

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

DECEMBER 2013

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



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27TH ANNUAL T.O.U.C.H. PICNIC

The 27th annual T.O.U.C.H. picnic was attended by nearly 1,100 people on September 29 at Wildlife Prairie State Park. This event brought together children who were born with heart defects and their families. It was truly a day of celebration and reconnecting. The weather was beautiful, and children and families of all ages enjoyed train rides, crafts, games, scavenger hunts, face painting, hair and nail color, balloons, music, food, and raffles.

The picnic would not be possible without the support of many volunteers and donors. The T.O.U.C.H. Board would like to thank the volunteers from the hospital as well as volunteers from various school groups. Appreciation also goes out to the families and heart "kids" who volunteered their time to work a shift. Turn to the next page to see a list of donors.



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.

PICNIC SPONSORS AND DONORS

The annual picnic is made possible through the generous donations of individuals and businesses. The T.O.U.C.H. board is working on a new format for those who wish to support the picnic in 2014. Donations of money, gift certificates, or merchandise will continue to be accepted for raffle prizes. There will also be a level system for sponsoring various areas of the picnic, such as balloon animals, a craft station, or the inflatable slide. There will be several opportunities to donate at a variety of financial levels. Watch for more details in the next newsletter and on the T.O.U.C.H. website.

Thank you to the following businesses and individuals who donated for the 2013 picnic:

The Anthony Family	ISU Redbirds
Avanti's	Jonah's
Biaggi's	The Kammerer Family
Bradley Braves	Nancy Meldrum
Conklin's Dinner Theater	Monical's Pizza
The DelaCruz Family	The Negray Family
Distihl	Oehrlein School of Cosmetology
Famous Dave's	Peoria Chiefs Baseball
Paula Feddericke	Peoria Riverfront Museum
Fire Fighters Local 50	Peoria Zoo
(Mike Loveless and Ryan Brady)	Pepper's Café
Fon du Lac Park District	Schooners
Fox & Hounds	Spotted Cow
The Hagedorn Family	Subway
Hampton Inn & Suites	Trefzger's
Holiday Inn	Wildlife Prairie Park

A special thank you goes to the Children's Hospital of Illinois Foundation for their ongoing support.

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!

Gina Hulett ~ (309) 678-3761 ~ gmhulett@gmail.com

CONGENITAL HEART DEFECT AWARENESS

CHD Awareness Week is an annual awareness effort to help educate the public about Congenital Heart Defects. Participants include individuals, local support groups, national and local organizations and congenital cardiology centers throughout the world. This year's Congenital Heart Defect Awareness Week is officially **February 7 - 14, 2014**.

According to The Congenital Heart Information Network:

Congenital Heart Disease is considered to be the most common birth defect, and is a leading cause of birth-defect related deaths worldwide.

Despite the fact that CHD affects approximately 1.8 million families in the U.S., a relatively small amount of funding is currently available for parent/patient educational services, research, and support.

By sharing our experiences and providing information, we hope to raise public awareness about conditions that affect approximately 40,000 babies each year in the United States alone.

It is our sincere hope that efforts to educate the public will result in improved early diagnosis, additional funding for support and educational services, scientific research, and access to quality of care for our children and adults.

To help promote awareness and celebrate the heart children who are, or have been, patients of the Congenital Heart Center, T.O.U.C.H. will be creating a short video to display on the website and Facebook in February of 2014. The video will consist of "heart kid" pictures submitted by T.O.U.C.H. families. The video will NOT include names or other identifying information. To be included in the 2014 video, your picture must be received by January 10, 2014. Please email a "jpg" file to gmhulett@gmail.com or send the file through the "contact us" link on the website at www.touchhearts.org. Thank you to all those who had their pictures taken at the Jr. T.O.U.C.H. tent during the picnic! We have some terrific photos to get the video started.

If you have ideas to help spread awareness, please share them on the T.O.U.C.H. Facebook page. Search "The Organization for Understanding Children's Hearts" on Facebook and "like" the page. Then interact with posts to be sure you will see the updates and activity on the page.

If you would like to book a stay at **Megan's Lodge**, please contact Wildlife Prairie Park at 309-676-0998. The cabin is located inside the park just west of Peoria.

The current cost for a stay, from one up to seven nights, is a total of \$100, which includes a one-year membership to the park. The intent of Megan's Lodge is to provide a place for T.O.U.C.H. families to enjoy a low-cost, relaxing time away from everyday life in a rustic vacation setting.

MEET THE HEART “KIDS”

Jake is 10 months old and lives in Altamont. He loves to army crawl and chew on everything. Jake has transposition of the great vessels, VSD, and mitral cleft. He’s had 1 heart surgery. His parents most liked the support from the hospital staff and liked the tubes and IV’s the least.

Bella is 3 years old and lives in Pekin. She likes to dance and watch Dora and Land Before Time. Bella has bi-cuspid aortic valve with stenosis. She’s had 1 heart intervention so far. Her parents most liked the nice hospital staff and Bella disliked getting shots and being sick.

Elijah is 5 years old and lives in Rock Island. He likes to ride his bike, play in the sand, and play soccer. Elijah has transposition of the great vessels and coarctation of the aorta. He’s had one heart surgery. His parents most liked the knowledge and support at the hospital and disliked the situation itself.

Ava is 7 years old and lives in Edwards. She likes to read and play with her friends. Ava has Tetralogy of Fallot. She’s had one heart surgery. She likes that the hospital is family-friendly. She doesn’t like being there for a long time and not seeing her siblings.

Cameron is 11 years old and lives in Collona. He likes to sit around and play outside. Cameron has transposition of the great vessels, heart block, and a pacemaker. He’s had ten surgeries and couldn’t think of much he liked about being in the hospital. He liked the pain the least.

Rachel is 15 years old and lives in Geneseo. She likes to draw and play video games. Rachel has Tetralogy of Fallot and has had one heart surgery. Her family liked the play room and the nurses. She didn’t like not seeing some of her family and just being there.

Matthew is 21 years old and lives in Macomb. He likes to ride motorcycles and play video games. He’s had a lot of heart surgeries. He liked that everyone at the hospital was friendly. He didn’t like getting shots.

Kayla is 22 years old and lives in St. Charles, MO. She has pulmonary atresia and has had 6 heart surgeries. Kayla is studying to be a pediatric cardiology nurse. Her favorite part of the hospital was seeing the doctors and nurses, but her least favorite was waiting for Dr. Geiss.

Tara is 32 years old and lives in DeKalb. She likes to read in her free time. Tara has pulmonary atresia. She’s had 6 heart surgeries. She most liked the nurses during her hospital stays. She disliked the pain the most.

May we introduce you or your child? Contact us with your information through the “contact us” link on our website at www.touchhearts.org.

COPING WITH A CHRONICALLY ILL SIBLING

Having a child with chronic illness is an incredible challenge, unique in the unhappiness it can bring. However, successfully learning to cope with a chronic illness rarely occurs without growth of every member of the family. It is important to recognize that having a brother or sister with a serious health condition is difficult, no matter what age. The act of providing medications and additional attention to the ill child is unavoidable, and brothers and sisters may feel ignored.

If the child is old enough to understand the reason for the extra attention, they might have additional stress created by concern for their ill sibling. If the child is too young to understand the idea of being seriously ill, they still notice (and can feel hurt by) all of the "extra attention" their ill sibling receives. These issues are just some of the ways in which chronic illness affects the lives of everyone in the family.

Emotions

There are a variety of emotions that may be present in siblings of a chronically ill child. These may include:

- Feeling guilty that they are not sick (the sentiment of "Why him/her and not me?").
- Wondering if something they thought about or did to the sibling might have caused his illness
- Worrying about becoming sick themselves
- Wishing they were sick (or pretending to be) so that they can become the center of the family's attention
- Feeling angry at having to work harder (such as assuming more household chores) than their ill sibling
- Becoming embarrassed if the sibling's condition draws attention in public, or teasing at school
- Feeling guilty about having any of the emotions described above

Warning signs

There are clues that a sibling may need some extra attention. Below is a list of warning signs that may indicate a need for extra support for the sibling

- | | | |
|--|--|------------|
| Anxiousness | Depression | Withdrawal |
| Decline in school performance | Pushing too hard to achieve | Anger |
| Rebelliousness | Blaming themselves for the sibling's illness | |
| Acting in ways to draw attention to themselves | | |

Ways to help

Be aware that while attending to the needs of your child with a chronic illness, you may be neglecting – or creating unfair expectations for – your healthy children. Too often, siblings become invisible unless they demand attention. On the other hand, siblings can participate in the family and feel pride and love in helping their brother or sister with his or her health problems. The presence of a family member with a chronic illness provides opportunities for increased empathy, responsibility, adaptability, problem-solving and creativity.

Try to establish some balance between the needs of your ill child and those of your other children. Spending time with each child individually may help. Develop a special relationship with each one of your children. Also, keep in mind that siblings need to have honest information about the illness and to have their questions listened to and answered.

Finally, it is always okay to ask for help. Counseling services may be invaluable to help a sibling cope and adjust during this difficult time. For information on counseling services in your area, please talk with your child's pediatrician or contact Pediatric Supportive Services at Children's Hospital of Illinois at .

Thank you to Bobby Lucia, of Pediatric Supportive Services, for the submission of the above article.

CONGENITAL HEART TEENS AND ADULTS

Connecting Teens and Young Adults

A group of teens and preteens who are congenital heart kids of T.O.U.C.H. board members have formed a group called Jr. T.O.U.C.H. They plan and work a booth at the picnic each year where they interview fellow “heart kids” and host activities to help connect teens and young adults. Some of the Jr. T.O.U.C.H. members decided to start a Facebook group where they can connect with others who understand what it’s like to live with a congenital heart defect. The group will be facilitated by T.O.U.C.H. board member, Gina Hulett, and individuals will have to gain permission to join the group. Any congenital heart teen or young adult who would like to join the group can do so by contacting Gina at gmhulett@gmail.com with your Facebook name. Gina will then add you to the group. This group will provide opportunities for congenital heart teens and young adults to talk with each other, offer each other support, and build mentoring relationships.

Adult Congenital Heart Association

The Adult Congenital Heart Association is a helpful and reliable resource for adults, teens, and parents of teens. The website (www.achaheart.org) offers access to blogs where congenital heart adults share their stories and experiences. There are several resources available through the website, including a series of free webinars on a wide variety of topics. All webinars are presented by professionals and are archived for future use. By registering an email with the website, individuals will be able to receive invitations to webinars and subscribe to specific blogs.

NEW T.O.U.C.H. BOARD MEMBERS

The T.O.U.C.H. board would like to thank recent board members, Angela Ludlum, Andrea Raycraft, and Julie Witte, for their time and service to the T.O.U.C.H. leadership team. Angela, Andrea, and Julie will continue to participate in T.O.U.C.H. events but have stepped down from the board, making room for new members.

Three new heart parents have recently joined the board. Please take a moment to meet and welcome Joe and Danielle McNear and Brittany Kruse:

My name is Danielle McNear. My husband, Joe, and I live in Lacon. We have 3 children: Allan, 23, Christian, 20, and Pete, 2 ½, and a grandson, Bryan, 23 months. Pete, aka PBJ, is our heart child. He was diagnosed in utero with Tricuspid Atresia. We are happy to be a part of such a great organization and look forward to connecting with other Heart Families!

My name is Brittany Kruse. I live in Little York, Illinois, with my husband, Doug, and daughter, Alexandria. Alex is almost 2 and was born with Hypoplastic Left Heart Syndrome. I joined the Board to help other families advocate for their children and raise awareness in our community about congenital heart defects.

FUNDRAISING EFFORTS

Vacation Bible School raises funds for T.O.U.C.H. Cabin

A small group of dedicated children spent four days at Community Vacation Bible School in Reddick, Illinois doing God's work. When planning the yearly bible school, volunteers consider the "theme" of the week, to decide their mission work. The theme for this year was "God's Big Backyard". Megan's Lodge was a perfect fit for their mission work!

Megan Fawver's Aunt Susan and her cousins, Jack and Andria, all volunteer at the Bible school and were honored to share Megan's story with the bible school children. The children worshiped the Lord with songs, stories, crafts, and games, and most



importantly, showed their kindness by giving to Megan's Lodge. They raised over \$1,000 and collected many supplies to be used by those who are blessed to stay at this special retreat.

Catechism Class chooses to help T.O.U.C.H.

The 5th grade Catechism Class from St. Mary's, St. Thomas, and Immaculate Conception Catholic Churches in Philo and Pesotum, Illinois, decided to raise money for T.O.U.C.H. as part of their 2013 Lenten project. The students held a raffle of knotted blankets that they worked together to make.

Thank you for your generous donations to T.O.U.C.H.

5th Grade CCD Class from St. Mary's, St. Thomas and Immaculate Conception Catholic Church, Philo and Pesotum, IL.

Graham Hospital Association and Graham Medical Group Employee's "jeans day"

Susan Denault and the Reddick Community Vacation Bible School

Gene and Mary Crean

Family and friends of Charlotte Dillefeld

**Thank you...your donations have
TOUCHED our hearts!**



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MARK YOUR CALENDAR...

- January 10** **Deadline to submit photo for CHD Awareness video**
Submit to gmhulett@gmail.com
- February 7-14** **Congenital Heart Awareness Week**
Help spread awareness by sharing facts and video
- February 15** **Children's Fashion Show, Luncheon & Concert with Julie K**
All proceeds will benefit Children's Hospital of Illinois
- September 28** **28th Annual T.O.U.C.H. Picnic**
Wildlife Prairie Park

Check us out and LIKE us on FACEBOOK!

Search on T.O.U.C.H. Like our page. Keep up to date on information and events!