

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

Summer 2019

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 Children's Hospital of Illinois and the University of Illinois College of Medicine, at Peoria. www.TOUCHHEARTS.org



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33rd Annual T.O.U.C.H. Picnic

You're invited.....

The 31st Annual T.O.U.C.H. Picnic at Wildlife Prairie Park, just west of Peoria, is coming up on

Sunday, September 29, noon to 5:00 p.m. Join other "heart families" for 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. Additional guest will be charged \$5 per person. **Please call the Congenital Heart Center at 309-655-2254 or 309-655-3419 to RSVP by September 13.** Please be prepared to leave a message with your child's name, the total number attending and total number of lunches needed.

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 (12:00-2:00 or 2:00-4:00)
- 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 for information on how to participate in these ways.



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.

Importance Of A Smooth Transition

Adolescence can be a confusing time for most, even those without a congenital heart condition. At the Congenital Heart Center, we want to help our patients navigate the physical, mental and social changes that come with adolescence and help them make a smooth transition from pediatric to adult-based care.

The transition program will start around your child's 14th birthday. Our transition team will begin by assessing your child's developmental and cardiac educational level. Then, in collaboration with the patient and the primary cardiologist, we develop a plan tailored to each individual to prepare them to take over their own healthcare as they enter into adulthood. This process will occur over several visits and is flexible enough to change as the patient matures or new issues arise.

By supporting our CHD patients throughout their teenage years, we hope to help them achieve even more success as adults. Topics that the team will be working on:

- Understanding their heart condition, treatments they have received and potential issues that may arise over time
- Understanding medications and how to obtain refills
- Understanding the need for lifelong care with a cardiologist trained in ACHD
- Learning what symptoms to watch for and when to call their cardiologist
- Learning about potential future heart health needs, including testing, surgeries and procedures
- Understanding how lifestyle choices like exercise, alcohol, smoking and drugs can affect people with congenital heart conditions
- Understanding which career choices are better suited for someone with congenital heart disease
- Learning about family planning needs, including contraception, considerations for pregnancy and genetic implications
- Maintaining medical insurance/coverage
- Understanding the importance of having advanced directives
- Understanding the importance of having good dental care
- Coordination of care with other specialty clinics and assistance with referrals

We also work with patients to determine if there may be any barriers to care and to provide additional resources to help ensure proper lifelong care.

The following organizations provide additional resources and support for teens and adults with congenital heart disease:

- 2HEARTS
- Adult Congenital Heart Association
- American Heart Association

1 in 100 Walk

There are many ways to raise awareness about areas that you are passionate about. One way that has become more and more popular is through activities such as walks, 5K runs and other types of fundraising events. Did you know that the most common birth defect and childhood illness is congenital heart disease? And that only about 10% of adults that should be receiving specialized congenital heart care are actually getting this. There are so many of these statistics that we want to get out to more people in the community. In addition, national research is needed to continue to improve the care to all patients that are born with congenital heart disease.

Some members from TOUCH and OSF St. Francis Congenital Heart Center joined together to explore how we can make an impact and get the community involved as well. In exploring our options we felt that the mission and values of the Adult Congenital Heart Association (ACHA) aligned well with our goals. For 2019, we are having what they are calling a “Virtual Walk”. This gives us the opportunity to join together and we can raise awareness through social media. We also hope to have some type of gathering or social event to celebrate once funds are raised. We are working with ACHA on bringing a Walk to 1 in 100 in Peoria soon.

The Adult Congenital Heart Association (ACHA) is devoted to supporting the full lifespan of the millions of people impacted by CHD. In 2019, the ACHA will host walks in 14 communities to raise money for outreach, research and more. The Walk for 1 in 100 was created to empower all of those who were born with a heart defect, their loved ones and the medical community that cares for them.

The ACHA is here to empower adults to take an active role in their cardiac care, to educate parents on the lifelong specialized care their young son or daughter will need, and to support young adults through the transition to adult CHD care. The ACHA is here for the person with a newly diagnosed heart defect, as well as the patient who's seen it all, and everything in between.

Please join CHD families and walk for the 1 in 100 children and adults impacted by congenital heart disease across the country and to help support the efforts of the ACHA which so closely align to our own. This Virtual Walk can be completed however you want, when you want! You can walk on your own or gather a group and walk together!

To join team **“HEART of Illinois”** please visit our website at https://secure.achaheart.org/site/TR/Walk/General?team_id=16718&pg=team&fr_id=1857 . You can also create your own personal page and share your CHD story. The link can also be found by going to achaheart.org and following the links for the “Walk for 1 in 100” and click on “Virtual Walk”. Thank you for your support!

**You are invited to attend a free Parent 2 Parent Support Group for parents/
caregivers of young children with special needs–
When: 1st Monday of the Month Time: 6:00 pm – 7:00 pm
Place: Easter Seals 507 E. Armstrong Ave. Peoria, IL 61603
RSVP: Call or Text Erica (309) 360-9743**

Staff Spotlight—Marla Turbett



1. What do you do at the Congenital Heart Center/CHOI?

I am the clinical manager for the day to day clinic operations. This includes the Peoria and Rockford locations as well as 9 satellite locations.

2. How long have you worked at the Congenital Heart Center/CHOI?

I have been with OSF since January 1995. I have been the manager of CHOI Congenital Heart since March 2017.

3. What do you love most about working at the Congenital Heart Center/CHOI?

In my 26 years of nursing experience I have been in many different roles as well as departments. I have never been more proud to be a part of a team where I witness our providers show such passion and love for the patients and families that come through our door. Our entire team strives to improve our patients quality of life through various programs such as transition and neurodevelopment. We are a unique specialty clinic where can have the opportunity to be apart of a patient's life from fetal care to adulthood.

4. What are your favorite pass times or hobbies?

I enjoy biking with my 11 year old son and being outdoors as much as possible. When there is sunshine you will always see an extra big smile on my face.

5. What would you like to say to our heart families?

If you ever have any concerns or issues that need addressed, please feel free to reach out to me. I want to provide everyone an opportunity to give any suggestions or feedback so we can improve your experience. My direct number is 309.655.6455.

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 five 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!**

Megan's Lodge

The T.O.U.C.H. Board would like to thank the families who have helped keep Megan's Lodge in good shape over the years. Every family that has contributed to cleaning the cabin or property, replacing worn or broken items, making needed repairs, restocking supplies, and donating to the upkeep of the cabin is greatly appreciated. Please accept the sincere thanks of the board members.

Please remember that the cabin is meant for families to enjoy a peaceful stay while abiding by Wildlife Prairie Park rules and exploring the property. In order to remain in good standing with the Park, cabin visitors are asked to refrain from hosting parties and bringing pets of any kind to the cabin. Pets are absolutely not allowed anywhere on WPP property.

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.

CHD Awareness/Community Outreach Update

During CHD Awareness Week this past February, we had a virtual challenge via Facebook where patients, along with family and friends, were encouraged to do a few daily challenges and post them on the TOUCH page along with various hashtags. Thank you for your participation and helping us spread awareness to all of our family and friends!

On August 10th, TOUCH is taking it to the market in Lincoln. Representatives from the TOUCH Board of Directors and patients will be on hand to answer questions, provide support, and spread CHD Awareness. If you happen to be in the area, please stop by the ALMH Market at the Logan County Fairgrounds and visit with other CHD families. While there, you will be given the chance to shop for food grown by local farmers as well as learn about other resources in the community.

Looking ahead to 2020 – TOUCH will once again be hosting a CHD Symposium. This event is still in the process of being finalized but we can promise there will be many topics discussed that will be of interest to both patients and family members of those affected by congenital heart defects. Stayed tuned for more information in the coming months!

**What would you like to read about in the newsletter? We welcome your ideas!
Please send them to kristen.e.anderson@osfhealthcare.org if you'd like to share.**

ADULT CONGENITAL HEART CARE

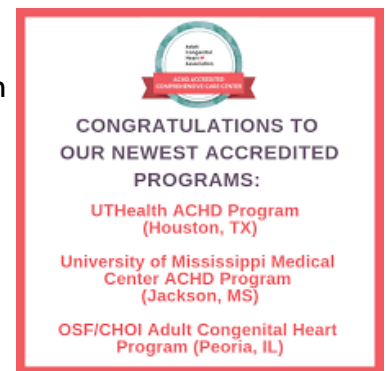


KRISTI'S KORNER by Kristi Ryan, Nurse Practitioner for Adult Congenital at OSF HealthCare Children's Hospital of Illinois

We are extremely happy to announce that our Adult Congenital Heart program has officially received national accreditation for being a Comprehensive Care Center. This is the highest level of accreditation possible and the OSF Healthcare Children's Hospital of Illinois is the first program in the state of Illinois and one of only 30 programs that has achieved this up to date.

Back in 2014 there were members from the Congenital Heart Center that sat in a meeting in Chicago and heard about the opportunity that was going to be coming for programs across the country to receive this recognition. The team quickly began gathering data about what best practices are and how we can truly establish the best center possible here in Peoria, IL. I feel very fortunate that they felt passionate about this. It not only has helped elevate the standard of care for our patients but it helped to identify what was really needed. This included a full time nurse practitioner and nursing care coordinator dedicated to care for the adult patients within our clinic. Then we were also able to identify the need for a social worker and lay out that important role for our patients.

Over the next several years the team worked to assure that proper requirements were in place to apply for the accreditation. Once the more than 200 documents were submitted we hosted members from the accreditation team at our institution. We were able to introduce many of our team members to them and discuss our best practices as they visited our campus back in November of 2018. We got notice in the April that we were officially accredited as a Comprehensive Care Center!



So, why is this important to you?

- Assures that you have access to high quality ACHD care
- Assures that the care you receive at our program, including the imaging that is performed and interpreted, is done by a CHD specialist
- All patients going for surgery are presented at a multi-disciplinary conference
- All cardiac surgeries are performed by congenital heart surgeons
- The team is focused and committed to providing patient centered care

What does the accreditation provide for our program?

- A template to build an ACHD program with leverage to add necessary faculty and staff
- Elevates the ACHD program within the heart center and the hospital
- Access to other high quality ACHD programs (new communication portal coming soon)

Recently I attended an international conference where the benefits above were presented. This is a list that was given out and I feel for the most part it is quite accurate. In my own words, I think this gives our patients the reassurance they deserve that they are receiving the best care possible and for our team it gives us the tools we need to provide that best care! This really does align with the OSF mission of PATIENT FIRST!

In the future we hope that we will also be able to use the accreditation to benefit our patients from a financial standpoint. Currently insurance companies often dictate that testing be done at their preferred centers which do not have congenital heart specialist. There is work being done in hopes that we can justify to insurance companies the need for our complex studies to be done by the appropriate specialties which will optimize quality of care. This is just one example of how our accreditation will directly help our patients in the future.

FUNDRAISING AND DONATIONS

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 the gifts received and strives to acknowledge donors regularly. Thank you for being a part of the mission to our CHD families!

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

Donations

Good Shepard Lutheran School

Visitation Catholic School

Memorials

Norwood Primary School– In memory of Joe Juchems

Online Donations Now Accepted

Donating to T.O.U.C.H. 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. 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 touched by congenital heart disease as well as honoring the memory of a loved one.

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

The Congenital Heart Center at



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MARK YOUR CALENDAR...

August 10 T.O.U.C.H. Market Day

Join us at the Logan County Fairgrounds market day and visit with other CHD families

September 27 Rock the House

Fundraiser for the Family House with featured band, Dr. Plunkett and the Heart Menders

September 29 33rd Annual T.O.U.C.H. Picnic

Join other hear 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!

Kristen Anderson ~ (309) 655-3419 ~ kristen.e.anderson@osfhealthcare.org