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

Winter 2019

The Organization for Understanding Congenital Hearts

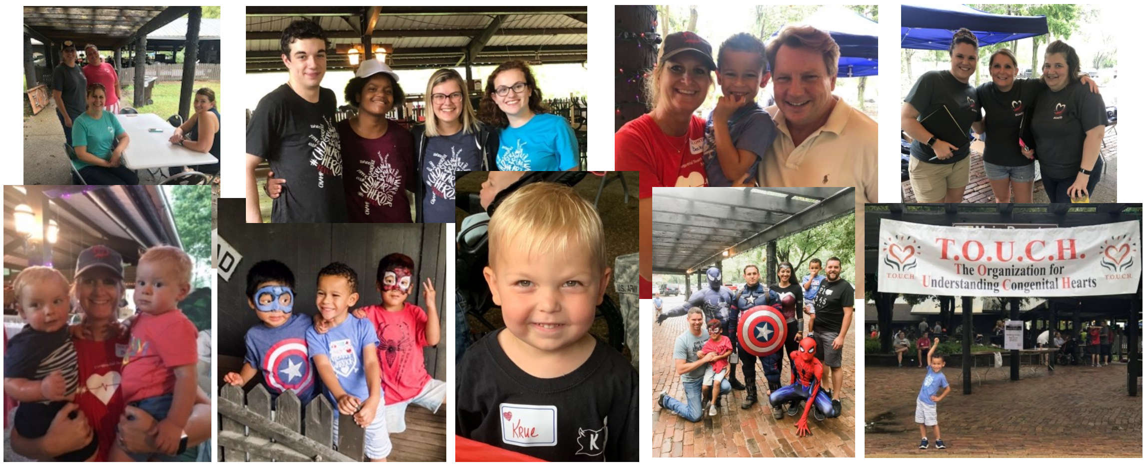
The mission of T.O.U.C.H. is to empower families, children and adults with congenital heart defects. We believe that through emotional support, education, information sharing and public awareness, we can make a difference. T.O.U.C.H. is supported by and affiliated with Children's Hospital of Illinois and the University of Illinois College of Medicine, at Peoria. www.TOUCHHEARTS.org

T.O.U.C.H. PICNIC

Our 33rd annual TOUCH picnic was on Sunday, September 29th at Wildlife Prairie Park. It rained most of the day but we still had approximately 600 friends of TOUCH in attendance. This picnic is more than just a day of fun activities. It's also a day for families to reconnect with one another and to meet others who are walking the same path of life. This event is a day of celebration for many families and it brings many smiles to both adults and kids who were born with a congenital heart defect. Activities included fun photo opportunities with Junior TOUCH, games with prizes, crafts, face-painting, popcorn, cotton candy, lunch, train rides and a raffle with fun items for every age.

Staff from the Congenital Heart Center volunteer to help with the picnic every year. It's a remarkable site to see congenital heart patients interacting with the staff and doctors outside of a hospital setting. So many people and organizations volunteer time, raffle items, food or money to make this day memorable.

We want to say a big thank you to them because without their support we wouldn't have a picnic. If you didn't make it to this year's picnic, we hope to see you next year and to those who came, thank you and we will see you soon!



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

Becky Todd & Kristen Anderson
Congenital Heart Center
(309) 655-5453

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Lincoln

Meredith Rensberry
Peoria

Erica Wright
Goodfield

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.

SAVE THE DATE

Mark your calendars for Saturday, February 8, 2020, the Congenital Heart Center at OSF HealthCare Children's Hospital and T.O.U.C.H. will once again be sponsoring a Congenital Heart Defect Awareness Symposium. A variety of professional speakers will be addressing issues that are of interest to many T.O.U.C.H. families.

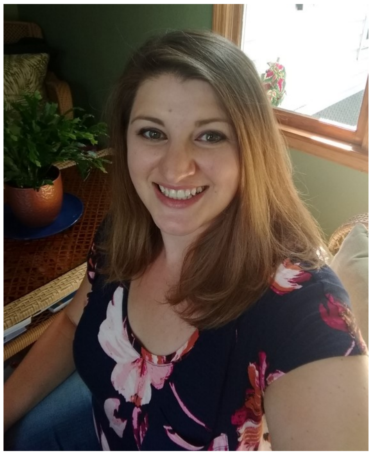
You won't want to miss this fun and informative day!

Drive for Miracles Radiothon 2019

This year's Drive for Miracles Radiothon will be held on December 12th and 13th. This will be the 19th Annual Drive for Miracles Radiothon and TOUCH is once again honored to be a part of this exciting event helping to raise funds for the Children's Hospital of Illinois. TOUCH has always been one of the top fundraising hours for the Radiothon and we would like to be at the top again this year! If you would like to be a part of this wonderful and exciting event, please contact Danielle McNear at danielle.mcnear@yahoo.com for more information.

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

My name is Meredith Rensberry and it is a joy to be the newest member of the T.O.U.C.H. board. I live in Peoria with my husband, Marcus, son ,James (11), and daughter, Carolina (9). Marcus works for OSF Home Medical and I homeschool our kids. My days are filled with teaching as well as taking the kids to ice skating and bowling practice. My hobby list is long and varied, but I most enjoy gardening, baking, reading and needle crafts.



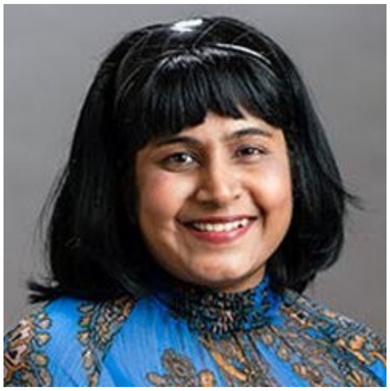
Our journey with T.O.U.C.H. began almost three years ago with the diagnosis of Hypoplastic Left Heart Syndrome in our youngest child, Leah, during a routine prenatal sonogram. Our little girl fought hard for just over two years before losing her battle this Spring.

Leah's life has forever changed mine. My mission now is to come alongside other families like ours and walk beside them through the joyful moments as well as the sorrowful ones. It is important to me that we spread awareness about heart defects and make certain our T.O.U.C.H. families have the support they need.

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

CONGENITAL HEART CENTER

Dr. Bogarapu Joins the Team



Dr. Anya Bogarapu joined the congenital heart team in June, 2019, with a specialty in echocardiograms and fetal echocardiograms. Dr. Bogarapu may already look familiar to some, since she had been previously working at the Congenital Heart Center- Rockford location.

Dr. Bogarapu grew up in India. She attended Andhra Medical College for undergraduate and graduate school. She attended the University of Illinois at Chicago for her residency program. She practiced as a pediatrician for 3-4 years in India. Her Pediatric Cardiology Fellowship was completed at University of Utah. Dr. Bogarapu's professional and research interests are in echo and fetal echo.

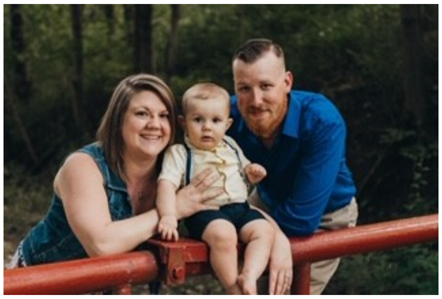
When asked why she was drawn to pediatrics and pediatric congenital cardiology she said, "I was first drawn to pediatrics because I felt like working with kids was more fun rather than work. I then became fascinated by pediatric congenital cardiology because it is very thought provoking and pushes my imagination while helping children in the process.

Dr. Bogarapu and her husband are the proud parents of a 11 year old son and a nearly 8 year old son. In her free time she enjoys spending time with her family, and playing with her children. She also enjoys meditation and yoga.

Welcome, Dr. Bogarapu!!!

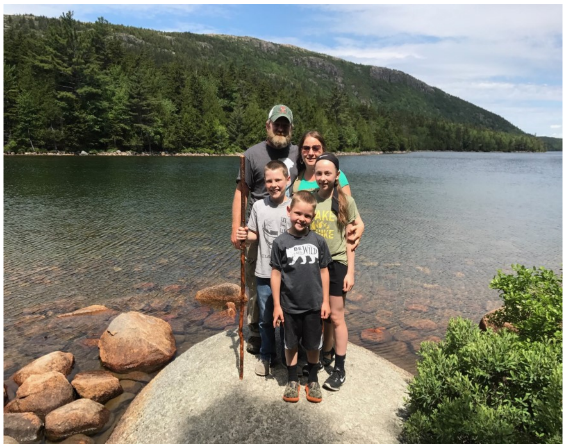
A Familiar Face Comes Back in a New Role

My name is Amber Jenke. I grew up in Indiana and moved to Illinois in 2008. I attended Robert Morris University to obtain my Medical Assisting License. From there I got my first job working at the Congenital Heart Center in 2011 as an MOA. I left this job in 2014 and began nursing school. From there I held various jobs throughout completing nursing school including, PCL for AMSU, Monitor Tech/PCL in PICU, and ending as a Tech in the ED. I completed nursing school December of 2018, and received my License in March of 2019. I then started out my nursing career working at an Oral Surgeon office before I accepted my Position here again at the Congenital Heart Center. Here, I am the Nurse for Doctors Hasselman, Albaro, Bogarapu, and Shula. I have been here since June 3rd, and I absolutely love it. I love the patients, the doctors, learning all about the heart conditions, and that I am always learning in this position. There is never a day that goes by that I am not learning something new or meeting someone new. I find this job highly rewarding!



When I am not working I love spending time with my Husband Nick, and one year old son Bentley. Bentley keeps us on our toes as he is a very busy body. We love to travel, camp, go boating, spend time with family, and go fishing.

Staff Spotlight—Becky Hoffman



1. What do you do at the Congenital Heart Center/ CHOI? I am the Congenital CV Surgery RN Coordinator. I work with the CV surgeons and Becky Todd, APN caring for and educating our patients and families before, during, and after surgery.

2. How long have you worked at the Congenital Heart Center/CHOI? I have been an employee of the Congenital Heart Center since June but have been a part of the Congenital Heart Program since July 2000 as a PICU RN. I still work in the PICU one day a week so you may see me in both places.

3. What do you love most about working at the Congenital Heart Center/CHOI? I love the patients!!! I feel blessed to be a part of their journey and watch them grow over the years. I am inspired daily by the strength I see in each of our patients and their families. Also, the team at CHC is amazing to work with!

4. What are your favorite pass times or hobbies? Spending time with my family. I have been married to my husband Caleb for 19 years. We have 3 children Elle (14), Sam (11), and Finn (9) that are very involved in church, school, and sports. If we ever get free time we enjoy being outside, fishing, hiking, and kayaking. We love to camp and enjoy visiting national parks.

5. What would you like to say to our heart families? It is an honor to be part of your care team. Thank you for entrusting your children to us. I am passionate about helping kids and am thankful for a job that allows me to do that. I am excited to grow and serve you in this position.

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!

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.

WHAT IS TRANSITION?

Have you recently gotten a letter from our program introducing your child to the transition program?

For years the Congenital Heart Center has been working on a comprehensive Transition Program for patients and families. This program is designed to help patients become better advocates for themselves in terms of their healthcare at an earlier age. While all adolescents need to learn to advocate for themselves, those with serious medical history have a more critical need to self-advocate.

Most parents struggle with a number of transitions as their child grows through the adolescent years into adulthood. When children have serious medical condition, parent's find it difficult to "let go" of some control. Often these particular children have spent their young lives in situations where they have had less control than most healthy children. As they transition into strong advocates for their own healthcare, they can gain some sense of control which can be very beneficial.

As your child is entering in the Transition program here are some questions for parents of adolescents to begin considering and discussing within your family:

- Does your teen know the name of his/her heart condition/defect?
- Does your teen know what medications and dosages he/she is taking?
- Can your teen talk about his/her medical and surgical history?
- Does your teen know how to contract his/her doctor's office or refill prescriptions?
- Will your teen monitor his/her own symptoms and talk with medical professionals directly?

Other tools that may be discussed or encouraged for your child to do during the transition visit is setting up your medical ID in the Health app and editing your emergency contacts on your smart phone. Here are the steps to setting those up:

Set up your Medical ID

- Open the Health app and tap the Medical ID tab.
- Tap Edit. If asked, tap Edit Medical ID.
- To make your Medical ID available from the Lock screen on your iPhone, turn on Show When Locked. In an emergency, this gives information to people who want to help.
- Enter health information like your birth date, height, and blood type.
- Tap Done.

Edit emergency contacts

- Open the Health app and tap the Medical ID tab.
- Tap Edit, then scroll to Emergency Contacts.
- To add an emergency contact, tap under emergency contacts. Tap a contact, then add their relationship.
- To remove an emergency contact, tap next to the contact, then tap Delete.
- Tap Done.

Having both of these set up on your child's phone can allow them to have this information wherever they take their phone.

If you have any questions about the transition program or feel like your child could benefit from any of the information mentioned above, please contact the Congenital Heart Center. Please note that this program is designed to help your child transition into adulthood but remain a patient at the Congenital Heart Center.

ADULT CONGENITAL HEART CARE

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

"Do you smoke?" This is a common question you are asked when you go to any medical visit. One year ago, when asking this question to my patients it seemed clear what I was asking. I was asking do you smoke cigarettes. Today there is so much more that we need to be addressing then just smoking cigarettes. Still this is important, anyone who is smoking cigarettes or exposed to second hand smoke is doing danger to not only your lungs but also your heart. This is especially important for our patients with congenital heart disease (CHD). Now we need to be expanding this question to, "Do you smoke, vape or use e-cigarettes?".

First, I'd like to discuss the risks that are associated with e-cigarettes. We certainly don't have any specific information yet on CHD and vaping. In fact we are still learning the effects that e-cigarettes have on anyone using them. We do know that they are harmful and addictive. But first, let's discuss what they are.

So, what is an e-cigarette and how does it work? E-cigarettes create an aerosol by using a battery to heat up liquid that usually contains nicotine, flavorings and other additives. Users inhale this aerosol into their lungs. Technically there is no smoke so often people will say "No, I don't smoke" when they do use e-cigarettes. E-cigarettes are known by a variety of names including vape pens, e-hookahs, mods, tank systems and e-cigs. Juuling is the most popular type of e-cigarette because it is small and looks like a flash drive which can be charged by a USB port. Teens like Juules because they are often not recognized by their parents or caregivers and they come in a variety of colors and flavors.

People believe that using e-cigarettes is better than smoking cigarettes because they do not contain tobacco. While it is true that there is no tobacco, nicotine carries its own problems. Nicotine is a highly addictive substance especially for adolescents. The brain continues to develop through the early to mid-twenties and nicotine use during this time can disrupt formation of brain circuits that control attention, learning and susceptibility to addiction. Long term effects of exposure to nicotine include risk of mood disorders and permanent lowering of impulse control. In addition to nicotine, e-cigarettes contain ingredients harmful to the lungs such as heavy metals (including nickel, tin, chromium and lead), ultrafine particles, and flavorants. One common favorant, diacetyl, has been linked to bronchiolitis obliterans, also known as "popcorn lung".

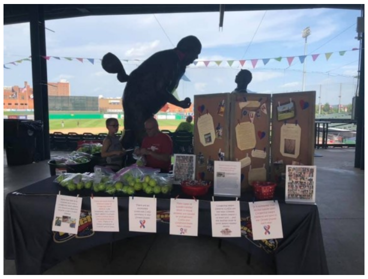
Recent cases have been seen in our area after young adults and teens have been using e-cigarettes. Most, but not all, of the cases involve "dabbing" which is small amounts of cannabinoid products, such as THC, used in e-cigarettes. Patients are presenting with severe lung disease. As of September 6th, there has been over 450 confirmed cases and five deaths including one in Illinois related to the use of e-cigarettes.

I feel I cannot end this article without mentioning smoking marijuana. I am unaware of any research or scientific evidence that has been published regarding CHD and the use of marijuana. I will say that smoking anything is not good for your lungs. Your heart and lungs have a close interaction so any lung disease will affect your heart. Therefore, most patients with CHD should avoid smoking marijuana. Marijuana does increase heart rate, there have been some cases that have been linked to cardiac events. I think in the very near future we will know the effects on the heart in general, and more specifically on CHD. There are no specific indications for marijuana use related to congenital heart disease, so, no I will not be prescribing medical marijuana.

If you have any comments, questions or thoughts about this article or ideas for future topics please feel free to reach out to me at Kristi.n.ryan@osfhealthcare.org

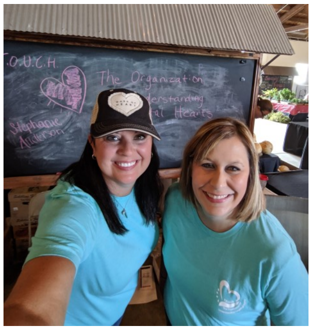
TOUCH Community Outreach Update

CHIEFS GAME



On June 29th we held our 5th Annual CHD Night with the Peoria Chiefs! As some of our heart kids, along with siblings and friends, wished the Chiefs good luck in the High Five Tunnel as they went out on the field, a "Dream Team" of our heart kids/adults also took the field to stand with the players during the National Anthem. We also had a very special first pitch this year to honor the memory of one of our heart warriors. Families had a wonderful time watching the game and connecting with other heart families. This is also a great time to be with physicians, providers, and staff from the Heart Center outside of the office/hospital setting. To end out a great night, the Chiefs won the game in extra innings and ended the night with a spectacular fireworks show!

ABRAHAM LINCOLN MEMORIAL MARKET



On August 10th, representatives of the T.O.U.C.H. Board of Directors help spread Congenital Heart Defect Awareness at the ALMH Market. The Market is located at the Logan County Fairgrounds. Representatives were there to answer questions, provide support to CHD families, and spread CHD Awareness. We had CHD Warriors Stephanie Anderson and Kinley Ray at The Market to share their CHD journey. The CHD warriors were featured on the ALMH Market video helping reach more members of the community. We had many people stop by our booth and ask us what we were about and, most importantly, reached a few CHD families in that area.

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

- **Graham Hospital**
- **Bremer Jewelry**

Memorials

In memory of Leah Rensberry

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

OSF HealthCare
Children's Hospital
of Illinois

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Peoria, Illinois 61603

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MARK YOUR CALENDAR…

December 2 – 13 12 Days of Giving
Watch for more information on Facebook– Please Share, Discuss and Donate!

December 12 - 13 Children's Hospital of Illinois Drive for Miracles Radiothon Hosted by 93.3 T.O.U.C.H. Hour– December 13th 3:30p.m.-5:00p.m.

February 8 Congenital Heart Defect Awareness Symposium
Speakers will be addressing issues that are of interest to many T.O.U.C.H. families.

April 6 Scholarship Deadline
Applications are available 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!

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