

Family Newsletter

Volume 1, Issue 2 CENTER FOR INFANTS AND CHILDREN WITH SPECIAL NEEDS

August 2003

The Center for Infants and Children with Special Needs Now Has a Web Site!

The web site is accessed through the Cincinnati Children's Hospital Medical Center web site at www.cincinnatichildrens.org/special-needs. One of the most exciting components of the web site is the Special Needs Resource Directory.

The goal of the Resource Directory is to provide comprehensive web-based information in one convenient location for both parents and professionals. Our hope is that the Resource Directory will be beneficial in the coordination of medical and psychosocial care of children with specialized chronic health care needs. To our knowledge, this is the most complete accumulation of resources for this purpose in the Southwest Ohio area.

The directory includes information on issues related to advocacy, assistive technology, community services, dental care, education, employment, estate and future planning, financial assistance, guardianship, home health care, mental health, MR/DD services, nutrition resources, summer programming, therapies, transition issues, transportation, and wish-granting organizations.

The printed and online versions of the Resource Directory were made possible through funding from the William Nutt Fund and BCMH. We would also like to express our appreciation to the following people who helped put this project together: Elizabeth Mathison, MSW, LISW, Center for Infants and Children with Special Needs, Cincinnati Children's; Lauri Levin, MSW, LISW Manager, Technical Assistance Division of Children with Special Needs, American Academy of Pediatrics; and Juli Bick, Web Content Coordinator, Cincinnati Children's.

We are interested in your feedback. Please let us know how the Resource Directory would be more useful or user-friendly. Also, please let others know!

Call 636-3000 Before Going to the ER.

Please remember to call 636-3000 before going to the emergency room. This number operates 24 hours a day.

What is the benefit of calling? Better coordination of care. We can provide necessary information about your child in advance of your arrival and communicate directly with the emergency room physician to assist in directing the evaluation and treatment. This also enables us to better follow-up on your child's visit in a more timely and efficient manner. Experience has shown us that this provides better care for your child.

If there is a life-threatening emergency, call 911 immediately and then notify our office after your arrival to the emergency room.

Parent Support Group: PANDA

In 2002 our center created a parent support group, PANDA – Parent's Advocacy Network Demanding Action. The goal of the support group was to help our families better network with each other, set up educational programs, improve the services of our clinic, and to create a unified voice for the purpose of advocacy for children with special health care needs in our community.

Recently, this group has been inactive due to inadequate participation. While we realize that families have very little free time, we would like to take this opportunity to determine if there is any current interest in rekindling this group. Some areas of focus for the group might include advocating for day care and respite programming, and offering input into the Resource Directory.

Contact our social worker Elizabeth Mathison by email at Elizabeth.Mathison@cchmc.org or call 513-636-5473 if you have an interest in pursuing PANDA.

Quality of Life Survey

We are about to initiate a quality of life survey where we will be evaluating the frequency and significance of any loss of function in patients with Cerebral Palsy (CP) as they enter adolescence and adulthood.

We will be looking at physical activities, mental health, and social issues. We first need a small number of families to help us “fine tune” the survey. If you or your child has CP, are between the ages of 10 and 22, and are interested, please contact our nurse practitioner Gina Krakovsky by email Gina.Krakovsky@cchmc.org or call 513-636-3000.

Parent Notebooks

Most hospital and physician offices maintain medical records that are incomplete, fragmented, and often not available when needed. Emergency Room visits, hospital admissions and new physician or therapist consults usually have little or no background on your child.

The Parent Notebook was designed to help you maintain important information that is necessary for the family, other caregivers and professionals involved to provide the highest-quality care for your child.

We hope you will find the Parent Notebook helpful in:

- Organizing contacts with many different specialists and providers in the health care system.
- Recording changes and details of the illness and treatments.
- Documenting your questions, concerns or changes that you would like to make in regards to your child's care.
- Planning for your child's future, both financially and medically.

We will have Parent Notebooks available for pick-up during clinics later this month.

HIPAA – What does it mean for you?

Many of you may have heard of the new Health Insurance Portability and Accountability Act of 1996, otherwise known as HIPAA. The HIPAA privacy rule guarantees patients access to their medical record, gives patients more control over how their protected health information is used and disclosed, and provides recourse if medical privacy is violated.

What does this mean for you as a parent? In order for our office to communicate with other professionals involved in your child's care, we will need your signature on a release form.

If you have further questions about HIPAA and how it affects you, please ask!

Songs of Love: The Medicine of Music

The Songs of Love Foundation is a non-profit organization that creates original personalized songs free of charge for children and teens with chronic or life-threatening illnesses. Each song is one of a kind and never duplicated. The songs are delivered on a personalized cassette or CD with accompanying lyrics. Song examples and an online application can be obtained at www.songsoflove.org. Song examples can also be heard by calling the song line at 1-718-441-7372. The organization can be contacted by phone at 1-800-960-SONG or by email at info@songsoflove.org.



Something Missing: Day Care and Respite

Our community lacks significant programs, available in other major metropolitan areas, which would greatly improve the quality of life for children with special health care needs and their families. These programs include chronically ill day care, acute ill day care and respite centers.

The demand for these programs has increased because of cutbacks in insurance and state coverage for home care and an inadequate pool of properly trained home caregivers. Other contributing factors are the increased numbers of single-parent families and families with two working parents to meet financial needs. Facilities offering these services are needed for children with chronic medical conditions, as well as mental health and/or developmental conditions. It is not uncommon for a child to have multiple conditions that include all three of these categories.

Day care and respite services for the chronically ill are able to utilize a ratio of one nurse to every three to five patients. In addition, patient attendants who function as “nurse extenders” would be utilized, helping to alleviate the severe shortage of home caregivers that currently exists and at reduced costs.

The need for these programs will vary based on each patient’s condition and on each family’s circumstances; however, there are some basic observations that help in considering how and where these facilities might be set up. For example, chronically ill day care is mostly needed before and after school, weekends, holidays and during summer months. Offered services would include occupational, physical and speech therapies; counseling; medication administration; respiratory therapies; and feedings. Acute ill day care is mostly needed during weekday school hours, from September through June when infectious illnesses are most common. Respite care is needed year-round to cover family illnesses, special events, vacations and stressful times necessitating a family break from care. Facilities need to be conveniently located and easily accessed.

A concerted effort by patients, families, friends, as well as medical professionals will be required to make these programs happen in our community.

It’s Back-to-School Time!

In an effort to better serve you, we ask that necessary school forms be provided one to two weeks in advance of needing them. Please understand that the volume of requests filled by our staff at this time of year is large.

We are available to help with any needed forms or orders and appreciate your patience.