

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

SUMMER 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



T.O.U.C.H. Board Members

Gail Eaton

Congenital Heart Center
(309) 655-2650

Angela Ludlum

Co-chair, Washington

Amie Love

Co-chair and Treasurer,
Washington

Tracy Bond

Secretary, Chillicothe

Terra Boeker

Germantown Hills

Stephanie Epperson

Washington

Gina Hulett

Germantown Hills

Joe & Danielle McNear

Lacon

Amy Orwig

Bloomington

Jenn Paulsen

Rockton

Julie Witte

Chillicothe

Amy Zbinden

Morton

CHILDREN'S HOSPITAL OF ILLINOIS TELETHON CELEBRATING YOU!!

This year's Children's Hospital of Illinois Telethon carried the theme "Celebrating You". A celebration of our children, families, caregivers, donors, sponsors and volunteers. The day's event was highlighted with carnival games, a magician, face painting, music and much more! All of the money raised during our T.O.U.C.H. hour will go directly to the Congenital Heart Center so that we can better meet the needs of all our congenital heart patients. **This year's 28th annual event raised a record amount of \$3,001,909!!**

One of the "miracle kids" featured was Dylan Gilbraith. Dylan is the son of James and Lori Gilbraith of Bloomington. Dylan was born with a complex heart defect consisting of Double Outlet Right Ventricle, Transposition of the Great Arteries, Mitral Atresia, Hypoplastic Left Ventricle and Severe Pulmonary Stenosis. He had a Kawashima procedure done in July of 2012 and is a very busy, happy two year old today.

Stories like those of Dylan's help us to remember why we support the CMN telethon. Please consider helping out next year when the telethon again raises money to help kids born with congenital heart defects.

A very special "thank you" and recognition goes out to the 2013 T.O.U.C.H. hour VIPs, who are listed on page 7 of this issue. Each of our VIP's is asked to raise a minimum of \$500 prior to telethon day. Great job everyone!!

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.

ADULT CONGENITAL HEART CARE

There are currently over 1.3 million adult congenital heart patients living in the United States. Adults now comprise more than 50% of all congenital heart patients. This population continues to grow and many will need regular monitoring and care through an Adult Congenital Program with expertise in both adult congenital and pediatric cardiology.

The Congenital Heart Center offers a team of experts who are specially trained in the complex anatomy and heart function of adults with congenital heart disease to provide state of the art care which is needed for this unique population. These physicians work alongside the pediatric cardiologists, congenital surgeons, and electrophysiologists on a daily basis,



Dr. Marc Knepp has recently joined the Congenital Heart Center as Director of the Adult Congenital Heart Program. Dr. Knepp grew up in Roanoke, Illinois, attended Illinois State University, and completed his medical training at the University of Illinois College of Medicine in Peoria. He trained under the physicians at the Congenital Heart Center and developed a respect for the program and the people. His Internal Medicine-Pediatric Residency, Pediatric Cardiology, and Adult Congenital Cardiology fellowships were completed at the University of Michigan. Dr. Knepp and his wife have three-year-old twins.

Dr. Knepp is excited about working with congenital patients and tracking them throughout their lives. He hopes to establish long term relationships with patients who will need lifelong follow-up. This may involve family planning and helping congenital moms through pregnancies, where they may face challenges unique to this population. Dr. Knepp's goal is to give his patients the best quality as well as length of life. He has seen such improvements in treatment and results over the last several years.

As patients reach their late teens to early twenties, they will be introduced to the Adult Congenital Heart Program if their history suggests close follow-up. Although some may be concerned that Dr. Knepp is planning to "replace" the cardiologists who have been treating their children for years, that is not his intention. Dr. Knepp is planning to work with those doctors as a team to provide the best care for the patients. The transition to adult care will happen gradually in a way that is best for the individual patient.

One of the contributions Dr. Knepp has already made is the development of "passports" for adult congenital patients. These passports will contain the patient's medical history as well as current medical information in order to aid the patients in advocating for themselves without relying on their parents. This will be an important tool in the transition to adulthood and self management of their health.

Please help us in welcoming Dr. Knepp to the Congenital Heart Center!

SUMMER SAFETY FOR HEART KIDS

Summer is a time of year that many children and families like to enjoy the outdoors. While everyone in the family will benefit from using sunscreen, staying hydrated, and being careful to avoid heat exhaustion, children with heart defects may need to take extra precautions. Some cardiac conditions may cause children to tire or overheat more quickly than normal. There are also some medications that may lead to children being more susceptible to dehydration and sunburn. If your child is on daily medications, you may want to check with your pharmacist for suggested precautions.

If your child has a cardiac history, be vigilant in observing your child's responses to the summer heat. Every child is unique, and some will handle the heat and sun better than others. Some signs to watch for are excessive sweating, flushed skin tone, shortness of breath, or slowed movements. These signs are all indicators that your child needs a break from the heat. Allow your child to cool off and be sure that he or she is drinking plenty of water. If symptoms do not start to improve within a short time, please seek medical attention.

As always, check with your child's doctor for the best advice on any precautions you should take.

CONGENITAL HEART AWARENESS PROJECTS

Congenital Heart Awareness Day is recognized every year on February 14. 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 our 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 1, 2014.

If you would like to submit a photo of your child, you may do so in one of the following ways:

Email a "jpg" file to gmhulett@gmail.com.

Mail a picture to Gina Hulett, 1345 Countryside Ct, Metamora, IL 61548.

Bring a picture to drop off at the picnic on September 29.

Have your child's picture taken in the Jr. T.O.U.C.H. tent at the picnic.

Another way T.O.U.C.H. would like to raise awareness is by holding a Bowling Night in February, 2014. This is still in the early stages of planning and we would like to know if anyone would like to attend this type of event. If you are interested in volunteering for or attending, please contact Danielle McNear at danielle.mcnear@yahoo.com. Watch for more information in the fall newsletter.



PEDIATRIC SUPPORTIVE CARE COUNSELING

The following information was provided by Laura Sollenberger, Counseling Supervisor of Pediatric Supportive Care Counseling Program at Children's Hospital of Illinois.

At Children's Hospital of Illinois, we recognize the significant emotional support needs of patients and families dealing with chronic and life-limiting medical conditions. Our specialized team of counseling providers is available to partner with you during the difficult times that illness often brings.

Counseling services are provided for pediatric patients meeting certain diagnostic criteria, such as long-term critical illness and single ventricle heart conditions. Counselors meet with children of all ages and also provide support to parents and siblings. Counseling can help with adjustment to new diagnosis, coping with illness, injury or disability, stress of hospitalization and treatment, and communication with the health care team.

Counseling staff can assist patients and families in decision-making, building effective coping techniques, and understanding the normal grief process associated with serious illness in children, adolescents and teenagers.

Counseling staff are also available to support siblings, grandparents and extended family members. Counseling services are available within the hospital, on an outpatient basis, and over the phone as needed. We also offer a variety of support groups.

There is no fee for counseling services. Counseling is available based on patient or family circumstance and for as long as needed. If you are interested in finding out if you qualify for this service, please speak directly with your healthcare provider, who will put you in touch with our program.

Some of the benefits of counseling services have been expressed as follows:

"Everyone else looked to me to be the strong one. It was helpful to not have to be that person when talking with the counselor."

"I do feel less anxious after something happens and I know I can talk with a counselor."

"Counseling was helpful in validating that it was okay to feel what I was feeling."

"I was so relieved to hear that this service was available at no cost. My son looks forward to his sessions, and I have seen such a decrease in his anxiety and level of depression."

In the fall issue of the T.O.U.C.H. newsletter, one of the Pediatric Supportive Care counselors will present information on siblings of children with critical illnesses.

MEGAN'S LODGE UPDATE

Hello to all! We are excited for another great summer for the cabin. If you have not heard, the park has recently changed hands. The State of Illinois signed over Wildlife Prairie Park to Friends of Wildlife Prairie Park, which is a private entity. The park is now operating as a not-for-profit. They are supported through admission fees, memberships, donations and grants. Due to this change, there has been a small increase in the cost of the stay at Megan's Lodge. Effective immediately, a stay at Megan's Lodge is \$100 which is good for a stay of up to 7 days. The \$100 covers the cost of a family membership, good for a year, and cleaning of the cabin. This fee will stay the same for the next 3 years. The increase was not an easy decision for the board, but in order to continue to offer the cabin to all of our heart families, it was a necessary one. We appreciate your understanding and if you have any questions, please don't hesitate to call. You can contact Amie Love at 309-472-9954. To make, cancel or change a reservation at Megan's Lodge, please call the park at 309-676-0998

MEET THE HEART KIDS

Please take a few minutes to meet some of our heart kids.

Ellie is 10 years old and lives in Peoria. She has had 4 heart surgeries. Her favorite thing about the hospital was The Spotted Cow. Her least favorite thing about the hospital was the surgery. In her free time, Ellie loves to do gymnastics.

Kathleen is 10 years old and lives in Peoria. She has had 2 heart surgeries. Her favorite thing about the hospital was that they took really good care of her. Her least favorite thing was having surgery. In her free time, Kathleen enjoys gymnastics, dancing, and playing with friends.

Justin is 13 years old and lives in Germantown Hills. He has had 5 open heart surgeries. His favorite thing about the hospital was the noise and lights always being on in the hall. His least favorite thing about the hospital was swarms of doctors. In his free time, Justin enjoys drawing, playing Xbox, and playing drums.

Caroline is 13 years old and lives in Germantown Hills. She has had 9 surgeries. Her favorite thing about the hospital was TV and internet. Her least favorite thing about the hospital was all the noise. In her free time, Caroline enjoys watching TV and reading.

May we introduce you or your child? Contact us with your information through the website at www.touchhearts.org.

FUNDRAISING EFFORTS

Sing From the Heart For the Heart

Kudos to the employees of the Congenital Heart Center!! Through the efforts of Ellen Bierwirth, Site Manager for the Congenital Heart Center and Lisa Lowry, Coding Coordinator for the Center an amazing \$9,000.00 was raised to benefit the Children's Hospital of Illinois Congenital Heart Center!!

It began with an idea to have a karaoke fundraiser called, "Sing From The Heart For The Heart" and snowballed into a six week marathon that ended on March 3rd at Crusen's on Farmington Road with the top four contestants remaining from the semi-finale competing for the number 1 spot.....and the winner was.....
Jessica McVey from East Peoria!!

Starting the last week of January and continuing throughout February (American Heart Month), Ellen set up karaoke contests on Mondays at Pitch Karaoke in Peoria and on Thursdays at BG Karaoke Saloon in Bartonville. Participants had a \$5.00 entry fee and an average of 20-25 singers competed each night.

The finalist performed with a live band composed of various performers of local bands. They called themselves "Dr. Chan's Throbbing Heart Club Band" and they were fabulous!! All of the staff at the Congenital Heart Center participated in some way. Some were judges, some helped to sell hearts and t-shirts and others showed their support with their attendance at the events and supporting the contestants.

Ellen says it was a great experience and she and Lisa even got the patients involved with the fundraising by selling paper hearts that were part of a balloon campaign and t-shirts with her original logo on them.

When asked what was most rewarding Ellen says, "The best thing was to see the community support coming out on week nights and supporting this great cause. So many people are unaware of the number of heart kids we care for here in Central Illinois," she says. "But when you can actually see where, what and for whom that money is going for, it speaks volumes." Plans are already under way for next year's event and Ellen says they are planning to expand it to include 2 more sites.

Thank you, Ellen, Lisa and all the employees of the Congenital Heart Center!! Through your efforts and dedication we know that our kids will continue to receive the best possible care.



FUNDRAISING EFFORTS (continued)

Pete's Pizza Party

Thanks to Joe and Danielle McNear for hosting an event to raise money and awareness and for sharing your story below with other T.O.U.C.H. families.

Our family became involved with the Congenital Heart Center in 2010 when I was pregnant with our youngest son, Pete aka "PBJ". When I was 19 weeks into my pregnancy, he was diagnosed with Tricuspid Atresia. Until that time, we did not fully recognize how blessed we were to have such a facility so close to us as the Congenital Heart Center at Children's Hospital of Illinois. It is because we are so blessed that we wanted to give back to those who have given us so much. So on May 4th we held "Pete's Pizza Party" to raise funds and awareness for Congenital Heart Defects. The event was held at Mud Puddle Pizza in East Peoria and we were honored to have two great bands join us for the evening, Robin Crowe and Gillkata. We raised funds by raffling an acoustic guitar and holding a 50/50 drawing, along with CD's donated by Robin Crowe with all proceeds from their sale being donated. The guitar was graciously donated by Mud Puddle Pizza owner, Jeff Hickerson. We also wanted to raise awareness so we took the opportunity to hand out information sheets with Congenital Heart Defect facts and talk to those who were there about CHD's. We were very happy to see so many of our family and friends come out and support this event. We are happy to say that we were able to raise \$1,100 that will be donated to the Congenital Heart Center.

Thank you to the following 2013 CMN Telethon V.I.P.s!

Frank Abdnour
Sydney Abdnour
Dr. Matt Bramlet and Lydia
Rob, Stephanie & Kylee Epperson
Amie Love and Emilee
Jenn Paulsen and Hannah
Brad, Denise and Beau Norris
Krista Kingery and Mychaela
Ellen Bierwirth
Lisa Lowry
John, Melissa and Birkeley Stigall
Brad, Shannon and Molly Brown

Becky and Elle Hoffman
Jeff, Vashti and Ella Berry
Doug, Brittany and Alexandria Kruse
Shelly & Brady Weaver
Brent, Shelly & Katelynn Allen
Brian, Angela and Gabe Ludlum
Justin Hulett
Caroline Shelton
Mike, Tracy and Joshua Bond
Dr. Ty Hasselman and Anna
Becky and Kelsey Todd
Joe, Danielle & Peter McNear

Lora Kinzer
Justin, Kristen and Jamison Cree
James, Lori and Dylan Gilbraith
Vince, Pam and Madelyn Hummel
Vickie Grimsley
Steve Thornton
Dawn and Brianna Thornton
Jason Kiel
Gina Landauer
Lacy Orabutt
Tammy and Jason Alsene
Angela and Hannah Trask

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

Matt and Summer Knobloch
Belinda Johnson
Wallace and Yvonne Heber
Roger and Louise Atkinson
Craig and Amy Orwig

Gary and Susan White
Peter and Tina Wenzel
Gerardo and Debra Grieco
Joshua and Diane Jeffrey
Benjamin and Lisa Mengarelli

David and Darla Anderson
Steven and Sharon Peterson
Shelby Fawver
Mary Nystuen

Thank you...your generosity has TOUCHED our hearts!



The Congenital Heart Center
at The Children's Hospital of Illinois
420 NE Glen Oak Avenue, Suite 301
Peoria, Illinois 61603

NON-PROFIT ORG.
U.S. POSTAGE
PAID
PEORIA, ILLINOIS 61637
PERMIT NO. 552

Check us out and LIKE us on FACEBOOK!

SAVE THE DATE ... 2013 T.O.U.C.H. PICNIC

Mark your calendars for Sunday, September 29, 2013, for the 27th Annual T.O.U.C.H. Picnic at Wildlife Prairie Park. Join us for an afternoon of fun with food, games, crafts, train rides, face painting, balloons, and more! Watch for an invitation with more details later in the summer.

If you would like to help with the picnic by soliciting donations for the raffle, helping plan activities, or working a shift during the afternoon, please contact us through the T.O.U.C.H. website at www.touchhearts.org.

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! Contact us through www.touchhearts.org.