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

Winter 2017

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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CONGENITAL HEART DEFECT AWARENESS

Mark your calendars for Saturday, February 11, 2017, 8:00 a.m. to 4:30 p.m. for the first T.O.U.C.H. symposium on congenital heart defects. The event will be held at the Jump Trading Simulation & Education Center, 1306 N. Berkeley Ave., Peoria. A variety of professional speakers will be addressing issues that are of interest to many T.O.U.C.H. families. These topics and presenters include:

- Keynote Address – Dr. Stephen Bash and Vicky Thiel
- Surgical Advancements – Dr. Mark Plunkett
- Cardiac Catheter Interventions – The Present and the Future – Dr. Priti Patel
- Importance of the Primary Care Physician – Dr. Craig Higgs
- Exercise and CHD – Kristi Ryan, APN
- Genetics and CHD – Dr. Michael Leonardi
- Pregnancy and CHD – Dr. Marc Knepp
- Neurodevelopment and CHD – Dr. Wm. Albers and Rebecca Todd, FNP
- Patient/Panel Discussion – Moderator Dr. Billie Winegard

The cost for the symposium is $10 per person or $25 for three or more people in the same family. Seating is limited, so participants must pre-register. The content is recommended for participants who are 12 years of age and older. No childcare will be available at the event. Continental breakfast and lunch will be provided.

Please register at childrenshospitalofillinois.org/touch.

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

Dr. Jeff Orcutt joined the congenital heart team in December, 2015, with a specialty in pediatric and adult congenital electrophysiology (EP).

Dr. Orcutt grew up in Saratoga Springs, New York, a small city three hours north of New York City. He earned his undergraduate and medical degrees from Boston University. While rotating at Boston Children's Hospital, he developed an interest in pediatric heart disease. He also met his wife, Sonia, there. He spent the entirety of his medical training in Houston, Texas, at Baylor College of Medicine and the Texas Children's Hospital, where he completed his internship and residency in pediatrics, as well as his fellowship in pediatric cardiology and pediatric electrophysiology.

Dr. Orcutt's professional and research interests include clinical pediatric electrophysiology, including medical arrhythmia management, ablation procedures in both children and adults with congenital heart disease, genetic arrhythmia syndromes, and implantable cardiac devices such as pacemakers, defibrillators and implantable monitors.

Dr. Orcutt specializes in performing "low-fluoro" ablation procedures. Using this technique, computer mapping software takes the place of using X-ray to visualize catheters in the heart. With this, a routine ablation can be done using a substantially decreased amount of radiation, and in many cases with no radiation at all. This technique is extremely beneficial for all our EP patients, both younger patients who have their entire life ahead of them and would rather not worry about radiation exposure, as well as our adult congenital patients, who potentially have more catheter-based procedures ahead of them, and minimizing radiation is important.

When not in the office or hospital, Dr. Orcutt enjoys spending time with his wife, tinkering with computers, playing golf and home-brewing beer.

Congenital Heart Center Employee Giving Back

Some of you may recognize Congenital Heart Center (CHC) employee Ashley Cooper. Ashley has been with the CHC for almost two years working as a medical office assistant. A little over a year ago, Ashley took on a side job and became a Rodan + Fields consultant. She loves her side job of helping people achieve the greatest skin of their life and seeing their self-esteem improve.

Ashley said, "Every day that I come to work, I am amazed at how strong these kids and those who are now adults are. I see every day what they have to deal with growing up with congenital heart problems. I am lucky to be healthy, and I have two nephews who are healthy little boys and bring so much joy into my life".

Because of what Ashley calls her blessings, and the kids she cares for every day, she decided she wanted to give back. Through her consultant business, she had a sale for month-end. In three days she had made $100 to give to the T.O.U.C.H. program! "I know this donation is not much, but it gives me so much joy to be able to give back to these patients and their families."

On behalf of T.O.U.C.H., thank you Ashley! While you may not think it is much, it is everything to us!!

ADULT CONGENITAL HEART CARE

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

Preparing for your Adult Congenital Heart Disease (ACHD) Appointment

Coming to see your doctor or provider can be stressful. It is unusual to find people that actually enjoy going to their appointments. What I have learned in talking with patients is that many symptoms of anxiety have started or increased in the weeks or days leading up to their appointment.

Here are a few ways that you can prepare for your appointment. Preparation can help your appointment be more productive for you and help to relieve some anxiety.

- Bring a list of all of your current medications including doses and how often you take them. Include all herbal supplements. Also if you have any implanted or injected medications these are important to include.
- Bring a list of allergies and what reaction you have with the allergies, if you know.
- If it is your first time coming to the office then you should also bring any medical history you have. Often times it is helpful to ask your parents about your surgical and medical history as a child. Your family history is also important, especially any relatives with congenital heart disease, arrhythmias, pacemakers or defibrillators.
- Think about what symptoms have been bothering you that you think may be related to your heart. You may find it helpful to write these down.
- List any questions that you want addressed during your visit. Prioritize these so that we are sure to cover the most important ones.
- Notify your cardiologist of any major life events that you are planning: big vacations, career planning or changes, relocation, marriage, or having children.
- If you have had any emergency room or hospital admissions since your last visit, be sure to talk with your provider about this. If you have had any testing done outside of OSF HealthCare, be sure to either obtain those records and bring them with you or notify our office prior to your visit, so that we can review them prior to your visit.

I hope that you find these tips helpful in preparing for your visit. I also recommend that you carry information about your heart with you. We have these available in the office and are happy to help you complete this. We have some with more information that is helpful to take when traveling and smaller ones with minimal detail that can fit in a wallet just like a credit card. Please let us know if you are interested in having a "Health Passport".

If you have any topics that you would like to read about in future newsletters, please email me.
Kristi.n.ryan@osfhealthcare.org

STELLA WILSON MEMORIAL SCHOLARSHIP

T.O.U.C.H. will be awarding one $500 scholarship to one eligible student through the Stella Wilson Memorial Scholarship in 2017. Applicants must meet the following eligibility requirements and complete the entire application process by April 1, 2017.

Eligibility Requirements:

- Have a congenital heart defect or acquired heart disease.
- Must be a patient of the Congenital Heart Center at Children's Hospital of Illinois.
- Must be a high school senior or enrolled college student.
- Complete the application and required supporting documents.

Application Process:

- Complete the 2017 Stella Wilson Memorial Scholarship Application.
- Provide a separate essay providing a brief history about yourself, your goals and aspirations for your future, and why you should receive this scholarship. The essay must be typed, double spaced, and two pages or less.
- Provide two (2) letters of recommendation. One (1) letter of recommendation is required from a teacher or school counselor and must be on your school's letterhead. One (1) letter of recommendation is required from a person of your choice.

Send Applications and supporting documentation to:
T.O.U.C.H.
c/o Congenital Heart Center
420 NE Glen Oak, Suite 301
Peoria, IL 61603

All applications and supporting documents <u>must</u> be received on or before April 1, 2017.

The selection of the recipient will be determined by the Scholarship Committee by June 1, 2017. All decisions are final and not subject to dispute or appeal. Supporting documentation will not be returned. For questions regarding the Stella Wilson Memorial Scholarship Program, contact Gail Eaton at (309)655-2650 or Gail.M.Eaton@osfhealthcare.org.

Application forms are available at the Congenital Heart Center and for download on the T.O.U.C.H. website at www.touchhearts.org.

The Wilson family presented the 2016 Stella Wilson Memorial Scholarship to Hannah Negray.

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

My name is John Phifer. My wife, Amy, and I have seven children: Ethan, in college in New Hampshire; Nicholas, a junior in high school; Sydney, a freshman in high school; Tyler, in 6th grade; Owen, in 1st grade; Addie, age 4; and Sam, age 2. I have worked as a registered nurse for 20 years, ten of those in the Cardiovascular Intensive Care Unit (CVICU) at OSF Saint Francis Medical Center. I met my wife, Amy, when we worked together in the CVICU. I currently work at OSF St. Joseph in Bloomington.

Sam was born in November 2014, with a balanced AV canal defect and down syndrome. His heart defect was initially repaired by Dr. Plunkett in February 2015. One week later, Sam required a mitral valve revision and a four month stay in the Pediatric Intensive Care Unit. Prior to Sam's first surgery, he had a long, trying course in and out of the hospital.

Our experiences with Sammy have given us an amazing perspective from the "other side of the bed." All of my experience as a cardiac nurse could not have prepared me for the roller coaster of challenges, disappointments, happiness, joy and love that we have experienced on our journey with Sam. The support that our family has received through T.O.U.C.H. has been amazing. We know that the program is successful only through the giving and sharing of experiences, time, compassion and understanding of those involved with T.O.U.C.H. We want to contribute positively to others who are experiencing similar life events, so that we can share the blessings we have been given.

Hello! My name is Stephanie Anderson, and I have recently joined the T.O.U.C.H. board. I was born with aortic stenosis and have had three open-heart surgeries throughout my lifetime. My first one was when I was 3, my second was at age 11, and my latest one was at age 32. I have always been interested in being involved in T.O.U.C.H. and promoting the education of congenital heart defects. I am excited about joining the T.O.U.C.H. board. I have had a desire to join the board because T.O.U.C.H. is an organization helping patients with a condition that I am passionate about, especially since I have dealt with it throughout my life. I am so excited to meet other patients, kids and adults alike, that share some of the same experiences I have had.

MEGAN'S LODGE

The T.O.U.C.H. board would like to extend our thanks to those who helped repair and restock the cabin after the break-in last fall. While Bill and Gail Eaton took care of physical repairs, several T.O.U.C.H. families made donations to replace items that was stolen or broken. Please join us in thanking Gail and Bill as well as the following families: Rhonda and Kevin Johnson, Shelli Jo Bump, Tom and Shelly O'Toole, and Trent and Katie Shumway. Thanks to all of you, the cabin was ready to go in record time!

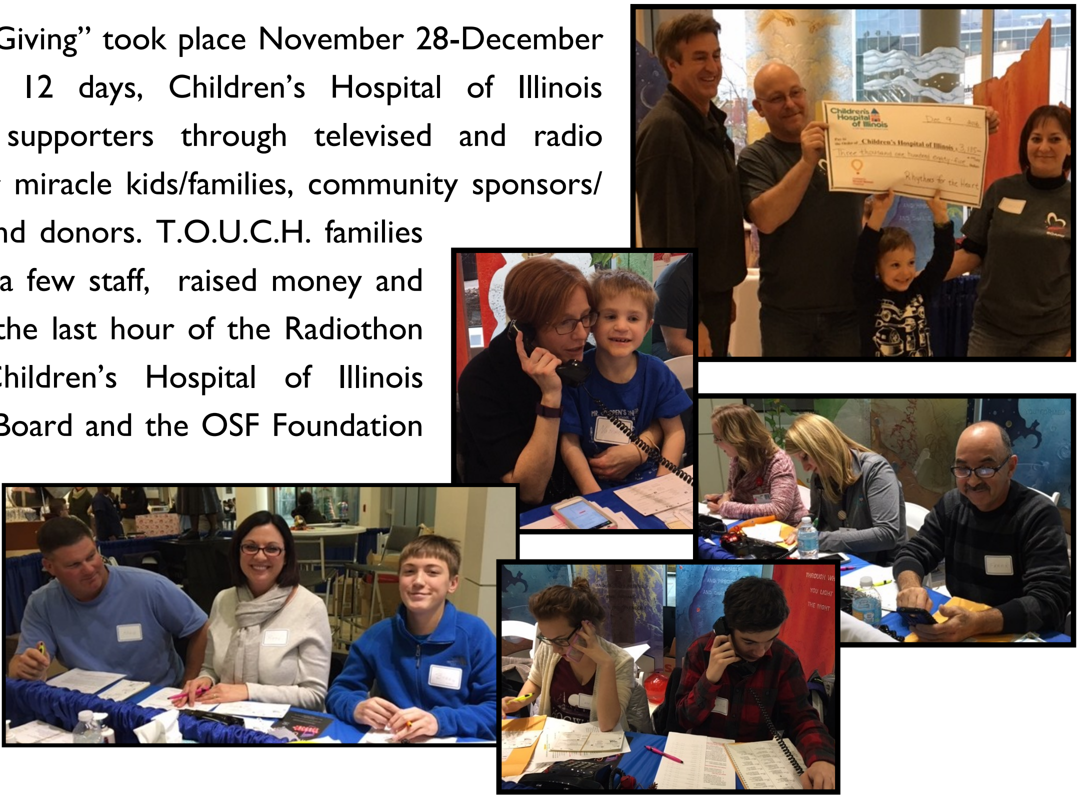
If you would like to book a stay at **Megan's Lodge**, please contact Wildlife Prairie Park at (309)676-0998. The cabin is located inside the park just west of Peoria. The current cost for a stay, from one up to seven nights, is a total of $100, which includes a one-year membership to the park. The intent 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.

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

The T.O.U.C.H. board would like to extend our heartfelt thanks to all of the individuals, groups and businesses who supported our 30th Annual T.O.U.C.H. Picnic, held in September at Wildlife Prairie Park. The monetary donations, raffle prize donations and volunteer services helped make the 30th anniversary a wonderful celebration! Children and adults, who were born with congenital heart defects, along with their families and Congenital Heart Center staff enjoyed a day of fun and inspiration outside of the hospital setting. We had more than 1,200 in attendance! It is through your support and donations that we were able to make the day so memorable!

TWELVE DAYS OF GIVING CHAMPIONS

The "Twelve Days of Giving" took place November 28-December 9, 2016. During the 12 days, Children's Hospital of Illinois celebrated generous supporters through televised and radio vignettes featuring our miracle kids/families, community sponsors/partners, volunteers and donors. T.O.U.C.H. families and teens, along with a few staff, raised money and answered phones for the last hour of the Radiothon on Day 12. 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.



FUNDRAISING AND DONATIONS

Thank You Bremer Jewelry Employees!

Bremer Jewelry is a name that most who live in and around central Illinois area have heard of. Bremer's is a local, family owned business that is dedicated to their communities. In just the past 10 years, Bremer Jewelry has made donations in excess of $500,000 to local charities. As they say, "It's just a part of giving back the happiness our communities have given us!"

T.O.U.C.H. was recently the recipient of that incredible generosity in the amount of $1,003! Each month, the employees donate and raise money for a specific charity. During the month of June, their efforts were selected and supported by Tim Galloway, Service Coordinator. Tim is the uncle of Megan Fawver, the namesake of Megan's Lodge. Tim is well aware of the challenges our kids face throughout their lives.

On behalf of our T.O.U.C.H. family, we would like to thank the Bremer family.
From the bottom of our hearts...thank you!

Donations

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

- Cynthia and Michael Zarate
- Mary Nystuen
- Lisa Adams
- Graham Hospital Association and Graham Medical Group Employees "Jeans Day"
- Memorial from the Joanne Zeeff Family
- Memorials from the JB Sprague Family
- Memorials from the James Lewis Family
- Memorials from the Dick Miller Family

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!

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 The Children's Hospital of Illinois
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Peoria, Illinois 61603

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MARK YOUR CALENDAR…

February 7 - 14 Congenital Heart Defect Awareness Week
Help spread awareness by sharing stories, facts and quotes on social media.

February 11 T.O.U.C.H. CHD Symposium
Join others at Jump Trading Simulation & Education Center to learn more about CHD.

April 1 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!

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