

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

Spring 2016

The Organization for Understanding Congenital 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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## CHD AWARENESS



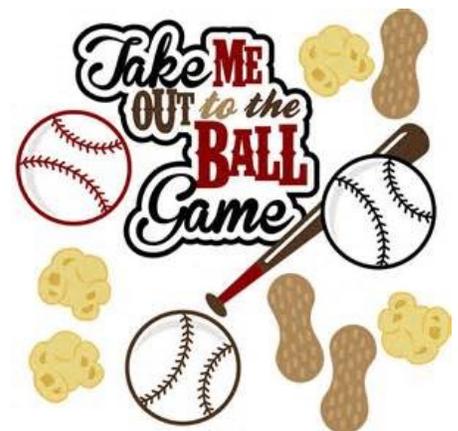
T.O.U.C.H. is having another Congenital Heart Defect Awareness night with the Peoria Chiefs! The game is on Saturday, June 18, at 6:30 p.m. in Peoria.

We have lined up two events for our CHD heroes this year. First is the "Dream Team" where 17 of our CHD kiddos can go out onto the field at the beginning of the game with the Peoria Chiefs players. Second will be the "High Five Tunnel" where the players will *high five* the kids as they come out onto the field. Other events taking place that evening include Fireworks and a post-game concert by Chris August.

Tickets are \$10.00 each for ages 3 and up (2 and under are free).

T.O.U.C.H. will receive \$1.00 for every ticket purchased, and funds raised will benefit this year's 30<sup>th</sup> Annual Picnic. If you purchase tickets and are unable to attend on June 18<sup>th</sup>, you will be able to use your tickets at an exchange night game.

This was a wonderful event last year and is a great opportunity for our T.O.U.C.H. families to get together and have some fun! To purchase tickets or for more information, please contact Danielle at [danielle.mcnear@yahoo.com](mailto:danielle.mcnear@yahoo.com).



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.

# CONGENITAL HEART CENTER NEWS

The Congenital Heart Center is pleased and excited to welcome and introduce Marsha Hurn, MSW, LSW. Marsha joined the Congenital Heart Center in April of 2016. She brings the much needed role of a Medical Social Worker to the team caring for our congenital heart patients. She completed her undergraduate degree in Social Work at Western Illinois University in 2000, later going on to complete her Master's Degree in Social Services from Illinois State University in 2007. She has been working in the field as a Social Worker for over 16 years.



Marsha began her career at the Illinois Department of Children and Family Services in the Bloomington area, and then returned to the Peoria area to work with high risk children and pregnant mothers at the Peoria City/County Health Department. She has also worked with children and adults with bleeding disorders at the Bleeding and Clotting Disorders Institute. Most recently she has worked with patients in the inpatient setting as a discharge planner.

Marsha enjoys spending time with family and friends, running, and nature. She and husband, Nate, have two girls, Emmerson, age 10 and Ellie, age 6. Marsha and her family are huge Cub fans and are looking forward to a great season! Go Cubs!!

## T.O.U.C.H. BOARD WELCOMES NEW MEMBER

Hi, my name is Erica Wright and I have recently joined the T.O.U.C.H board. I was born with a congenital heart defect, Transposition of the Great Vessels. I have been going to Children's Hospital of Illinois my whole life. I have had two major open heart surgeries, one when I was 7 and the other when I was 25. T.O.U.C.H has always had a special place in my heart since I was very little. Growing up I attended many T.O.U.C.H picnics with my family and had a great time. It was always nice seeing other children, who also had a congenital heart defect like me, having fun together.



I am very excited to join the T.O.U.C.H board and help spread awareness about congenital heart defects to our local communities. I am also very passionate about the Adult Congenital Heart program and hope to be an advocate for other adult congenital heart patients like myself. It is great that I can give back and support a cause so close to my heart!

**What would you like to read about in the newsletter? We welcome your ideas! Please send them to [gmhulett@gmail.com](mailto:gmhulett@gmail.com) if you'd like to share.**

# CH-CH-CH-CHANGES...NO MORE TELETHON

After 30 years of Children's Hospital of Illinois Telethons, it's time to move into a new era of fundraising and donor recognition. The Children's Hospital of Illinois Community Advisory Board and the OSF Foundation team have worked together to brainstorm how to combine the best of the Children's Miracle Network Telethon and Drive For Miracles Radiothon into an exciting year end celebration of fundraising and donor appreciation.

A new event is being planned that will represent the culmination of a year's worth of friend raising, fundraising and donor recognition. The "Twelve Days of Giving" will take place November 28 - December 9, 2016. Hosting the finale of the twelve day event in the Children's Hospital of Illinois Lobby and Jump Center will bring our patient families/miracle kids, donors, volunteers, caregivers, community and corporate partners close to the Children's Hospital of Illinois where miracles happen daily. During the twelve days, we will celebrate our generous supporters through televised and radio vignettes featuring our miracle kids/families, community sponsors/partners, volunteers and donors.

Of course T.O.U.C.H. will be a part of the 12 Days, and more information defining that participation will be coming soon. The Children's Hospital of Illinois Community Advisory Board and the OSF Foundation team appreciate the generous support from T.O.U.C.H. families and friends over the years. They look forward to T.O.U.C.H. being a part of this exciting year of fundraising and look forward to a fabulous 2016!

## T.O.U.C.H. RECEIVES ADVOCACY AWARD

The T.O.U.C.H. Board was honored to accept an award at the May meeting. The 2016 Children's Hospital of Illinois Community Group Advocacy Award was presented to The Organization for Understanding Congenital Hearts in recognition of an organization that works continually over time in a variety of ways to improve the lives of children. Some of the cited reasons for the honor were mentoring connections between families, CHD awareness efforts, participation in 30 years of telethons, annual picnic, Megan's Lodge, and the Stella Wilson Scholarship. Thank you to all who have contributed over the years to make T.O.U.C.H. what it is today!



# ADULT CONGENITAL HEART CARE

**KRISTI'S KORNER** by Kristi Ryan, Nurse Practitioner for Adult Congenital at Children's Hospital of Illinois



“Transition of care” is becoming an increasingly more common phrase heard in healthcare. Most commonly this is used in discussing the transition of care from a pediatrician to an adult doctor. We also discuss this in terms of patients with chronic illness requiring transition from pediatric specialty to adult specialty. Here in the Congenital Heart Center we have been working on a program that will help our patients and their parents adapt to the changes that are necessary for the patient to take responsibility of their own health.

By the time our patients reach 18 years old we want them to feel prepared to speak about their heart condition, understand why they need to continue regular follow up and know how having a congenital heart defect can affect the important decisions they are making. We will be starting discussions about transition around age 12, depending on the child.

We do recognize that this transition process will be difficult for parents. They have been used to giving all of the history for their child and having the cardiologist speak to them. We hope that parents find comfort in knowing that we are preparing their child/adolescent so that when they are at college, traveling away from home or away from their parents they will have the knowledge they need in case of emergencies.

Our program focuses on assisting adolescents with congenital heart disease to continue specialized cardiac care as adults. This may mean transitioning to an adult congenital cardiac specialist or maintaining care with the same specialist that they have been following with.

The transition program is set up to ensure that our adolescents and adults with congenital heart defects receive the best care, including:

- Ongoing, lifelong care with the appropriate physicians and team to prevent complications
- Education that is individualized for each patient and directed at understanding what defect they were born with and surgical procedure(s) they have had
- Encouraging each patient to carry their health information with them. This could be helping them to enter their information into their smart phone, filling out a Personal Health Passport (provided by the Adult Congenital Heart Association (ACHA) and available in our office), or signing up for OSF MyHealth
- Understanding what they need to consider when selecting career paths and insurance
- Discussing family planning including what to discuss with a partner prior to marriage, risk of pregnancy with their specific congenital heart defect and the potential of passing on heart disease to their children
- Learning to refill medications and understand why they take all of their medications
- Knowing when to call the cardiologist and what specific symptoms they should be watching for

We recognize that all of this teaching cannot happen at one time. This is a process that we want to start early and build on throughout several clinic visits. As we start the program we are learning more about what works and what doesn't. We welcome any feedback to help improve the program and we hope that parents and patients alike see the benefits of a formal transition program.

# CONNECTING CHD ADULTS AND TEENS

As kids with congenital heart disease reach adolescence and young adulthood, the importance of connection with others who share similar experiences grows. T.O.U.C.H. would like to help facilitate these connections. The board now has a member who is a young adult with CHD as well as a parent of an adolescent and young adult, both with CHD. Congenital Heart Center also has staff who specialize in the area of Adult Congenital Heart Disease.

One idea that has been mentioned is to host a light social event of some sort, maybe a pizza hour where young adults and teens, 16 and older, could come together to meet others who are interested in sharing stories, experiences, and support.

T.O.U.C.H. would like to hear ideas from adults and teens themselves. Please send suggestions to [gmhulett@gmail.com](mailto:gmhulett@gmail.com) or post to the Jr. T.O.U.C.H. Facebook group. To become a member of this private, monitored group, please email Gina at the address above with your Facebook name.

## CONNECTING CHD FAMILIES

On Saturday, February 13, 2016, T.O.U.C.H. held their first **CHD Night with the Peoria Rivermen**. Approximately 80 people participated representing kids with congenital heart disease as well as friends and family who support them. Everyone had a great time...even though the Rivermen lost!

T.O.U.C.H. is open to new ideas for outings such as this one to connect families and raise awareness. Suggestions may be posted to the T.O.U.C.H. Facebook page or T.O.U.C.H. Heart Parents Facebook group or sent to [danielle.mcnear@yahoo.com](mailto:danielle.mcnear@yahoo.com).



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.

**\*\*Cabin availability is filling quickly, so book your stay today!**

# 30TH ANNUAL T.O.U.C.H. PICNIC

## Save the Date

This year will mark the 30th year for the annual T.O.U.C.H. picnic at Wildlife Prairie Park!

On **Sunday, September 25, noon to 5:00 p.m.** “heart families” are invited to participate in an afternoon of fun with food, games, crafts, train rides, raffle prizes, face painting, balloons, and more! The picnic is free to all the heart kids and their immediate family members up to a total of 7 people. An invitation card will arrive in the mail later this summer and specific information will be posted to the webpage and Facebook.

## Group Picture

Since we’re celebrating a big anniversary, all “heart kids” will receive a free t-shirt at the picnic and a group picture will be taken. Please be prepared to give a t-shirt size for your “heart kid” when you RSVP for the picnic.

## New Activities

As activities are being planned for the picnic, new ideas are often sought. Besides they typical face painting, balloons, crafts, and simple carnival games, what else would families enjoy? With many “heart kids” becoming older teens and young adults, the board would like to continue making the picnic appealing to this age group. Suggestions are welcome at [gmhulett@gmail.com](mailto:gmhulett@gmail.com).

## Pay it Forward

Many families ask how they can give back or be a more active part of the annual picnic. Here are a few ways to get involved...

- Volunteer to work a shift at the picnic (11:45-2:00 or 1:45-4:00)
- Donate your services on the day of the picnic
- Solicit donations of raffle prizes or sponsorships from business owners you know
- Create and donate a theme basket for the raffle
- Sponsor an activity with a monetary donation

Please contact Gina at [gmhulett@gmail.com](mailto:gmhulett@gmail.com) for information on how to participate in these ways.

## Online Donations Now Accepted

Donating to the T.O.U.C.H. picnic fund is easier than ever! The T.O.U.C.H. website is now equipped with a “Donate Here” button on the home page at [www.touchhearts.org](http://www.touchhearts.org). Donations may be made by credit card and will be processed through a secure PayPal account.

Tax-deductible donations to T.O.U.C.H. can be a great way of honoring a friend or family member with a congenital heart defect as well as honoring the memory of a loved one. Donating can also be a great way to “pay it forward” after experiencing the picnic for many years.

# FUNDRAISING AND DONATIONS

## Children's Hospital of Illinois - Congenital Heart Center Fundraiser



You're invited to enjoy an evening of cultural diversity, demonstrated through a storytelling and dance extravaganza for the whole family! The event will be held at Five Points Theater in Washington, Illinois, on Saturday, August 13, 2016, at 7:00 p.m. Tickets are \$20 for adults and \$10 for children. CHD "kids" attend for free. All proceeds will benefit the Children's Hospital of Illinois - Congenital Heart Center.

T.O.U.C.H. is excited to be a part of the "Dancers with Heart" event this year. The performance two years ago was outstanding, and this year's performance will be nothing less. The Mythili Dance Academy presents a theatrical extravaganza with a unique fusion of Indian dances along with collaborative performances of guest artists from local Chinese and Middle Eastern communities and Cornerstone Academy for Performing Arts.



Watch the T.O.U.C.H. website and Facebook page for details. Contact Gail Eaton at Congenital Heart Center or Danielle McNear at [danielle.mcnear@yahoo.com](mailto:danielle.mcnear@yahoo.com) for more information on ticket sales and sponsorships.

## Donations

Since the printing of the last newsletter, T.O.U.C.H. has received donations from the following individuals and families:

- Graham Hospital Association and Graham Medical Group of Canton
- Dr. Michael and Cathy Vidas
- The Nancy Raycraft Family and Friends
- Ryan and Beth Gehlsen

The generous donations of friends and family are what make many of the T.O.U.C.H. activities and events possible. The board sincerely appreciates all gifts received and strives to acknowledge donors regularly. Thank you for being a part of the mission to our CHD families!

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



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## **MARK YOUR CALENDAR...**

**June 18 T.O.U.C.H. Night with the Peoria Chiefs**

Join other families to promote and celebrate CHD Awareness.

**August 13 Dancers with Heart Fundraising Event**

Experience an evening of multicultural dance and storytelling while raising funds and awareness for Congenital Heart Center

**September 25 30th Annual T.O.U.C.H. Picnic**

Join other heart families at Wildlife Prairie Park for a day of fun activities.

## **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!

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