The Center for Infants and Children with Special Needs

Family Newsletter
July 2009

2009 Golf Outing

benefiting

The Center for Infants and Children with Special Needs

The 6th annual Golf Outing benefiting the Center for Infants and Children with Special Needs at Cincinnati Children's will take place on
Monday, August 31, 2009, at the Wetherington Golf and Country Club in West Chester, Ohio.
Lunch and registration will begin at 11 am with a 1 pm shotgun start.
The cost is $200 for an individual golfer or $800 for a foursome.
We are looking for hole sponsorships and silent auction items. Over the last five years, the Golf Outing benefiting the Center for Infants and Children with Special Needs raised more than $235,000, enabling the center to care for more than 200 additional patients and expand participation at state and community levels. We are always appreciative of silent auction donations. The auction is a crucial part of the golf outing and your donation will help ensure its success.
Please visit www.cincinnatichildrens.org/special-needs to upload a gift-in-kind form.
If you or anyone you know would like informational packets mailed with more details please let us know.

And especially if you would like to join us, be a volunteer or know someone who wants to be a part of the fun please contact our office at 513-636-3000.

If You Missed Our Special Needs Community Resource Information Fair……You're in Luck Your Next Chance to Attend is in November!!

This year's event was BIGGER and BETTER. Families met with and learned about valuable resources for children with special needs in our community from agencies like: R.S.V.P. Home Care, Interim Health, Paragon Financial, Conductive Learning Center of Greater Cincinnati, Hamilton County MRDD, Special Needs Resource Directory, Family Resource Center, MC Mobility, The Perlman Center… AND MANY MORE!
Our Next fair is scheduled for **November 30, 2009 from 10am-3pm** in the auditorium across from the cafeteria at our main campus. Mark Your Calendars!

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

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

- ***Getting Started After a New Diagnosis*;** Suggestions on where to begin finding resources when your child has special health care needs.

- Caregivers take time for yourself and have time to do the things you enjoy new additional resources are now on our ***Daycare and Respite*** page.

- Not all children with chronic debilitating illnesses can be managed at home and therefore require care in some type of long-term, or extended care, facility. The ***Residential Options*** link has new resources for families to consider when making this hard decision.

- Multiple financial assistance programs are available for the families of children with special needs, on a local, state and national level. Take time to look into these resources your child may be eligible for on our ***Financial Assistance*** page.

- There are sometimes inexpensive and creative solutions to improve accessibility in your home. Our ***Housing and Home Modifications*** page has links to changes to consider when thinking about your child's needs.

- Children with significant chronic illness often have extra nutritional requirements based on their particular illness or disability check out some of our new resources on the ***Food and Nutrition Resources*** link.

- Find local condition-specific meetings on updated ***Community Calendar.***

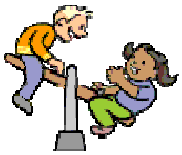
We Need Your Email Address

We are again trying to collect all of our families email addresses. We would like to have email addresses in order to send out our special needs directory newsletter, as well as periodic important information throughout the year. Your email address will be kept confidential and only used by our staff. Email will not be used for medical care issues. If you would be willing to be put on our list, please email Della at dellasmith-sokol@cchmc.org or ava.fried@cchmc.org . Thanks in advance for your cooperation.

Summer Recreation is MORE than just Camps

To find other fun activities for your special-needs child in your community, whether it be sports, horse back riding, adaptive playgrounds, or resources for helping plan and create a safe, integrated playground at your home we have it on the Special Needs Resource Directory.

For more information or to find an activity to fits your child's interest, development, and needs visit our website at www.cincinnatichildrens.org/special-needs and click on Recreation and Camps.



We are excited to announce that on June 29, 2009 the Special Needs Department went LIVE on EPIC.

The Epic scheduling system is the first step to the future of electronic medical record keeping for us when setting up appointments. We look forward to the features it offers for patients, such as itineraries' mailed to the parents prior to appointment giving lots of needed information about the appointment. Please be patient when scheduling appointments, as we get use to the system.

Patient Communication Requests

Request #1- We are asking for at least 1 week for all faxed forms and 2 weeks due to the mail system for any forms being mailed to our office. These forms include School Forms, FMLA forms, Guardianship Paperwork, Plans of Care, and anything else that requires review and a signature of a physician.

Request #2- Please make sure school forms are sent in and physicals are done early! Parents if you could fill the 1st page or as much information as possible and make sure to give us directions for sending these forms back to you or the school this can expedite the process and will make it much easier for our nurses.

Request #3- We are asking families that require any refills, especially monthly refills, of their medications that we are given at least 24 hour notice before they need to be picked up. Remember we are only in Liberty on Monday, Thursday and Friday afternoons for prescription drop off from the office. PLEASE refill all medications during business hours (M-F) unless urgent.

Request #4- Please do not Email urgent matters, as it can take 2 business days to respond. Please call the office (636-3000) with urgent matters. If you do not get a response to your email in 2 business days please call to speak to someone directly.

Thank you in advance for your understanding.

Welcome New Editions

*Molly Sicking, one of our Social Workers, gave birth to a healthy baby girl on Saturday June 27th, Megan Marie Sicking.

*Katy Lyons joined Special Needs in May as an administrative assistant. Many of you probably have talked to her on the phone when scheduling appointments!!

*Jennifer Thornton, new social worker in the Family Resource Center. Please tell your friends and family, who are not patients, she can help with resources at the hospital and in the community. Contact the Family Resource Center at 636-7606.

*And please help us welcome; Emily Boone a nurse practitioner joining our team this month.

Congrats on Your Success

Here in Special Needs we want to congratulate all our patients who have graduated from schools and programs and are transitioning on to new endeavors.

As Dr. Seuss says

"The more that you read, the more things you will know. The more that you learn, the more places you'll go."

Good Luck

Act as a Resource and Support to Your Aging Young Adult

- With teens, check eligibility for SSI the month he/she turns 18. At age 18, the teen's financial resources are evaluated, not parents/guardians'.
- If on an IEP, you may want to encourage young adult to stay in a school program until age 21.
- If young adult is on an IEP, continue to encourage participation in IEP meeting and transition planning with IEP team, including employment and adult life activities.
- Encourage young adult to participate in support groups and/or organizations relevant to his/her special health care need.
- Finalize health care coverage with young adult.
- For young adult attending college, encourage continued contact with disabled student services as needed for accommodations.
- Encourage young adult to investigate services provided by Bureau of Vocational Rehabilitation (BVR) in Ohio if he/she has not already done so.

More info can be found on our Special Needs Resource Directory and click on Education & Transition Planning.
www.cincinnatichildrens.org/special-needs