

North Carolina Family to Family
Health Information Center's
"The Beacon"

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

E-letter March 2007

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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 care needs.

Each month we will address at least ten different subject areas by providing valuable website links. We hope that you will find this information helpful!

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

2007 Summer Camp Directory

A Resource Guide for Families in NC with Children Who Have Special Needs:

<http://www.fsnc.org/camps/start.asp>

2. Transition

Adolescent autonomy checklist:

cincinnatichildrens.org/NR/rdonlyres/.../0/transitionchecklist.pdf

3. Monthly Health Topic: Nutrition

For nutrition information including weight management, shopping, cooking, meal planning and even food assistance programs see:

<http://www.nutrition.gov/index.php?mode=homepage>

4. Disaster Preparedness/Emergency Planning

Preparing for Disaster for People with Disabilities and other Special Needs:

http://www.fema.gov/pdf/library/pfd_all.pdf

5. Financial Concerns/Insurance Issues

Unique opportunity! Grant funds available to assist FAMILIES with the cost of medical services not fully covered by commercial insurance plans. Up to \$5,000 may go to speech therapy, physical therapy, medical equipment, braces, glasses, dental treatments etc.

Certain eligibility requirements apply. See if you qualify: <http://www.uhccf.org/>

6. Parent/Professional Collaboration- Medical Home

Center for Medical Home Improvement:

<http://www.medicalhomeimprovement.org/>

7. Advocacy

Talking to your child's physician:

<http://www.partnershipforparents.org/guide/item/37>

8. Record Keeping

This resource is a guide to help families develop a future plan for their sons or daughters with cognitive, intellectual or developmental disabilities and provide personal, financial, and legal protections for these individuals after the parents either die or can no longer provide care or support:

<http://www.thearc.org/publications/futureplanninghandbook.doc>

9. Legal Information

Are Kids with Disabilities Illegally Losing Medicaid?:

<http://www.healthlaw.org/library.cfm?fa=download&resourceID=67271&print>

10. Provider Issues

Before You Pick a Therapist:

<http://specialchildren.about.com/od/therapies/bb/pickathera.htm>

11. Other Links and Information

Protect your child's privacy online:

<http://www.ftc.gov/bcp/conline/edcams/kidzprivacy/kidz.htm>

*Classified ads to connect people with Assistive Technology. "Trading Post" from Partners in Assistive Technology: <http://www.ncexchange.org/>

* Link provided by reader, Thanks Leigh!*

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

For questions on these or any health services questions please contact me via email as listed above or call (800) 962-6817 ext. 35 Wendy Ward.

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

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

We are in the editing phase of several packets of information on various topics. If you are interested in signing up for a packet, please send us an email and we will put your name on the list for distribution as soon as they are available. The packets that will be ready very soon include:

Health Consumer Rights and Related Laws (HIPAA, Cobra, FMLA etc.)

Private Insurance (Managed Care, How to appeal a denial etc.)

Public Programs 1 (Medicaid, Waiver Programs, EPSDT, SSI, Medicare)

Public Programs 2 (Title V, NC Health Choice, Public Health Dept, Free Clinics etc.)

Prescription Assistance Programs.

Support Group News:

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

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 and we will post in the next month's e-letter.

For information on workshops and training opportunities in your area check the ECAC website at www.ecac-parentcenter.org