

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

Winter 2015

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 at OSF Saint Francis Medical Center and The University of Illinois College of Medicine. TOUCHHEARTS.org



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CHD AWARENESS WEEK

Congenital Heart Defect Awareness Week is February 7 - 14, 2015. In honor of CHD Week, the T.O.U.C.H. Board will be hosting a pizza lunch for parents of children who are currently in the Pediatric Intensive Care Unit and Pediatric Intermediate Care Unit. Heart-shaped cookies will also be distributed to each room in those units during the week.

A video celebrating and honoring our "heart kids" is being made from the pictures taken at the picnic. The video will also include pictures of some of the "kids" who were not able to have their pictures taken at the picnic but who sent them to gmhulett@gmail.com. The deadline for pictures to be included in the video is February 5. This year there will also be a segment of the video honoring the "heart angels" who are no longer here with us. Those photos may also be sent to the above address. Please include first name with each picture. The completed video will be posted to YouTube and shared on Facebook and the T.O.U.C.H. website. Please help spread CHD awareness by sharing the video with others. To view the 2014 video, visit YouTube and type in "Celebrating CHD Champions".

For more ways to celebrate Congenital Heart Defect Awareness week, watch Facebook for posts from T.O.U.C.H. and join one of the groups, T.O.U.C.H. Heart Parents (for parents only) or Jr. T.O.U.C.H. (hearts kids who are teens or young adults). Feel free to share ideas in the groups and to post links to other sites with good information and ideas.

More awareness often leads to more funding for research and services. Please help spread the word about Congenital Heart Defects. Thank you.

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 ACHIEVEMENTS

Please note that "first" refers to first at OSF Saint Francis/Children's Hospital unless otherwise stated.

- 1967 Dr. William Albers, Pediatric Cardiologist and first specialist arrives in Peoria
- 1969 First Cardiac Catheterization in area performed by Dr. William Albers
- 1972 First Congenital Open Heart Surgery (ASD) at OSF Saint Francis by Dr. Harold Collins
- 1975 First M-Mode Echocardiography by Thom Rothfolk
- 1977 First Registered Pediatric Cardiac Sonographer in the state, Greg Frary, RDCS, FASE
- 1978 First 2D Pediatric Echocardiography by Thom Rothfolk
- 1979 First Fetal Echocardiography by Greg Frary
- 1980 Congenital Cardiovascular Surgery Program started by Dr. Dale Geiss
- 1981 First Mustard Procedure for Transposition of the Great Vessels by Dr. Dale Geiss
- 1982 First Tetralogy of Fallot Repair by Dr. Dale Geiss
- 1983 First Echo Guided Bedside Balloon Septostomy, Dr. Wm. Albers
- 1984 First Pulmonary Valve Angioplasty in the State by Dr. J.J. Shah
- 1984 First Fontan Procedure for Single Ventricle by Dr. Dale Geiss
- 1985 First Atrial Transeptal Catheterization performed by Dr. Stephen Bash
- 1986 First Arterial Switch Operation by Dr. Dale Geiss
- 1986 First Norwood Procedure by Dr. Dale Geiss
- 1986 First Extracorporeal Membrane Oxygenator Inserted by Dr. Dale Geiss
- 1987 First Youngest Pacemaker Recipient – Dr. Dale Geiss Inserted and Dr. Stephen Bash Programmed Pacemaker within 15 minutes of age
- 1996 First Pediatric Mitral Valve Homograft Replacement by Dr. Dale Geiss (Dr. Geiss and Dr. Christopher Acar worked in unison to perfect the technique and train other pediatric cardiovascular surgeons throughout the world)
- 1998 First Stent Placement in Pulmonary Artery by Dr. J.J. Shah
- 1998 ECMO Program Started by Dr. Wm. Hayden
- 2001 First Atrial Septal Amplatzer Device closure performed by Dr. Douglas Schneider
- 2002 First Congenital Transesophageal Echo Performed by Dr. Stephen Bash
- 2003 First PFO Amplatzer Device closure performed by Dr. Stephen Bash
- 2004 First Robotic Surgery Done on a Congenital Cardiac Patient for Mitral Valve Repair by Dr. Dale Geiss
- 2007 Accredited Fetal Cardiac Echocardiography Program, Second in the State
- 2008 First Radiofrequency Wire Perforation for Pulmonary Atresia by Dr. J.J. Shah

- 2008 First Congenital Cardiac Hybrid Procedure
- 2008 Congenital Cardiac MRI Performed
- 2009 First Extracorporeal Membrane Oxygenation (ECMO) Program in the state to be recognized as a Designated Center of Excellence
- 2009 First Congenital 3D Echo Performed by Greg Frary, RDCS, FASE
- 2009 First Full Time Pediatric Electrophysiologist Joins Congenital Cardiac Program, Dr. David Chan
- 2012 First Full Time Adult Congenital Cardiologist Joins Congenital Cardiac Program, Dr. Marc Knepp
- 2012 First Exit ECMO Procedure by Dr. Randall Fortuna
- 2013 First Congenital Cardiac MRI with 3D Printing
- 2013 First Worldwide Report of 3D Model Reconstruction of Cardiac MRI by Dr. Matthew Bramlet

Thank you, Gail Eaton, for compiling this history to celebrate the Congenital Heart Center and all the blessings and milestones that have occurred since Dr. Albers first came to Peoria in 1967. So many lives have been saved and families have been touched by all of the staff over the years. The congenital heart care provided in Peoria is due to a whole team of specialists who are dedicated to providing high quality services to the children and families. While individuals may occasionally leave the area, the quality and commitment of the program and team approach will continue. Thank you, Congenital Heart Team!!

T.O.U.C.H. BOARD MEETS WITH DOCTORS

When Dr. Geiss and Dr. Fortuna both left Peoria in the time span of a few months, parents and patients began to express concern about the uncertain future of the Congenital Heart Center. In an effort to advocate for families, the T.O.U.C.H. Board met with Dr. Chan, Dr. Bash, Dr. Welke, and Dr. Plunkett. The doctors were very open and receptive at the meeting. The doctors were asked what message they would like shared with families and patients. Dr. Chan shared that he is dedicated to do everything he can to have a congenital heart program here for 20, 30, 40 years to weather any storm and care for patients in the best way possible. Dr. Welke and Dr. Plunkett are excited about working together in surgery and want to put hearts and minds at ease that the program is headed in the direction of long term success and growth. Gail Eaton summed it up well with the following statement, "As sad as everyone is at losing those we love (Dr. Geiss and Dr. Fortuna), the program will continue to grow."

The T.O.U.C.H. Board would like to thank the doctors for taking the time to meet with us.

INTRODUCING THE NEW SURGEON



Dr. Mark Plunkett specializes and is Board Certified in Congenital Cardiac Surgery. He has an extensive background in cardiac surgical procedures and congenital heart research. He began his career working alongside Dr. Dale Geiss at Children's Hospital of Illinois in Peoria for three years. After 15 years of surgical experience, the progression of the Congenital Heart Center has brought Dr. Plunkett back to Peoria. He is excited about joining the Congenital Heart Center team.

Dr. Plunkett received his Bachelor of Science in Biology from Duke University and then his Doctor of Medicine degree from the University of North Carolina School of Medicine. He completed his residency in General Surgery and then a fellowship in Cardiothoracic Surgery from Duke University Hospital. Finally, he completed a fellowship in Pediatric Cardiac Surgery from UCLA Medical Center and Mattel Children's Hospital. Dr. Plunkett then came to Peoria to work with Dr. Geiss in 1996. After three years at the Children's Hospital of Illinois, he was recruited back to UCLA to work with his mentor in the area of child and adult congenital heart surgery. Throughout his career, Dr. Plunkett has completed approximately 4000 cardiovascular surgeries with excellent outcomes.

Dr. Plunkett and Dr. Welke are collaborating to bring a new surgery model to Peoria. Both surgeons will work together in the operating room for every surgery. The doctors are pleased to be working as a surgical team and believe this model will be very beneficial to patients as decision making is often required in the midst of procedures. One of Dr. Plunkett's goals is to grow the Congenital Heart Program so that more resources become available to the patients and families right here in Central Illinois. He is another welcome addition to the cardiac team.

THANK YOU DR. DALE GEISS

Thank you Dr. Geiss
for 34 years of caring
for our children and
young adults born
with congenital
heart defects.



You gave us hope.....you gave us life!!

We Love You.....



TOUCH.
The Organization for
Understanding Congenital Hearts

The **O**rganization for **U**nderstanding **C**ongenital **H**earts

MEET SOME GROWN UP “HEART KIDS”

Dylan Henricks is a nursing student who was born with Tetralogy of Fallot and Pulmonary Atresia. He wrote a few words to share with other “heart kids” and their families...

We are incredibly blessed to live near a hospital that excels in Congenital Heart Care. Growing up as a CHD kid, many of us have spent days and weeks of our lives in the PICU at Children’s Hospital of Illinois. Although it’s not a place we would like to spend our time, we are thankful for support and love of the nurses and doctors that have helped save our lives over the years. Whether it has been through a checkup that ended with a surprise surgery date the next month, or a summer of fun plans that became interrupted by steri-strips and hunched shoulders, I think those of us who have had life-threatening illness have been blessed with a knowledge of how precious life is. When it came time to decide what I wanted to study in college, nursing was the natural choice for a job in which I could care for the lives of others. I am in my last year of school here at Saint Francis Medical Center College of Nursing and couldn't be happier with my decision. Lord willing, I would love to work in the Congenital Heart Center and serve families of kids with CHD’s being able to share and relate to the current trials in their lives. As with most weaknesses, we eventually realize they can be used as strengths if we choose.



Raising three daughters, Tara Shane knows princesses are electrifying and inspiring to little girls. That is why she decided to start A Royal Remembrance – a business which brings recognizable royal characters to parties and events throughout Central and Northern Illinois. In September, Tara attended the annual T.O.U.C.H picnic as the Snow Queen. The queen greeted children, signed autographs, and posed for photos with congenital heart patients and their families. “Of course the Snow Queen is always popular,” said Tara. “But she has never received a reception like the one at the T.O.U.C.H. picnic. I didn’t even make it past the entrance until the event was over!” A few observant children noticed the Snow Queen has scars on her chest like theirs. Thinking fast, Tara simply told them she had her frozen heart mended. Tara’s had six open heart surgeries and countless other surgeries and procedures, all at Children’s Hospital of Illinois. Tara said lighting up the faces of other CHD patients was a real joy. “Every time I meet a CHD kid, I can tell there is something special about them. To be able to survive in spite of poor odds, there has to be a strong will and a passion for life. Even the physically weaker children exude these qualities. It’s really inspiring.” You can keep up with Tara and the princesses of A Royal Remembrance by visiting aroyalremembrance.com.

Hi, my name is Kayla Pepmeyer. I am 23 years old and live in St. Peter's, Missouri. I have Pulmonary Atresia and was airlifted to Peoria when I was a day old. I have had 6 open heart surgeries and received a pacemaker during my last surgery. Dr. Shah is my cardiologist, and Dr. Geiss did all of my surgeries. I spent three months in the hospital when I was 2 years old, and I was a Miracle Child for Children’s Miracle Network. We still travel to Peoria for all of my appointments and surgeries because the doctors, nurses, and staff are like part of our family. Growing up with a heart problem wasn't as hard for me as most people think it would be. I was still able to participate in many sports and activities. As a child, I was very ashamed of all my scars and never wanted anyone to see them. As I've gotten older, I've realized that without those scars I wouldn't be alive today and able to do the great things I've done. Our family loves coming to the T.O.U.C.H. picnic and have not missed one since I was born. I am getting married in May and will continue the tradition of coming to the picnic. I have made so many lifetime friends at the picnic and enjoy spending time with others going through the same issues. Come find me at the picnic, I look forward to meeting you.



\$500 SCHOLARSHIP ANNOUNCED

T.O.U.C.H. is offering an exciting new opportunity for high school seniors and college students. In the spring of 2015 the first T.O.U.C.H. Scholarship winner will be chosen. The scholarship will award \$500 to a “heart kid” who has been treated through the Congenital Heart Center and who is enrolled for the fall in a college, vocational, technical, or trade school.

The Scholarship application and instructions will be posted on the website at www.touchhearts.org in February. The deadline for applications and supporting documents to reach the Congenital Heart Center office is April 1, 2015. Among the supporting documents are proof of enrollment in a post-secondary program, two letters of recommendation, and a personal essay, written by the applicant, describing a brief history of the student, goals and aspirations for the future, and why the student should receive the award.

The recipient will be chosen by a scholarship committee designated by the T.O.U.C.H. Board. Due to conflict of interest, doctors and nurses at the Congenital Heart Center will not be permitted to write letters of recommendation. Recommendations are requested from people who have a relationship with the student outside of the hospital setting.

ONLINE COMMUNICATION CHANGES

The T.O.U.C.H. website is going through some updates and changes. With the organization name being changed from “children’s” to “congenital”, it is time to revisit the website and bring it more up to date. One of the planned changes is the addition of a way to accept donations online. Updated information and links will also be available.

The Facebook page is also undergoing some change. One goal is to make the page more searchable and more widely followed. Facebook groups, *TOUCH Heart Parents* and *Jr. TOUCH*, will remain the same.

An email distribution list has also been created. If you have not received a T.O.U.C.H. email and wish to be included in the list, please send an email with a request to be included to gmhulett@gmail.com.

Other suggestions for improving communications or assistance with communications are also welcome.

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.

DONATIONS

T.O.U.C.H. activities and events rely on the generous donations of people and organizations. Private and corporate gifts are tax deductible and enable yearly events such as the picnic at Wildlife Prairie Park, Megan's Lodge and the T.O.U.C.H. Scholarship also operate through donated funds.

Most of the donors have connections to families of "heart kids". T.O.U.C.H. would like to thank all who encourage co-workers, friends, and family members to donate throughout the year. Donations of gift cards, services, and merchandise are also welcome and encouraged for use at the annual picnic.

Donations may be mailed to T.O.U.C.H., 420 NE Glen Oak Avenue Suite 301, Peoria, Illinois 61603. Plans are being made to accommodate online donations in the near future.

Below is a list of people who have donated to T.O.U.C.H. during the past four months.

- Dr. Randall Fortuna (Scholarship Fund)
- Galina Bush in memory of Nikolay Stikin
- James and Lisa Keyser Family in memory of Michael Keyser
- Graham Hospital Association and Graham Medical Group, Canton
- Douglas and Lori Simmons
- Tim and Deb Galloway
- Bremer C & R Jewelry, Inc. Employees
- Terry and Joan Stralow
- David Dart
- Walter and Doris Payne
- Linda Kagan and David Pott
- Marc and Beth McCormack
- Jan and Kelley Richardson
- Barbara Czarnik
- Pamela Loza
- Heather Locus
- Jamie Lourash
- Michael and Kenna McCall
- Jennifer Busey
- Penelope Turk
- Don and Jan Morton

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



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

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MARK YOUR CALENDAR...

February 7 - 14 CHD Awareness Week

Help raise awareness for congenital heart defects during this week. Check out the front page for details on the event.

June 7 Children's Hospital of Illinois Telethon

Serve as a V.I.P. to answer phones and raise money for the Congenital Heart Center.

September 27 29th 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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