



# 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>

February, 2008

Volume 2, Issue 1

# Happy Birthday Beacon!



We would like to take this opportunity to thank you, our readers and supporters, for making the first year of "The Beacon" a successful one! It is through your emails and calls that we have learned how important this type of information really is.

Please let us know if you come across a web site or link that you would like to share or if you know of a group you feel should be highlighted on our "Lifeline" page.

The staff here at the NC Family to Family Health Information Center looks forward to putting this monthly electronic newsletter together and we thank you for all your encouragement. Please be sure to tell other parents so our distribution list can continue to grow!



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## The NC Family to Family Health Information Center

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We're on the web:

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

# Support Groups Around the State



Please Note: Meetings are listed alphabetically by city.

## 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 Support Group in Alamance County**

Support group meets the last Tuesday of every month from 6:30-8:00pm. Child care provided with registration. Meeting location is at the Alamance Partnership for Children. For more information and to register contact Ashley Moore (336) 513-0063 ext. 108.

## 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@asncc-ccc.org](mailto:mariaanthony@asncc-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)

## Henderson, NC:

### **The Autism Society of NC Vance/Warren**

Chapter support group meetings are held on the 1st Thursday of each month. The business meetings are held on the 3rd Tuesday of each month. Refreshments and childcare are provided. Anyone with an interest in autism is welcome. For more information contact Shanna Capps at [shannacapps@netzero.com](mailto:shannacapps@netzero.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 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:

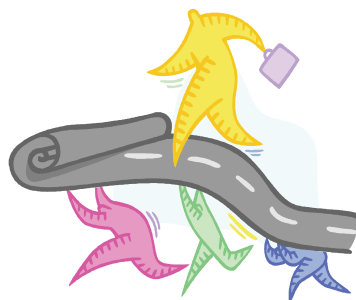
### **Family Support Network of ENC Parent Resource and Support Group in Wilson County**

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... Kids As Self Advocates (KASA)

## **KID'S AS SELF ADVOCATES (KASA)**

### **A Project Of Family Voices**

Kids As Self Advocates (KASA) is a national, grassroots project created by youth with disabilities for youth. We are teens and young adults with disabilities speaking out. KASA knows youth can make choices and advocate for themselves if they have the information and support they need.

We are leaders in our communities, and we help spread helpful, positive information among our peers to increase knowledge around various issues. We also help health care professionals, policymakers and other adults in our communities understand what it is like to live our lives and we participate in discussions about how to help each other succeed.

KASA believes young people with disabilities will have control over their own lives and futures. We help this happen by teaching youth about their rights, giving peer support and training, and changing the systems that affect our lives to include us.

## **We are Kids As Self Advocates!**

We model leadership and the power of self-advocacy. We are active in our schools, communities, families, and places of employment. We share our message with other youth who have disabilities or chronic health conditions, as well as with our friends and peers. Our activities include:

Representing the voice of youth living with disabilities and chronic health conditions by speaking to policy makers at public events and hearings

Educating our communities, including students, teachers and administrators at our schools; medical students and physicians; and federally funded care and agencies and state programs

Serving as advisors to the over 40,000 members of Family Voices across the country and organizations and agencies interested in promoting youth involvement and leadership

### **KASA's Mission Statement (what KASA believes the project should focus on)**

Kids As Self Advocates (KASA) is a project created by youth with disabilities for youth to educate society about issues concerning youth with a wide spectrum of disabilities and health care needs. KASA believes in supporting self-determination, creating support networks and proactive advocacy for all youth with disabilities in our society.

### **Our Vision**

Our goal is to increase understanding of disability and health care rights as they relate to youth with disabilities and health care needs.

KASA will empower youth to learn how to advocate for themselves and others through better knowledge in areas such as school, health care, technology, and other current issues related to youth.

Through this education youth will start to hold themselves and society responsible for upholding the rights of those with disabilities and health care needs.

Youth with disabilities and health care needs will understand their rights as members of our society, will determine the supports that they need to be independent within communities that are accepting of them as individuals.

For general information about KASA, please email us at [info@fvkasa.org](mailto:info@fvkasa.org)

### **PROJECT STAFF:**

**Naomi Ortiz, Project Director**

[ortizn@fvkasa.org](mailto:ortizn@fvkasa.org)

(785) 273-3398 **FAX:** (505) 872-4780

# Inter'NET' Links

## 1. Children and Youth with Special Health Care Needs (CYSHCN)

**How to Research a Disability on About Parenting Special Needs.** Whether you have gotten a diagnosis for your child or looking into the possibilities, this About Parenting Special Needs site is a great place to start.

<http://specialchildren.about.com/od.gettingadiagnosis/ht/researchabout.htm>

## 2. Transition: "Since You're Not A Kid Anymore"-This booklet for middle school students will help them start thinking about their health care needs and health care transition.

<http://www.doh.state.fl.us/AlternateSites/CMS-Kids/TRANSITION/SinceYoureNotAKidAnymore07.pdf>

## 3. Monthly Health Topic: Childhood Obesity-

Childhood obesity is one of our nation's leading health threats today.

<http://www.americanheart.org/presenter.ihtml?identifier=3049109>



## 4. Disaster Preparedness/Emergency Planning: Emergency Plans for Children with Special Health

**Care Needs:** Included in the article you will find links to additional information such as: Ten Steps to Take in an Emergency and examples of Emergency Care Plans.

[http://www.childrensmemorial.org/depts/emergency\\_medicine/special\\_needs.aspx](http://www.childrensmemorial.org/depts/emergency_medicine/special_needs.aspx)

## 5. Financial Concerns/Insurance Issues: What Medical Expenses are included in the IRS deductions?

What is included, how much can you deduct and what is not deductible. These are some of the questions answered in this Internal Revenue Publication. <http://www.irs.gov/publications/p502/ar02.html>

## 6. Parent Professional Collaboration-Medical Home: Elements for Successful Parent Professional Collaboration: The Fundamentals Apply as Time Goes By.

The Individuals with Disabilities Education Act (IDEA) mandates parent-professional collaboration. <http://escholarship.bc.edu/cgi/viewcontent.cgi?article=1412&context=education/tecplus>

## 7. Advocacy: Learning to Negotiate is Part of the Advocacy Process

Helpful negotiating techniques compiled by a Parent Advocate

[http://www.wrightslaw.com/advoc/tips/palmer\\_negotiation\\_process.htm](http://www.wrightslaw.com/advoc/tips/palmer_negotiation_process.htm)

## 8. Record Keeping: "For the Record", a record keeping system which parents and caregivers can use when advocating for their child. <http://www.pinofpa.org/resources/record.html>

## 9. Legal Information: Guardianship: Answers to your questions about obtaining guardianship in North Carolina

<http://info.dhhs.state.nc.us/olm/manuals/doa/gs/man/APSc8-04.htm>

## 10. Provider Issues: Is your Provider agency family friendly?

A survey that your provider agency can complete to find out if they are a family friendly organization.

You can complete the survey as well and compare answers. <http://olrs.ohio.gov/Other/checklistagency.pdf>

## 11. Other Links and Information:

### Discovery Toys

There is something for everyone from birth to adult. [http://www.discoverytoyslink.com/esuite/home/vd\\_small](http://www.discoverytoyslink.com/esuite/home/vd_small)

## Upcoming Events:



- February 19, 2008, 7:00pm - 8:00pm Public Health Programs 1 Workshop Henderson, NC
- February 20, 2008, 5:30pm-7:00pm Medical Home Parent Workshop Henderson, NC
- February 21, 2008, 5:30pm - 7:30pm Navigating and Negotiating Mental Health and Developmental Disabilities Services Workshop Asheville, NC



- March 5, 2008, 5:00pm - 7:30pm **SPANISH** Medical Home Parent Training Hendersonville, NC
- March 10, 2008, 5:30pm - 7:30pm Navigating and Negotiating Mental Health and Developmental Disabilities Services Workshop Clyde, NC
- March 15, 2008, 10:30am - 1:00pm Medical Home Parent Training Gastonia, NC
- March 19, 2008, 6:30pm - 8:00pm Public Health Programs 1 Clayton, NC
- March 29, 2007 8:45am-4:00pm Train the Trainer Workshop on Navigating and Negotiating Mental Health and Developmental Disabilities Services Hickory, NC

**Call us so we can do a workshop for your parent group!**

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



### **FYI**



### **Grants for Families of Children with Autism**

The following organizations may be able to provide some financial assistance upon qualification:

National Autism Association:

<http://www.nationalautismassociation.org/helpinghand.php>

ACT Today!:

[http://www.act-today.org/ACT Today Grant Application 2008.pdf](http://www.act-today.org/ACT_Today_Grant_Application_2008.pdf)

Autism Family Resources:

<http://www.autismfamilyresources.org/needassistance2.htm>





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

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

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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# *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:

- ***Parenting Children with Health Issues*** by: Foster W. Cline, MD, and Lisa C. Greene
- ***A Health Handbook for Women with Disabilities*** by: Jane Maxwell, Julia Watts Belser, and Darlena David

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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 grants from CMS and HRSA. The views and opinions herein do not necessarily reflect views or policies of CMS, HRSA, The NC Family to Family Health Information Center, or The Exceptional Children's Assistance Center.

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