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## **We Need You!**

**We are looking for parents across the state to participate in leadership and mentoring activities involving transitioning youth with special health care needs from pediatric to adult health care providers. If you would like more information please call us for the details!**

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



We're on the web:

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

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

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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](mailto: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](http://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](http://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](mailto: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](http://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](mailto: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](http://www.triadhitchup.com) or call Pamela Bensimhon at (336) 638-6111 or email her at [info@triadhitchup.com](mailto: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 email Brooke Juneau at [brooke.juneau@ncmail.net](mailto:brooke.juneau@ncmail.net) or call (336) 334-5601 ext. 252.

## 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 1<sup>st</sup> and 2<sup>nd</sup> 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](mailto:alisaoliver@gmail.com)

## Wilson NC:

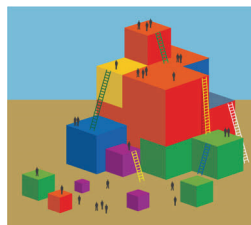
### **Family Support Network of ENC Parent Resource and Support Group in Wilson County**

Serves families with children that have special health care needs. Meets the 1<sup>st</sup> 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](mailto:kt trout@nhhn.org).





## Lifeline for Parents...

# Brain Injury Association of North Carolina



### **What is BIANC?**

#### Mission Statement

Our mission is to offer help, hope, and a voice for people with brain injury, and their families; by

- Prevention
- Education
- Research
- Advocacy

The Brain Injury Association of North Carolina develops, supports, and/or administers programs, services, and activities that make a difference in the lives of men, women, and children who have been affected by the trauma of brain injury.

### **Family Helpline: 1-800-377-1464**

#### *Brain Injury Association of North Carolina Offers You...*

BIANC is an important source of information about brain injury in our state. It is a vital resource for survivors of brain injury, their families, and professionals.

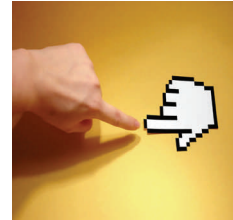
We provide...

- peer support
- support groups across the state
- Family Helpline
- an annual camp retreat for survivors
- educational conferences
- training workshops
- newsletters about brain injury

The Brain Injury Association of North Carolina strives to improve the lives and quality of care available to survivors of brain injury by...

- Working with state and federal agencies
- Playing an active role in shaping public policy on brain injury in our state
- Partnering with major medical and academic institutions throughout NC

# Inter'NET' Links



1. **Children and Youth with Special Health Care Needs (CYSHCN): Vision USA:** Vision USA is a year round program that can help by providing basic eye health and vision care services free of charge to the many uninsured low-income people and their families. <http://www.aoa.org/x5607.xml>
2. **Transition: Guideposts for Success:** Youth with disabilities may need extra supports throughout their transition period in order to make informed choices and become self-sufficient adults. This website is packed full of information, including youth development, quality education and workforce development programs. [http://www.ncwd-youth.info/resources\\_&\\_Publications/guideposts/](http://www.ncwd-youth.info/resources_&_Publications/guideposts/)
3. **Monthly Health Topic: Eye Injury Month:** An alphabetical list of common eye problems in children and adults. Also listed are ways to take care of your sight. [http://www.preventblindness.org/vlc/eye\\_problems.htm](http://www.preventblindness.org/vlc/eye_problems.htm)
4. **Disaster Preparedness/Emergency Planning: Emergency Preparedness at home for persons with Disabilities: A Guide.** Protecting you and your family before a disaster strikes requires planning. This checklist will help you get started. <http://www.ici.umn.edu/products/impact/201/over13.html>
5. **Financial Concerns/Insurance Issues: North Carolina Health Choice: Information for Children with Special Health Care Needs and Their Families.** A booklet you can print off packed full of information if you have a Child with special health care needs and are covered under NC Health Choice. [http://www.dhhs.state.nc.us/DMA/CHIP/sn\\_booklet.pdf](http://www.dhhs.state.nc.us/DMA/CHIP/sn_booklet.pdf)
6. **Parent Professional Collaboration-Medical Home: Families+Health Care Professionals=Partners for Healthy Children:** This handout that will assist parents and families in communication and partnership with their child's Health Care Professional. <http://www.brightfuturesforfamilies.org/pdf/familypartnership.pdf>
7. **Advocacy: Writing Letters of Medical Necessity:** Information for parents as well as professionals in how to write a Letter of Medically Necessity. How to file and appeal is also included. [http://www.medhomeportal.org/issues/index.cfm?issue\\_id=88&diag\\_id=107&menu\\_id=193](http://www.medhomeportal.org/issues/index.cfm?issue_id=88&diag_id=107&menu_id=193)
8. **Record Keeping: FILE: Folder of Information and Life Experiences:** Your file will help you organize the information you need and the information that you will share with others along the way. <http://www.sdparent.org/file.html>
9. **Legal Information: Choosing a Trustee for Your Child's Special Needs Trust:** There are a number of Special Needs Trust Jobs that need filling. Find out what these are by going to the following website. [http://www.eparent.com/main\\_channels\\_legal/Choosing\\_a\\_Trustee\\_for\\_Your\\_Child.asp](http://www.eparent.com/main_channels_legal/Choosing_a_Trustee_for_Your_Child.asp)
10. **Provider Issues: Finding a Doctor for your Child.** What are your options and what you should look for. Facts are also available in Spanish. [http://kidshealth.org/PageManager.jsp?dn=KidsHealth&lic=1&article\\_set=21692&cat\\_id=173&](http://kidshealth.org/PageManager.jsp?dn=KidsHealth&lic=1&article_set=21692&cat_id=173&)
11. **Other Links and Information:**
  - One Place for Special Needs:** This website was created for families who are trying to locate resources and support raising a child with special health care needs. <http://www.oneplaceforspecialneeds.com/>
  - How to Help Your Children Make a Fireworks Celebration on Paper:** Now you and your child can enjoy a fun activity without the danger of live fireworks [http://www.ehow.com/how\\_17584\\_help-children-make.html](http://www.ehow.com/how_17584_help-children-make.html)
  - STOMP (Specialized Training of Military Parents):** is a federally funded Parent Training and Information Center (PTI) established to assist military families who have children with special health and education needs. You can click on the locations tab on the main page and locate the NC location. <http://www.stompproject.org/default.asp>
  - Firework Safety: The National Council on Firework Safety.** Keep your family safe when using fireworks this summer. <http://www.fireworksafety.com/>

# Upcoming Events:



## Summer Teleconference Series

**This series of conference calls is designed to enable you to participate in educational opportunities without leaving your house! Since summer is such a busy time we wanted to make it easy for you to join us. No gas to buy! No need to worry about a sitter! It's FREE!**

**Although these are monthly calls you can join in even if you haven't participated before. Please register by the deadline so that we can send you all the materials before the call. You will be given the call in number and guest code with complete instructions upon registration.**

- July 16, 2008 7:00pm-7:45pm. Family Leaders Conference Call Topical call on "How to Make Public Comment". Please register by July 9th by calling Shanna Capps at (866) 740-4135 ext. 17**
- July 31, 2008 11:00am- 11:45am. Community Partners Conference Call Topical call on "What is a CAP MR-DD Waiver?". Please register by July 24 by calling Kerri Eaker at (866) 545-5299.**



# *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:

- *Chicken Soup for the Soul Children with Special Needs* by Jack Canfield, Mark Victor Hansen, Heather McNamara, and Karen Simmons.
- *Special Needs Trusts Protect Your Child's Financial Future* by Attorney Stephen Elias.

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**The NC Family to Family Health Information Center**  
**A project of The Exceptional Children's Assistance Center**  
**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.

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