

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

Spring 2014

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



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REACHING NEW HEIGHTS 29th Annual Children's Hospital of Illinois Telethon Sunday, June 1, 2014

Will you please consider being a VIP Phone Volunteer for the T.O.U.C.H. hour during the Children's Hospital of Illinois Telethon? This year will be the 29th Annual Telethon and will once again be a celebration of miracles.

This year's fundraiser will air on WEEK-TV from 12:00pm to 5:00pm from two sites – the RiverPlex Recreation and Wellness Center in Peoria and the Parke Hotel and Conference Center in Bloomington. Once again our T.O.U.C.H. hour will be from 3:00 p.m. to 4:00 p.m. and as always you are encouraged to bring your very special "heart child" with you!! **We need to fill 28 seats, so.....**

Won't you please consider being a VIP this year to help celebrate all of our children, young adults and most important your child!!!

"What does a VIP do?" The answer is simple; commit to one hour on Sunday afternoon to answer phones during the broadcast, raise \$500.00 prior to telethon day, have fun, and return home feeling good because you know you just helped to give a little bit back....Our T.O.U.C.H. hour is from 3:00 p.m. to 4:00 p.m. and one parent and their "heart" child answer phones during that hour. Each person that answers phones during that hour is asked to raise \$500.00 prior to the day of the telethon. You would be very surprised how easy this is done when you ask friends and family to donate to such a great cause. We can even give you some ideas for fund raisers like; A Theme Party, Neighborhood Cookout, Movie Night and lots more. Our new on-line fundraising has become one of the quickest and easiest ways for our phone VIP's to raise money as well.

Please help to make this year's telethon a huge success and consider becoming a VIP. Call Gail Eaton at 1-800-443-9898 or 309-655-2650 as soon as possible if you would like to help or just want more information. Thanks!!

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

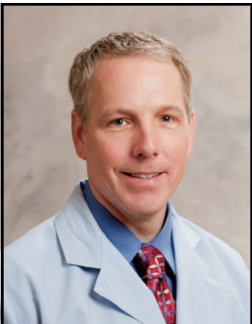
The Congenital Heart Center is pleased to introduce two physicians who have joined the team this past year, Dr. Cecilia Albaro and Dr. Karl Welke.

Dr. Albaro specializes in Fetal Echocardiography. She is passionate about early detection of congenital heart defects. Dr. Albaro helps to educate OB practitioners and sonographers on proper anatomic assessment of the fetal heart. She encourages empowerment of parents to ask specific questions about the development of their baby's heart.



Dr. Albaro grew up in Canada, attended medical school at the University of Utah with research in a Congenital Heart Center, completed residency in Vermont with a rotation at Boston Children's Hospital, and did a fellowship at British Columbia's Children's Hospital in Vancouver. She joined the Congenital Heart Center in Peoria in July, 2013.

Hiking, camping, dancing, and travel are some of Dr. Albaro's hobbies. She and her husband have a three-year-old daughter, so she relates especially well to young families. Her desires as part of the Congenital Heart Center team are to help the center become more well-known for the work they do right here in central Illinois and to help families be comfortable during the process of fetal echocardiography and diagnosis. With her approachable personality and genuine care for people, Dr. Albaro is sure to be another wonderful asset for T.O.U.C.H. families.



Dr. Welke specializes in Pediatric Cardio-Thoracic Surgery. He is very involved with research at the national level and believes in the importance of building connections with other professionals in order to provide the best care for patients. Dr. Welke is passionate about collaboration amongst the entire medical team at the Congenital Heart Center. One of his goals is to increase the quality of care for each individual patient through intellectual collaboration of the surgeons and cardiologists at Children's Hospital of Illinois as well as with professionals across the country.

Dr. Welke grew up in the Midwest, attended University of Michigan, University of Illinois College of Medicine in Peoria, and Dartmouth Medical School in New Hampshire. He completed residency and fellowships in New Hampshire and at University of Iowa Hospitals and Clinics. He has worked as a surgeon in the states of Washington and Oregon before returning to practice in Illinois.

The Midwest is "home" to Dr. Welke, his wife, his three children, and soon-to-be fourth child. He is happy to be back in the area close to family and to be part of a great Midwest congenital heart program. He looks forward to becoming invested in his community. T.O.U.C.H. families will benefit from Dr. Welke's humble approach to providing the best quality of care.

CONGENITAL HEART DEFECT AWARENESS

February 7 - 14 was Congenital Heart Defect Awareness Week. The T.O.U.C.H. Board members celebrated the week by sharing daily posts on the T.O.U.C.H. Facebook page, distributing heart-shaped sugar cookies to patients and staff on the intensive and intermediate care units at Children's Hospital of Illinois, and publishing a video of children and adults affected by congenital heart disease. To find the T.O.U.C.H. Facebook page, search "The Organization for Understanding Children's Hearts" and *like* it to follow the posts. The page shares information on current CHD topics, research, and events. To view the video, go to www.touchhearts.org and click on the *home* tab. A link to *Celebrating CHD Champions* will pop up. The video may also be found on YouTube by searching ***Celebrating CHD Champions***.

Thank you to everyone who contributed to the video by providing pictures or having pictures taken at the picnic. Please help spread more awareness by sharing the YouTube video with your friends and family. Watch for the opportunity to contribute to next year's video in the fall.



Thanks also to those who helped spread awareness during the month of February by sharing CHD information through Facebook and email. Although February 7-14 is the week specifically chosen for congenital heart defect awareness, please continue to help spread awareness throughout every week of the year.



MAKING CONNECTIONS

Families affected by congenital heart disease can often benefit from connections and relationships with other families in similar situations. Here are a few ways to make such connections:

- ***T.O.U.C.H. Heart Parents*** is a Facebook group for **parents** of children, teens, and adults who have congenital heart defects. To join the group, search the group name on Facebook and request to join. This group is for parents only.
- ***Jr. T.O.U.C.H.*** is a Facebook group for **teens and young adults** who have congenital heart defects. To join the group, search the group name on Facebook and request to join. This group is for "heart kids" only but will be monitored by a member of the T.O.U.C.H. board.
- ***Congenital Heart Teens*** is a website created by Justin Hulett, a "heart kid" who would like to provide a place for teens with CHD to share their stories. To share a story, go to www.congenital-heart-teens.weebly.com.
- ***Email Connections*** are a great way for parents to connect if they do not use Facebook. To get connected to another parent in a similar situation, please visit www.touchhearts.org and go to the "contact us" tab.

MEET THE “HEART KIDS”

Pete, a.k.a. PBJ, is 3 years old and lives in Lacon. He loves music, playing with cars, and riding in his “boogie”. Pete was born with Tricuspid Atresia. He’s had 2 heart surgeries and is preparing for his third this spring. He enjoys watching movies in the hospital, but he does not like wearing hospital gowns.

Trace is 5 years old and lives in Galesburg. He loves playing games, playing outside, and going places with his mom. Trace has Hypoplastic Left Heart Syndrome and has had 4 heart surgeries. He and his family most liked the staff at the hospital but didn’t like when things were disorganized.

Eric is 8 years old and lives in Geneseo. In his free time, he likes to play his xbox. Eric was born with Transposition of the Great Arteries and Pulmonary Atresia. He had 2 heart surgeries as an infant. His parents most liked when Cookie sang to him and least liked the amount of time he was in the hospital.

Hannah is 10 years old and lives in East Peoria. She enjoys singing Hannah Montana songs and church music. Hannah was born with Transposition of the Great Vessels. She’s had 3 heart surgeries. While she was in the hospital, she liked the good nurses and doctors the most and disliked all the needles.

Emilie is 11 years old and lives in Washington. She loves all kinds of stuffed animals. Emilie has Ventricular Septal Defect and Coarctation of Aorta as well as Turner’s Syndrome. She has had 2 heart surgeries. She loved watching cartoons at the hospital but did not like the tubes and wires.

Ledy is 14 years old and lives in Germantown Hills. In her free time, she likes to hang out with her friends and spend time outside. Ledy came to Peoria with the Haitian Hearts program when she was very young. She’s had 4 heart surgeries. She liked the food at the hospital but did not like the fact that she had to be there.

Jenna is 37 years old and lives in Washburn. In her spare time, she likes to play the Wii and spend time with children. Jenna has Truncus Arteriosis and has had 4 heart surgeries. She liked that her family could come to visit her in the hospital but didn’t like having to stay in one room.

May we introduce you or your child? Contact us with your information through the “contact us” link on our website at www.touchhearts.org.

“HEART KID” ACHIEVING HIS DREAM

My name is Kristal Barnett and many of you may know me because I am a pediatric intensive care nurse at the Children’s Hospital of Illinois. The reason I am writing you is because my son Dane has been given an incredible opportunity to achieve a major dream of his this summer. Before I tell you about the opportunity Dane has been given, I want to tell you Dane’s story.

Dane was born with a Congenital Heart Defect known as Double Outlet Single Ventricle with Pulmonary Stenosis and Dextrocardia. Dane has had 3 open heart surgeries with his final staged correction being a Fenestrated Fontan. He also had a permanent pacemaker placed when he was 3½ years old due to the development of complete heart block. Dane has also had lead and battery changes performed on his pacemaker at the required intervals.

At age 10, Dane had an embolic stroke when a small clot went through his fenestration of his Fontan circuit and went to a small vessel in his brain. Dane spent several days in the hospital to regulate the blood thinners and was sent home on Coumadin. Dane spent the next several months on Coumadin, enduring many blood draws, appetite changes, and activity alterations. This new Coumadin regimen brought some unwelcome adjustments to Dane’s lifestyle. Shortly after his 11th birthday he requested a meeting with his heart surgeon, Dr. Dale Geiss. They met together with my husband, Kevin, and I of course, and decided that Dane was a candidate for having his fenestration closed surgically. This allowed Dane to stop the Coumadin regimen and resume some of his previously restricted activity.

Dane graduated high school in 2010 and received several scholarships both for his citizenship, community involvement, and ACT score. He is now preparing to graduate from Cedarville University in May 2014 and has accepted an internship with Preemptive Love Coalition in Iraq. Preemptive Love Coalition is an organization which brings doctors from the United States to Iraq to perform life-saving heart surgeries on the children there. Iraq has a very high percentage of Congenital Heart Disease due to the years of chemical warfare in the country. Dane will be leaving for Iraq shortly after graduation and serving as the Marketing and Communications Intern. His duties will include updating donor information, writing blogs and newsletters, creating a year-long marketing campaign, and teaching English. He will be in Iraq for 12 weeks.

If you would like more information about Dane’s work in Iraq or Preemptive Love Coalition please email Dane at danebarnett@cedarville.edu.

PICNIC SPONSORS NEEDED

This year will be the 28th annual picnic on September 28th, 2014. This picnic is a gathering of families whose lives have been touched by congenital heart defects. This event is free to our children and adults with CHD's and their immediate family members. Last year's picnic had nearly 1,100 participants and we are looking forward to even more participants this year.

The picnic is held at Wildlife Prairie Park. Activities held during the picnic include a giant inflatable slide, an inflatable bouncer, a balloon artist, face painting, crafts, and games. The Make-A-Wish Foundation also participates in this picnic and shares information for "wishes". There is even an opportunity to support and give back by donating blood at an American Red Cross Blood Drive.

Sponsorships and raffle donations will help T.O.U.C.H. continue to provide a variety of activities at the picnic as well as support heart families in a number of other ways.

Families and businesses can touch the lives of other families affected by congenital heart defects by providing a sponsorship to this year's picnic. There are a large range of sponsorships available, including \$40 for a carnival game, \$300 for face painting, \$650 for balloon artists, \$3000 for park rental, and several more in between. All sponsors will be recognized on signs located throughout the picnic area and again in the quarterly newsletter.

To submit the name of a business who might like to sponsor a portion of the picnic, please send the information and contact name to Danielle McNear at danielle.mcnear@yahoo.com. Danielle can make the contact or send the letter and sponsorship form to other families to make contacts.

Another area where families and businesses can help is with the raffle of children's and adult prizes. Prizes range from toys, games, electronics, to event tickets, hotel stays, and restaurant gift cards. To donate funds or items toward the raffle, please contact Amie Love at 472-9954 or jalove_love@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.

SAFETY IN AN EMERGENCY

Providing specific medical information to first responders immediately following an accident or other emergency can make the difference between life and death. In a moment of crisis, it is helpful to have medical information written or recorded in a manner that is easily accessible. There are a number of ways to provide that information.

Medical I. D. bracelets are an effective means of sharing critical information with emergency personnel. There are a variety of companies that make medical identification jewelry. Some are simply engraved with information while others include an identification number and phone number linked to a database where the person's specific medical needs and history are stored. MedicAlert is one company that provides this service for a small annual fee. They offer personalized jewelry



for children and adults in the form of bracelets, necklaces, and shoe tags. Check out what they have to offer at www.medicalert.org.

The **Yellow Dot Program** is an initiative of the Illinois Department of Transportation designed to provide vital medical information on the driver/passengers in a vehicle in the case of an accident. A yellow sticker is placed on the rear window of a vehicle, and a card with a picture of the person along with their medical condition and history is placed in the glove compartment of the vehicle. When emergency personnel in Illinois see the “yellow dot”, they know to look for the yellow medical card in the designated place. Go to www.yellowdotillinois.org to find out more about the program and to find the nearest yellow dot distribution center.



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

Paula Sims

Michael and Cynthia Zarate

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



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

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MARK YOUR CALENDAR...

June 1 29th Children's Miracle Network Annual Telethon

Come celebrate YOU and the many lives touched by Children's Hospital of Illinois as we are "Reaching New Heights" for patients and their families at this year's telethon. Visit the Kids Zone with carnival games, crafts, card making, and a special appearance by Julie K! If you'd like to volunteer in the Kids Zone contact Kristie Weniger at 309-566-5680 or Kristie.weniger@osfhealthcare.org.

September 28 28th Annual T.O.U.C.H. Picnic

Join other heart families at Wildlife Prairie Park for a day of fun activities. If you would like to volunteer to work a shift at the picnic, please contact Gina Hulett at 309-678-3761 or gmhulett@gmail.com.

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!

Gina Hulett ~ (309) 678-3761 ~ gmhulett@gmail.com