

The Center for Infants and Children with Special Needs Family Newsletter January 2009



From the Staff at the Center for Infants and Children with Special Needs

Our current clinic hours at Liberty are Monday afternoons, Thursday and Friday all day.
Base (Clifton) location hours are currently Tuesday afternoons.
Our office is open Monday through Friday 8:30am – 4:30pm

CCHMC Liberty
Located on the 3rd Floor
7777 Yankee Road
Liberty Township, OH 45044

CCHMC Base
Located on the 2nd Floor,
C pod
3333 Burnet Ave.
Cincinnati, Ohio 45229

Used Durable Medical Equipment

Due to the high cost of equipment and lack of coverage from some insurance companies our families run into high costs and decide against products. We have found that companies like Second Home and RE-Uzit Medical save families from these financial hardships. Both non-profit organizations offer slightly used equipment free or for a small cost. Both companies go the extra mile locating a product that may not be in stock. Families can also donate equipment not being used in the home.

Definitely worth the call!

Child Wellness Fair's Second Home Phone: 513.943.1900
PO Box 54478
Cincinnati, Ohio 45254



Re-Uzit Medical Phone: 859.322.8595
2040 Madison Ave.
Covington, KY 41014

Update on Incoming Phone Calls



Please be aware we are short staffed at the moment and we are using our answering service more regularly. Just because you get our voice recording does not mean staff is not in the office during regular business hours listed above. (Fridays in particular since Della is not here)

When getting the answering service please DO NOT hang up, leave us a message so that staff can assist you with any problems or concerns.

We appreciate your patience.



Unexpected High Bill for Services ...call us!

Our practice is committed to advocating for the needs of all of our families. While we believe the work we do is valuable and deserves compensation, we do not wish any of our families to be burdened with unexpectedly high medical bills. If you receive a bill that you were not expecting, or which would be a burden to pay, please call our office to discuss it. Often times, the matter can be resolved by a simple phone call. We can help advocate with insurances and BCMH too. Other times, we can connect you with hospital or community resources to assist you with your bills. Please do not feel that you have to do it alone.

We want to help, call our Social Workers;
Molly or Suzan @ 636-3000.

New updates and information can be found on our Special Needs Resource Directory:

<http://www.cincinnatichildrens.org/special-needs>

Find local condition-specific meetings on updated
[2009 Community Calendar](#).

Find applications for many financial assistance programs
on the [Ohio Department of Job and Family Services web site](#).

It is important to start planning early for summer programs, and sports programs as many have limited availability. The Center for Infants and Children with Special Needs at Cincinnati Children's Hospital Medical Center offers resources to patients and families to help in the planning process. Visit our website and click on [Recreation](#). Here you will find several online camp directories, sport organizations and information about how to obtain printed directories. We also recommend consulting with your MRDD worker about available opportunities.

We like to update our Special Needs Resource Directory regularly please provide us feedback on topics, ways to expand topics and topics that may be helpful to add that we have overlooked. Your help makes us a success.

Tips for the New Year in the field of financial planning for kids with special needs on how to get started:

1) **Establish legal guardianship.** After a child reaches the age of 18, he/she is considered an adult. But some kids may still need a guardian. One test includes asking whether or not your child would be able to make or understand a medical procedure and long-term affects. If the child should not be held responsible for such a decision, then he needs to have a legal guardian, or else the contract would be binding.

2) **Describe your child in writing.** Start by writing down a "mini-biography" of your child/ren that could be given to any future guardians or caretakers. It should include medical information like allergies but also personal preferences, goals, and details about friends.

3) **Protect your child's eligibility for public benefits.** Medical care can be so expensive that even relatively wealthy families may need to rely on Medicaid and Social Security income. Because having more than \$2,000 in assets threatens that eligibility, you want to make sure that if your child is going to receive any money, that it's in a special-needs trust so it doesn't disqualify them. A lawyer or financial professional can help establish a special-needs trust, which doesn't count against the \$2,000 limit. Money left to the child through a will should be directed into this trust. See our special needs resource directory under estate and future planning for lawyers in your area.

4) **Consider insurance policies.** Life insurance that pays out upon the death of the second parent—often called "last to die" policies—can help parents ensure their child has enough money after they both die without straining their budgets too much beforehand.

5) **Avoid common family-related mistakes.** A lot of parents say, "How about if I give money to a relative?" but doing so is a mistake, because not only is the relative not legally bound to spend that money on your child, but a creditor or divorce settlement could take it. Family members and friends planning to leave money to a child with special needs should also be encouraged to do so through a special-needs trust instead of leaving money directly to the child, which could interfere with benefits eligibility. Grandparents may even want to have their wills looked over by an attorney to make sure any gifts don't threaten that eligibility.

US News Report; Jan 2009 excerpt

Observation & Opinions wanted on Disaster Planning



In September of 2008 we faced a “hurricane like” disaster in our area due to hurricane Ike. This brought attention to significant deficiencies in our community’s ability to provide disaster support, especially for those with disabilities. Resources were available but we did not anticipate the difficulties people would have finding and accessing them. Our clinic encourages families to have a Disaster Plan; we notify local Fire and Paramedic Services of the patient’s condition and special needs, and we send a letter to the Utility Company requesting that they prioritize the patient’s home in the event that services are interrupted. Yet none of these actions really helped in this disaster. Large areas had no power and thus prioritizing an individual house was of no value. Most of the children and adults with special needs were medically stable so Paramedics were not needed, but they could not plug in their equipment or charge their batteries. Some had generators but there were only a few gas stations open and they quickly ran out of gas. Patient transport required 1) gas in the tank, 2) the ability to get around fallen trees, and 3) finding a location with power. Running out of medications or supplies was a mini disaster in itself as homecare companies, pharmacies, groceries and most hardware stores were closed. Land lines and cell phones were not working in many areas so families had difficulty calling for help, and health professionals were unable to check on some patients except by driving to their homes.

It was as if we had no resources at all!

So, what do we need?

Certain basic services need to be prioritized and made operational ASAP such as gas stations, public transportation, pharmacies/homecare companies, groceries, and hardware stores – at least one of each for a given neighborhood.

Homes with technology dependent patients need to be prioritized with utility companies. Generators should be available for those households as well as for vital businesses.

Local community “havens” such as schools, YMCAs, warehouses, or churches need to be designated where technology dependent patients can be transported to “plug in” equipment. They would be expected to bring their own equipment, supplies, medications, and caregivers. Backup caregivers including aids, nurses and respiratory therapists could be assigned to these “havens” to provide additional assistance.

Communication options such as short wave and CB need to be available as land lines and cell phones may not work.



Another way our clinic advocates is making sure the community hears your concerns. We are asking for feedback on what you and your family experienced and how you managed during this disaster.

We all encountered challenges during this disaster but those with complex medical issues faced more than imaginable.

In 2009, Dr. Levin is attending a committee with professionals, families, and representatives of large community resource organizations to figure out how this great community can fix these problems...and we need your help.

Please email us with your input at specialneeds@cchmc.org or call us at 636-3000