

The Center for Infants and Children with Special Needs

Family Newsletter

April 2009



Upcoming Events and Fundraisers

Mark Your Calendars....

**Please join us for the
Community Resource**

Information Fair

hosted by

**The Center for Infants and
Children with Special Needs &
Special Needs Resource Directory**

When: Monday June 1st, 2009
10:00 AM to 3:00 PM

Where: Cincinnati Children's Hospital
3333 Burnet Ave. Cincinnati,
Ohio 45229-3039
Sabin Auditorium
(outside cafeteria)

This year's event will be BIGGER and BETTER. Learn about valuable resources for children with special needs in our community from agencies like: R.S.V.P., Max's House (Day Care), Family Resource Center, MC Mobility, Paragon Financial Group, Maxim Health Care, ARC, The Perlman Center... AND MANY MORE!

If you can't make this June event we will be having another fair on November 30, 2009.

Check us out on the web at
<http://www.cincinnatichildrens.org/special-needs>

2009 Golf Outing Benefits 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.

"Being involved with the Golf Outing is a great way for me to give back to Cincinnati Children's," says golf committee chair, Sandy Foley whose son, Jeffrey, has been a patient at the Center for Infants and Children with Special Needs since birth. "I am so grateful that we do not have to travel far for Jeffrey to receive expert care. The funds from this Golf Outing are helping to expand the services that the Center provides to patients and families."

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.

Over the last five years, the Golf Outing has raised nearly \$235,000 enabling the center to care for more than 200 additional patients and expand participation at state and community levels.

We are looking for sponsorships and silent auction items. Please let us know if you or anyone you know would like informational packets mailed with more details.

If you would like to be a volunteer or know someone who wants to be a part of the fun please contact our office at 513-636-3000.



More Events and News!

Cincinnati Children's Hospital's Aaron W. Perlman Center along with United Cerebral Palsy of Greater Cincinnati will be hosting the 2nd Annual Conference on Cerebral Palsy, titled "Live Your Dream".

The conference will be held on Saturday, April 25th, 2009.

Please visit our Special Needs Resource Directory booth during the event & Say hi to Ava!!

This will be an informative and inspiring event for parents and others whose lives are touched by cerebral palsy. Registration materials are available online at www.cincinnatichildrens.org/perlman and www.ucp-cincinnati-org.

If you have any questions regarding the conference you can call 513-636-4601.



Cincinnati Walks for Kids: Every Gift Matters

It's not too early to start thinking about forming your team for the 2009 Cincinnati Walks for Kids. The Center for Infants and Children with Special Needs brought in the 3rd highest amount within CCHMC and we couldn't have done it without you. We are the smallest department and yet were the 3rd highest recipient. We are optimistic this fall we will raise even more money, with hopes you can join us! Participants in the Walk may designate which of the medical center's departments or programs they would like to receive their contributions, and 100 percent of the money raised goes directly to the specific area indicated by the donor.

More than 6,000 participants formed over 400 teams for Cincinnati Walks for Kids last October. Employees from departments throughout the hospital rallied together with friends, family and other coworkers to join them. As the teams grew in size, so did the number of gifts and dollars raised to benefit Cincinnati Children's.

Since the Walk, 10,000 individual gifts have been received and carefully recorded. The 10 areas receiving the most donations from the 2008 walk are:

1. Hematology/Oncology	\$66,731.33
2. The Heart Institute	\$24,076.57
3. The Center for Infants and Children With Special Needs	\$21,720.18
4. Child Life	\$19,672.35
5. RCNIC	\$16,329.55
6. Max Paul Global Integrative Pediatric Brain Tumor Program	\$13,411.37
7. Gastroenterology	\$12,901.00
8. Audiology	\$11,788.00

Start Planning for Summer Programs & Camps Now

April is not too early to plan for summer 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. When searching for a summer program for your child, it is important to find a program that focuses on your child's interests and can meet your child's developmental and medical needs. Specialty programming that serves children with specific medical conditions or diagnoses and traditional programming with integration are both available. To find out more information or to find an activity to fits your child's needs visit our website at www.cincinnatichildrens.org/special-needs and click on Recreation. Here you will find several online camp directories and information about how to obtain printed materials. If possible we also recommend consulting with your MRDD worker about available opportunities.



Please keep in mind that all medical forms needed for these programs must be turned into the office 3 weeks in advance to give our staff time to complete and send them back. Also financial grants for any recreational opportunities will need to be completed now!

Check your deadlines!!



New Nurse Joins Special Needs Team



Please welcome LouAnn Smith RN, BSN. She has been at CCHMC for 5 years and was previously staffed in the RCNIC with all our babies. She is working with us full-time and going to school for her master's degree. LouAnn is married with 4 children and 2 dogs.

Make sure to say hi, but don't scare her off!



Not too Late to Get Extended School Year Services

Extended school year (ESY) services are defined in Section 300.309 of the IDEA legislation under "Subpart C Free Appropriate Public Education."

ESY services are services beyond the regular school year that are necessary for a student with a disability to make educational progress during the school year.

Services must be individualized to meet specific objectives in the Individualized Education Plan (IEP) and must be at no cost to the parents of the child. EYS services should be considered yearly by the IEP team.

Some important factors to remember and consider in determining whether ESY services are appropriate for your child are:

- Issue of regression with substantial loss and/or ability to recover a loss of critical life skills
- Nature & severity of child's disability
- Areas of learning that are crucial to the attainment of self-sufficiency and independence
- Child's progress, both behavioral and physical
- Areas of the child's curriculum needing continuous attention

Our office can assist you in the process of securing ESY services by providing a letter for support and recommendation to the IEP team in advance of the IEP meeting. For more detailed information on ESY services check out the on-line Special Needs Resource Directory (www.cincinnatichildrens.org/special-needs) under the Education tab.

What is a Special Care Planner?

Financial professionals with specialized training in helping people with special needs and their life care plan who work by a set of core values: *integrity, honesty, teamwork, and respect.*

Special Care Planners work with you and your professional advisors to review your financial situation and offer options that will best benefit you, your loved ones, and your entire family.

What is the role of a Financial Professional?

- Provide a financial needs analysis. Understand the financial needs of the individual and how the social, medical and legal needs impact their life care plan.
- Coordinate financial strategies with the attorney and other professionals on the team.
- Offer financial options that make the most sense based on your goals and needs.
- Work with an attorney to help you ensure that benefits such as Medicaid or Supplemental Security Income won't unintentionally be jeopardized.
- Help the parent/caregiver maintain the lifestyle of the special needs individual.

10 Comprehensive Life Care Planning Steps

- Address Primary Issues
- Create a Life Care Plan Vision
- Choose Guardian(s) & Conservator(s)
- Identify Financial Resources
- Determine Life Care Plan Costs
- Prepare Letter of Intent
- Prepare Will(s)
- Establish Special Needs Trust
- Hold Family Meeting
- Review Life Care Plan Annually

Top 10 Questions?

- What is important to me?
- Who depends on me today and who might in the future?
- Who is providing for my dependents now?
- What risks have I overlooked or not considered?
- Are my plans flexible enough?
- What if I already have a plan?
- What is the downside of putting this off?
- What am I waiting for – how do I get started?
- Where do I go for resources and understanding?
- How do I pick the right professionals to work with?

Please read information provided on our Special Needs Resource Directory Website (estate planning) or feel free to contact our friends at Paragon Financial who are Special Care Planners. Scott Silver or Chris Collier have answers to these questions and more.....Scott Silver 513.698.1341 shsilver@finsvcs.com or Chris Collier, CLU 513.698.1333 ccollier@finsvcs.com