



## North Carolina Family to Family Health Information Center's



### "The Beacon"

A Project of The Exceptional Children's Assistance Center (ECAC)

**E-letter July 2007**

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

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 health care for children with special health needs.

**If you are involved in a support group or training classes relevant to children with special needs please send me the details to share with others!**

#### **Support Group News:**

##### Greater Charlotte Metropolitan Area ( Mooresville NC):

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.fsnn.org](http://www.fsnn.org) (704) 336-7173.

##### Davie County Autism Society Support Group (Advance NC):

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.

##### ParentVOICE Adult and Youth Support Groups (Charlotte NC):

ParentVOICE 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)

##### Wilson County Parent Resource and Support Group (Wilson NC):

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.

##### Sensory Integration Support Group (Hickory NC):

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.

##### Circle of Parents Support Group Stokes County Family Support Network (King NC):

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.

##### Iredell County Chapter of the NC Autism Society (Statesville NC):

Autism support group will meet June 12 from 7-8:30 at the St. Philip the Apostle Catholic Church, 525 Camden Drive in Statesville. Child care will be provided. RSVP to Shelley Cote at (704) 799-1068.

##### Circle of Parents Support Group in Alamance County (Burlington, NC):

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.

Circle of Parents of Children with Down Syndrome Support Group in Alamance County (Burlington, NC):

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.

**IMPORTANT MEETINGS:**

**Public Health Programs 2 Training (Asheville NC):** Covers: Title V, NC Health Choice, Health Department Programs, Children's Special Health Services, Low Cost/Free Clinics

FREE information and training session July 16, 2007, from 5:30-7:30pm. To be held at Mission Reuter Children's Outpatient Center on 11 Vanderbilt Park Drive in Asheville. Child care and dinner provided with reservation. For more information or to register contact Roxanne Colwell at (828) 213-0044 or Grace Sisco (800) 962-6817 ext. 11.

**INFORMATION PACKETS AVAILABLE:**

The NC Family to Family Health Information Center provides packets of information FREE to NC parents. To order a packet or schedule a training workshop for your group, please contact Wendy Ward at (800) 962-6817 ext. 35 or [ward@ecacmail.org](mailto:ward@ecacmail.org). The available packets/fact sheets include:

**Health Consumer Laws and Rights** (HIPAA, ERISA, COBRA, EMTALA, FMLA, MHPA)

**Private Health Insurance** (Private Health Insurance, Denials, Appeals, Complaints)

**Public Programs 1** (Medicaid, CAP, EPSDT, SSI, Medicare)

**Public Programs 2** (Title V, NC Health Choice, Public Health, CSHS, Low Cost/Free Clinics)

**Prescription Assistance Programs** (Help with prescriptions)

**Medical Home Parent Training Curriculum**

For information on other workshops and training opportunities in your area check the recently revised ECAC website at [www.ecac-parentcenter.org](http://www.ecac-parentcenter.org)

**FOR YOUR INFORMATION:**

Durham County Health Department now provides dental services and nutrition education to pregnant women and children from 6 months to 21 years old under a program called Healthy Smiles, Healthy Kids. For more information contact Kelly Warnock at (919) 560-7890. For appointments call (919) 560-7861.

To be added or removed from "The Beacon" mailing list <mailto:hic@ecacmail.org>

For medical equipment to sell or trade please contact us at [hic@ecacmail.org](mailto:hic@ecacmail.org) and we will post in the next month's e-letter.

**Useful Links:**

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

Need for and Use of Family Leave Among Parents of Children With Special Health Care Needs. *Pediatrics*. Official Journal of the American Academy of Pediatrics.  
<http://pediatrics.aappublications.org/cgi/content/abstract/119/5/e1047?etoc>

**2. Transition**

Transition Planning for the Future. A school to work checklist which will assist parents in keeping records that will support their child in transitioning. (03/06) The University of Illinois at Chicago.  
<http://internet.dsc.uic.edu/forms/psu/4204.pdf>

**3. Monthly Health Topic: Sun Safety**

A fact sheet about sun exposure with links to a "Sunburn Instruction Sheet" and "Heat Exhaustion & Heatstroke Instruction Sheet". The Nemours Foundation.  
[http://kidshealth.org/parent/firstaid\\_safe/outdoor/sun\\_safety.html](http://kidshealth.org/parent/firstaid_safe/outdoor/sun_safety.html)

**4. Disaster Preparedness/Emergency Planning**

Preventing accidental injury, Special Needs. Safe Kids USA.  
[http://www.usa.safekids.org/tier2\\_rl.cfm?folder\\_id=2020](http://www.usa.safekids.org/tier2_rl.cfm?folder_id=2020)

**5. Financial Concerns/Insurance Issues**

For diabetics: To receive a free One Touch Mini glucose meter free, call: (866)469-4166. You can choose from these colors; Black, Silver, Lime Green, or Pink Glo. Also, join the One Touch Gold website as well, it is: [www.onetouchgold.com](http://www.onetouchgold.com) for free diabetic recipes and free samples of Sun Crystals Natural Sweetener.

## **6. Parent/Professional Collaboration- Medical Home**

Family-Centered Care and the Pediatrician's Role. *Pediatrics*. Official Journal of the American Academy of Pediatrics. <http://pediatrics.aappublications.org/cgi/content/full/112/3/691>

## **7. Advocacy**

Will the Real Professional Please Stand?

Advice for doctors, nurses, teachers, therapists, administrators and other professionals meeting with parents of special needs children. By: Pat Linkhorn. Comeunity: Special Needs. Parenting Support for Your Unique Family. <http://www.comeunity.com/disability/advocacy-professional.html>

## **8. Record Keeping**

Record Keeping. Family Voices of Colorado.

[http://www.familyvoicesco.org/record\\_keeping.htm](http://www.familyvoicesco.org/record_keeping.htm)

## **9. Legal Information**

HIPAA Guide for Parents and Patients. About.com: Pediatrics. From "About, Inc.", A part of the New York Times Co.

[http://pediatrics.about.com/cs/pediatrics101/a/hipaa\\_guide.htm](http://pediatrics.about.com/cs/pediatrics101/a/hipaa_guide.htm)

## **10. Provider Issues**

An innovative program uses theater training to instill "clinical empathy". By Sandra G. Boodman. The Washington Post. From Newsday.com.

[http://www.newsday.com/news/health/ny-hscov5242352jun05\\_0,2784855.print.story?coll=ny-health-print](http://www.newsday.com/news/health/ny-hscov5242352jun05_0,2784855.print.story?coll=ny-health-print)

## **11. Other Links and Information**

### **Doug Whispers**

A forum for those who care about the disabled can voice their concerns, propose solutions and advocate against the denial of services for our least capable citizens.

<http://web.mac.com/dward7097/iWeb/Doug%20Whispers/Blog/Blog.html>

### **101 Things to Do When There's Nothing to Do**

Terri Mauro. About.com: Parenting Special Needs. From "About, Inc.", A part of the New York Times Co. <http://specialchildren.about.com/od/behaviorstrategies/a/timewasters.htm?nl=1>

### **Travel with Children with Special Needs.**

About.com: Parenting Special Needs. From "About, Inc.", A part of the New York Times Co.

<http://specialchildren.about.com/od/travelwithspecialneeds/>

Have you found valuable links you would like to share? Please email them to Wendy Ward, Parent Educator, ECAC, NCF2FHIC at [hic@ecacmail.org](mailto: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 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.

