

# Keeping in T.O.U.C.H.

FALL/WINTER 2010

The Organization for Understanding Children's Hearts

The mission of T.O.U.C.H. is to empower families, children and adults with congenital heart defects. We believe that through emotional support, education, information sharing and public awareness we can make a difference. T.O.U.C.H. is supported by and affiliated with The Children's Hospital of Illinois at OSF Saint Francis Medical Center and The University of Illinois College of Medicine. [www.TOUCHHEARTS.org](http://www.TOUCHHEARTS.org)



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## 2010 T.O.U.C.H. Picnic 24th Annual Event is the Best Yet!

A huge THANK YOU to everyone who came out to this year's T.O.U.C.H. Picnic held at Wildlife Prairie State Park on Sunday, September 19th. More than 750 attendees, children with congenital heart defects and their families, gathered as a community of people touched by the Congenital Heart Center here in Peoria.

As read in the Journal Star, "Aside from demonstrating how active the children are, the picnic provides a good opportunity for doctors to get to see their patients outside the hospital setting and vice versa," Dr. Albers said.

"For once they are going to get to see a doctor and not have something bad happen to them," he said. Albers' colleague, Dr. Priti Patel, who was attending her first picnic for the organization, commonly called T.O.U.C.H., was excited to see the children. "It's nice to see them when they're not sick," she said. "It's different to see them here, where they don't even recognize you."

Special thanks to the T.O.U.C.H. Board, and especially Gail Eaton, for coordinating this annual event. Also, a special thanks to all our in-kind donors and volunteers.



As members of the T.O.U.C.H. Board and fellow parents of children with congenital heart defects, we encourage you to contact us with your concerns, questions and ideas. No input is insignificant when your child is involved.

# DSCC CORE Program

The DSCC (Division of Specialized Care for Children) CORE program is available to all Illinois residents whose child has an eligible heart condition. It is one of the last assistance programs of its kind available through the state of Illinois. Many families are unaware of the offerings that this program supports, particularly case coordination and access to family support resources. If you have any questions feel free to call me at 309-655-3727. Sarah Kelly, LCSW, PICU

## **What conditions are eligible for Core Program services?**

A child must have, or be suspected of having, a treatable chronic medical condition in one of the following categories to be "medically eligible" for services:

- Orthopedic conditions (bone, muscle, joint disease)
- Heart defects
- Hearing loss
- Neurological conditions (nerve, brain, spinal cord)
- Certain birth defects
- Disfiguring defects such as cleft lip, cleft palate, and severe burn scars
- Speech conditions which need medical/dental treatment
- Certain chronic disorders such as Hemophilia and Cystic Fibrosis
- Certain inborn metabolic problems including Phenylketonuria (PKU) and Galactosemia
- Eye impairments including cataracts, glaucoma, strabismus and certain retinal conditions - excluding isolated refractive errors
- Urinary system impairments (kidney, ureter, bladder)

DSCC only assists with specialized medical care and services. DSCC cannot provide help for acute childhood illnesses, routine dental or well-child care, immunizations or school physical examinations.

## **How does DSCC help eligible children?**

**Care Coordination** - Care coordination services are available at no cost to any family whose child has an eligible medical condition. This includes helping families and care providers develop a plan of care, coordinating services, linking families with other resources and programs, parent-to-parent support, information provision, helping families advocate for their child and making the best use of insurance and other payment sources.

**Diagnosis** - DSCC offers services that include a no-cost medical evaluation, regardless of family income, when an eligible condition is suspected.

On the website there is information about how to contact your nearest regional office as well as application forms and other information.

***Continued on next page.***

# DSCC CORE Program– Continued

**Treatment** - DSCC can assist with payment for specialized medical treatment such as surgeries, medications, therapy, wheelchairs, hearing aids and other medical services for families who are financially eligible, based upon income and family size, when needed to treat an eligible condition.

## **Who is financially eligible?**

Illinois families whose child is found to have an eligible medical condition may apply for financial assistance. Financial eligibility is determined by the family's size and total annual income. For more specific information about Core program financial assistance, contact the DSCC [Regional Office](#) that serves your community.

## **What about health insurance or KidCare benefits?**

DSCC coordinates with other insurance benefits. If you have health insurance or are eligible for KidCare, you must use those benefits before DSCC can provide financial assistance. If your benefit plan does not cover the care your child needs, or if you have no insurance, DSCC can assist you.

Taken from DSCC website [http://internet.dsccl.uic.edu/dscclroot/core\\_prog.asp](http://internet.dsccl.uic.edu/dscclroot/core_prog.asp)

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## **Adult Congenital Heart Association**

Is your heart child approaching adulthood? Adulthood brings a new set of challenges for those living with congenital heart issues. The Adult Congenital Heart Association can help you and your child navigate through some of those challenges. The A.C.H.A. provides helpful information and offers free educational webinars presented by professionals. To visit the A.C.H.A. website, follow the link on the T.O.U.C.H. website at [www.touchhearts.org](http://www.touchhearts.org).

## **The Congenital Heart Information Network**

As parents of heart children, we are often seeking the latest information pertaining to congenital heart conditions. A wealth of information is accessible through the Internet. Unfortunately, every website or source is not completely reliable and can lead to misguided worries or reassurances. T.O.U.C.H. is an affiliate member of The Congenital Heart Information Network, which is a source of invaluable assistance for families like ours. C.H.I.N. is a national organization that provides reliable information, support services, financial assistance and resources to families of children with congenital heart defects and acquired heart disease, adults with congenital heart defects, and the professionals who work with them. If you are looking for a reliable website to help answer your questions, we recommend visiting [www.tchin.org](http://www.tchin.org).

# American Heart Association “Start” Heart Walk

This year more than one million walkers will participate in nearly 350 American Heart Association events. On Saturday, October 9<sup>th</sup>, we were among that one million! The American Heart Association “Start” Heart Walk was held at Laura Bradley Park where our children, nurses, physicians and all their families came together to celebrate, honor and memorialize all of our children and adults born with congenital heart defects. Our own Dr. David Chan, Medical Director of the Congenital Heart Center, gave the opening speech and was followed by Cathy Rathjen, mother of Kennedy Rathjen. Cathy spoke from her heart about what it means to have a child with a congenital heart defect and how thankful she is for our medical community and the American Heart Association.

The American Heart Association is actively working to meet the needs of children and adults with congenital heart defects, funding at least \$15 million annually in research grants that directly relate to prenatal cardiovascular system development and to congenital heart disease.

If you weren't able to join us this year, we hope that you will consider joining us next year as we continue our mission to empower families, children and adults with congenital and acquired heart defects.



## READERS...send us your ideas!

We encourage your comments and input. Please contact us to share your story or if you have a question or concern you feel should be addressed in an upcoming issue of *Keeping in T.O.U.C.H.*

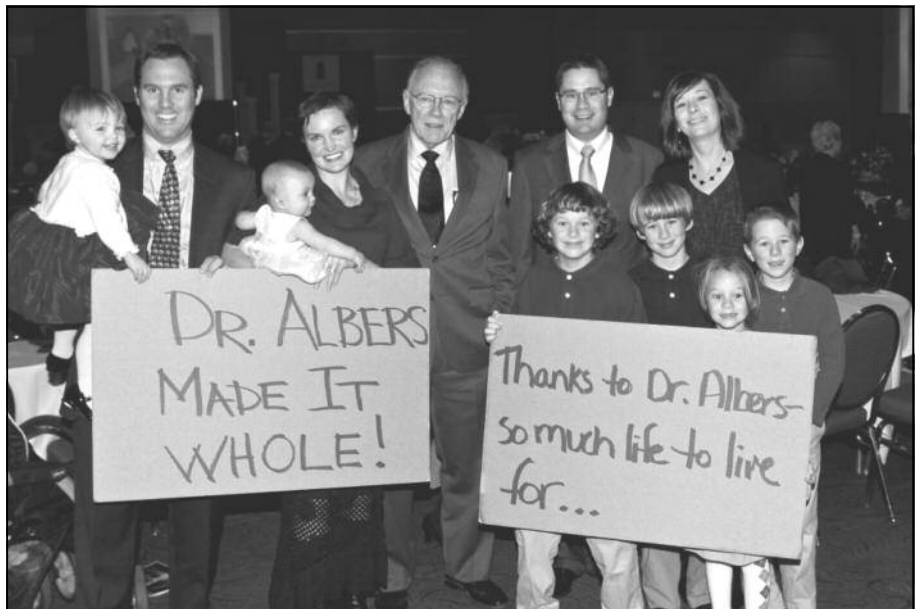
We look forward to hearing from you! Julie Witte

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# DR. WILLIAM ALBERS HONORED as a Pillar of Distinction

On November 13th, Easter Seals honored the University of Illinois College of Medicine at Peoria (UICOMP) for the 20th Annual Tribute Dinner. UICOMP is celebrating its 40th anniversary and more than 830 gathered to recognize the institutions many and varied contributions to the Peoria medical community. As a key part of the evening, five Pillars of Distinction were honored for their part in establishing the university here in Peoria. These are individuals who, from the beginning, played in integral role in establishing the college and then significantly advancing its mission of outstanding medical education, research, and patient care. They are Dr. Dean Bordeaux, Dr. Patrick Elwood, Mayor Dick Carver, Dr. Donald Rager and our own, Dr. William Albers.

Dr. Albers was honored for serving as Dean of UICOMP, being a pioneer in pediatric cardiology for our region and serving as Chair of Pediatrics. As a part of the evening, two special guests joined the program to thank Dr. Albers for his life saving work. Tara Shane and Adam Garey along with their families attended to represent all of our heart families. **Congratulations and thank you, Dr. Albers!**



## HELP PASS the Congenital Heart Futures Act!

Senator Dick Durbin recently led the bipartisan charge to introduce the [Congenital Heart Futures Act](#) in both houses of Congress. Up until now there has been virtually no federal investment to address the research and education needs of the 1.8 million Americans now living with congenital heart disease. What can we, as families touched by congenital heart disease, do to help advance this groundbreaking legislation? Like any piece of legislation, the Congenital Heart Futures Act has to get majority support in both the House and Senate in order to be passed. Please email your Senators and Congressmen today to ask them to become a co-sponsor of this legislation. It just takes a minute—please visit [www.tchin.org](http://www.tchin.org) to join the efforts.

## Just for KIDS!

This new feature will include activities, information and features designed especially for kids.

**KIDS**– send in your favorite recipes, games or special interests!

## HAVE A HEART!

Andria Denault's 3<sup>rd</sup> grade class did a February project called "Have a Heart" where the students are encouraged to do things for others. Andria's mother Christine says, "She knew right away that she wanted to raise money for Megan's Lodge." Andria spoke to the members of her church one Sunday morning and explained T.O.U.C.H. and Meg's cabin to her congregation. After church she had a "bake sale" of homemade cookies and caramel corn and collected donations.



In addition to helping her mom bake cookies she also prepared a poster that she put pictures of the cabin on for people to see during the bake sale.

She collected donations from family members as well. As a result of her hard work and her family and friends support she presented T.O.U.C.H. with a check for \$550.00. Andria is Megan's cousin and she was only three when Meg died, so her memories are vague. Yet, her family all keep Megan's spirit alive, in so many ways. Her mother Susan says that Andria understands the importance of this lodge project and it being a part of Megan's dream. As a family, the Denault's were more than happy to work together to raise money for Meg's Lodge.

From all of our T.O.U.C.H. families and those who have experienced Megan's Lodge we would like to give a special "thank you" to Andria and her family.....there is no doubt that you "Have a Heart" .... a very special heart! Thank you!

## CHECK OUT OUR NEW SIGN IN THE CONGENITAL HEART CENTER!



# A Great Way to GIVE BACK!

## Casual For A Cause

Every Friday throughout the year, employees at Graham Health System (Canton) enjoy participating in their “Casual for a Cause” program, which was started about 2 years ago. Employees sport a more laid-back look and are seen dressed in jeans and wearing a sticker with the charity selected for that particular day.

As we know, February is “American Heart Health” month, and the perfect time of year to offer additional support for the T.O.U. C.H. Organization. Through donations collected on a Friday jean day in February, Graham Health System employees proudly donated \$366.40 to a cause SOLELY focused on understanding and caring for hearts....big (adults) and small (children).

Year after year, the T.O.U.C.H. Organization will continue to receive a donation based on the money collected during a “Casual for a Cause” day at Graham.



## THANK YOU Woodland Baptist Pre-School

We want to shout out a special “Thank You” to the Woodland Baptist Pre-School on North Allen Road, Peoria. One of their preschool students recently had open heart surgery at the Children’s Hospital of Illinois and her mother told them about T.O.U.C.H. and the support they offer to families of congenital heart patients. Another one of their students also had open heart surgery as an infant and is now three years old.

As a result on February 25<sup>th</sup> and 26<sup>th</sup> the Woodland Baptist preschoolers participated in a Hop-a-Thon to raise money for T.O.U.C.H.. An unbelievable amount of \$952.00 was raised through the generosity of their preschool families and friends.

## THANK YOU— Your generous gifts to TOUCH have TOUCHED OUR HEARTS

Andria Denault and the Denault Family

Graham Hospital Staff

The Richard Hawkins Family and Friends

Beta Sigma PHI – Laureate Beta PSI Chapter

Catherine Hatfield

Linda Hanson

Woodland Baptist Preschool

Matt and Summer Knobloch

Shelby Fawver



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## **Children's Hospital of Illinois & OSF Saint Francis Foundation CALENDAR OF FUNDRAISING EVENTS**

- November -           **Brighten a Child's Life Holiday Card Campaign sponsored by CEFCU**  
December
- December 9 - 11   **2010 Children's Hospital of Illinois Radiothon for Kids**  
                          **hosted by John Riley & 93.3 The Drive**  
Broadcasting live from the New Children's Hospital of Illinois &  
OSF Saint Francis Medical Center  
Listen live on 93.3 FM or streaming live at <http://www.933thedrive.com>.
- January 15           **Joyce Thome Benefit hosted by Jim Thome for Children's Hospital of Illinois**  
6:00 to 10:00 PM at the Peoria Civic Center Ballroom

**For more information, please contact Shauna Skowronski- Children's Hospital and  
OSF Saint Francis Foundation at (309) 566-5674.**