

The Center for Infants and Children with Special Needs Family Newsletter Spring Edition 2011



Did you miss our Remarkable Families Symposium on April 8th, 2011 Building Resiliency in Families Raising Children with Special Needs?

This year the Remarkable Families Symposium was proudly cosponsored by [Cincinnati Children's Center for Infants and Children with Special Needs](#) and [Xavier University](#).

The Remarkable Families Symposium presents the opportunity for families raising children with special needs to access resources, learn of new programs and to network with other families in order to not only survive but to thrive! CCHMC's very own Dr. Sorter was our Keynote speaker and did a wonderful job presenting "Stories of Resilience: Child and Family Success When Faced With Mental Illness". Additionally, there were over 60 vendors and service agencies there to answer questions and present breakout educational sessions.

The annual award began because of Pat and Dolores Diangelo, who were trailblazers in the world of disability rights, inclusion and resiliency. Their example of dedicated parenting, family, and resiliency should serve as a model for all families. This year's award was presented to Shelly and Marc Hingsbergen at the symposium to honor them for their remarkable resiliency and how have learned to thrive in their family life. Shelly has dedicated her life into finding a cure for Mitochondrial Disease with the support of her family, friends and her support network. Mitochondrial Support Group of Cinti meets monthly at CCHMC. Congrats!

For more information www.xavier.edu/familyresiliency
or on [Facebook](#), find us under "Remarkable Families."
Information on next year's Symposium coming soon....





Take Action To Protect Medicaid

Call your Senators today and ask them to speak up
and support us in this fight.
How Important is Medicaid to Your Child?

Get involved in the fight to preserve it

Please call:

- U.S. Senator Rob Portman (R-OH)
- U.S. Senator Sherrod Brown (D-OH)

Call Here: (202) 224-3353

Washington, D.C. office of U.S. Senator Rob
Portman (please call between 9am & 5pm)

Here are some examples the Arc suggests of what to say:

- Medicaid is a lifeline for people with chronic health needs and disabilities and we need you to be our champion;
- Please oppose block grants or caps for Medicaid that would hurt programs that help people with intellectual and developmental disabilities live in the community; and
- Don't risk the health and safety of people with disabilities by slashing funding for Medicaid.

As many of you are aware and have been hearing in the media, the state of Ohio faces a \$8 billion budget shortfall. At Cincinnati Children's we understand there will be cuts and Medicaid, the program that covers the most vulnerable children in our community, will not be exempt.

Here at Special Needs our number one priority is to save, protect and enhance the lives of children by ensuring access to high quality health care. Until the Federal Government fully addresses Medicaid's inadequate payment for children's health care services, including pediatric specialty care, our nation will not experience significant improvement in children's access to care.

For more information: www.thearc.org

Advocacy & Action Section



SPECIAL CONNECTIONS Family-to-Family New Online Community

We encourage all our patients and families to join the pilot for CCHMC's new Family to Family online webpage.

What is Family to Family?

Family-to-Family is a program at Cincinnati Children's that helps provide support to families by helping connect you with other parents or caregivers who have experienced parenting a child with special health care needs. Family-to-Family provides a means for families to connect one-on-one by phone or email or connect online with this new community. We believe that another parent opinion or advice can be as beneficial as ours.

How do I sign up?

To sign up, follow these simple steps:

- Go to <http://www.inspire.com> and click "Join" to create your personal account.
- Go to the "Search Inspire" box in the upper right-hand corner and type "Cincinnati Children's."
- Click "Join this Group."

Once you've signed up and joined the Cincinnati Children's Online Community group, you can post a questions, read posts by other families or start a journal. One of the most meaningful sources of support can be another parent or caregiver who has experienced parenting a child with special health care needs. We encourage you to join and talk to each other!



Join Us
2011 Golf Outing Benefiting
the Center for Infants and
Children with Special Needs
August 29, 2011



On August 29, 2011, friends and supporters of the Center for Infants and Children with Special Needs at Cincinnati Children's will meet at Wetherington Golf and Country Club for the 2011 Golf Outing.

Over the last seven years, the Golf Outing has raised more than \$320,000, enabling the center to care for more than 250 additional patients and expand participation at state and community levels. We are looking for sponsorships for Golf and Silent Auction items. If you or your company can afford to golf, donate a gift basket or item please let us know.

We will mail informational packets with more details on playing golf or tax donation forms if you are interested supporting our outing.

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



Visit Our Special Needs Resource KIOSK!!



Keep your eyes open for our new Patient and Family Resources kiosk located near the Welcome Desk by the Location B parking elevators. The touchscreen computer will connect you directly to Special Needs Resource Directory, created by the Center for Infants and Children with Special Needs. You will find information and quick links to local, regional and national resources to help you:

- Locate information on specific disabilities
- Identify strategies to help you advocate for your child
- Develop community connections for ongoing support
- Overcome barriers to access health care resources

According to Dr. Levin, "Many families are not aware of the thousands of useful resources available on Cincinnati Children's website and/or don't have immediate access to a computer. So now we have a Special Needs Resource Directory kiosk to introduce families to this Directory and help them access needed information that may help them better care for their child with special healthcare needs."



The kiosk also has a variety of informational brochures, flyers and announcements of interest to families.