

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

Summer 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 OSF HealthCare Children's Hospital of Illinois at OSF HealthCare Saint Francis Medical Center and the University of Illinois College of Medicine at Peoria.



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

Gail Eaton
Congenital Heart Center
(309) 655-2650

Danielle McNear
Co-Chair, Lacon

Amie Love
Co-Chair/Treasurer,
Washington

Stephanie Anderson
East Peoria

Stephanie Epperson
Downs

Gina Hulett
Germantown Hills

Joe McNear
Lacon

Amy Orwig
Bloomington

John Phifer
Bloomington

Rendi Ray
Lincoln

Erica Wright
Eureka

31st ANNUAL T.O.U.C.H. PICNIC

You're invited.....

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

Sunday, September 24, 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 309-624-3901 or 309-655-2650 to RSVP by September 15.** 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, fellow parents of children with congenital heart defects, and adults with CHD, we encourage you to contact us with your concerns, questions and ideas. No input is insignificant when your child is involved.

Understanding Outcomes Data for Pediatric and Congenital Heart Surgery



Mark D. Plunkett, MD
Chief, Pediatric and Congenital Heart Surgery
Co-Director, CHOI Congenital Heart Center

Collaboration, Data, Transparency..... **What Does It All Mean????**

In this era of computer technology and healthcare transparency many of us have questions as we surf the internet in search of answers to our questions. As increased data has been collected on those born with congenital heart defects and public reporting has permeated our culture, we decided to ask Dr. Mark Plunkett, MD, Chief of Pediatric and Congenital Heart Surgery at OSF HealthCare Children's Hospital to help us make sense of it all.

In recent months, I have had the opportunity to present our surgical results at several forums. I wanted to write this article to help inform those who have not been able to attend my talks. Understanding surgical outcome data is very challenging, even for those who do it on a daily basis! Below I try to summarize the methods and available information to help better inform all of you. These reporting tools are one avenue to help families know they are getting high quality congenital heart care. I also strongly encourage an open, honest conversation with your congenital heart provider.

History

The Society of Thoracic Surgery (STS) Database was established in 1989 as an initiative for improving quality and patient safety in cardiothoracic surgery. These efforts began with adult heart surgery and expanded to include the congenital heart population in 2002. There are currently 116 congenital heart surgery centers reporting outcomes data to the STS. This includes the majority of existing programs in the United States and Canada. Currently, there are over 435,000 operations in the STS Congenital Database that can be accessed and utilized for clinical research, outcomes benchmarking, and observation of national trends in congenital heart surgery. In 2007, CHOI began submitting data annually to STS and we have currently submitted over 2500 operations to the database. The original intention of the STS national data collection and comparison of congenital heart surgery outcomes was to improve patient care and patient safety across all participating centers. This was a good idea, but unfortunately it has also led to a great deal of misinterpretation of information and misleading statements and conclusions by the media and others.

Public Reporting

STS voluntary public reporting for congenital heart surgery outcomes data began in 2015. CHOI was among the first of 26 centers in submitting our data to this public forum. Currently, 69 of the 116 participating STS centers are publicly reporting their outcomes data. In this "era of transparency", that number is expected to grow in the near future.

STS Data is reported as cumulative averages over a four-year rolling time frame. This reduces some of the variation that can occur at each center on a year to year basis. The STS outcomes data from each center is updated every 6 months and public reporting is updated every year. CHOI's publicly reported outcomes can be found on the STS website and our Congenital Heart Center website by following the links below:

<http://publicreporting.sts.org/congenital/1790734127>

<http://www.childrenshospitalofillinois.org/services-and-clinics/specialty-services/congenital-heart-center/outcomes/>

Overall Operative Mortality

Operative mortality is defined as (1) all deaths occurring during the hospitalization in which the procedure was performed, even after 30 days (including patients transferred to other acute care facilities), and (2) those deaths occurring after discharge from the hospital, but within 30 days of the procedure. The most recent overall mortality for congenital heart surgery program at CHOI is 2.9% and compares quite favorably with the STS mean of 3.1%. Therefore, the overall survival for congenital heart surgery patients at CHOI is currently greater than 97%.

STAT Categories

Complexity stratification is a tool for grouping many different operations into groups according to their mortality risks. The categories are called STAT (The Society of Thoracic Surgeons-European Association for Cardio-Thoracic Surgery) and range 1-5 with 1 being associated with the lowest mortality risk and 5 the highest mortality risk. Mortalities by STAT categories are, therefore, considered “risk adjusted” and allows outcomes of lower risk operations and higher risk operations to be compared separately. But comparing outcomes by surgical procedures still remains challenging as even the STAT categories do not account for many other existing acute and chronic conditions or risk factors seen in our patients that can have a direct effect on outcomes. So, although we have come a long way in being able to compare “apples to apples” with these various congenital heart operations, it is a complex process with many opportunities to refine both risk stratification and analysis of surgical outcomes in the future.

CHOI congenital heart center outcomes by STAT categories can be found in our publicly reported data on the STS and congenital heart center websites. Our recent data report for the previous four years reveals that we not only compare favorably to STS outcomes data in all STAT categories, but we also have lower mortality in the STAT 5 category that includes the highest risk and most complex procedures.

Star Ratings

The STS Congenital Database further categorizes each program with a 3 star rating system. This “grading system” is based on risk adjusted mortality but is also statistically dependent on overall surgical volume. This makes the achievement of an STS 3-star ranking almost impossible for most medium and small volume programs, even with excellent outcomes and no mortalities. It is, therefore, a somewhat misleading grading system, as it favors larger volume programs and does not relate directly to only quality of surgical outcomes. By the most recent STS report, there are eleven 3-star programs, seventy-four 2-star programs, and eighteen 1-star programs. Thirteen programs have submitted insufficient STS outcomes data to allow any star rating. CHOI congenital heart program is currently listed as one of the seventy-four 2-star programs in the STS Database.

In Summary

The historical success of our surgical outcomes is a direct result of the coordinated team efforts of many specialized physicians, nurses, and ancillary staff that offer patients every experienced hand needed to give them the highest level of patient-centered care. As a part of those efforts, it is also important that patients and families have a good understanding of the complex information available to them. I hope you find the information above helpful in providing some clarity and perspective to our Congenital Heart Center STS outcomes data. If there are any questions, please feel free to contact our office. Our team is always available to answer any questions you may have regarding our congenital heart program.

CONGENITAL HEART CENTER NEWS

Have you been in the clinic recently and noticed some changes? Here's what is happening in Hillcrest.....

All of the Children's Hospital of IL Medical Group clinics including:

Pediatric Surgery, Orthopedics, Urology, and ENT have relocated to join the Congenital Heart Center on the 3rd floor of the Hillcrest Building.

This has been a great way for our specialty providers to collaborate and provide extended multi-disciplinary clinics to our patients.

The ECHO department now has their own waiting room!

With the addition of Pediatric Urology, Orthopedics, and ENT there would be more patients in the large waiting room. Providing ECHO a separate space right outside of the testing area allows patients a place to check-in and have a short wait prior to their imaging.

Something new! Occasionally situations arise that create an extended wait time, such as the doctor getting called for an emergency or maybe you are seeing your Congenital Heart provider and also have to see Pediatric Urology with a wait in between. Before you may have had to hang around the CHC waiting room until your provider was available....now CHC has a new paging system that allows you to go to the cafeteria, bistro, gift shop, Subway, or anywhere else you want to go on campus! Your pager will buzz and a message will inform you when it is time to return to the clinic for your appointment.

The best is yet to come...OSF HealthCare and Children's Hospital of IL are in planning stages of building a **NEW BUILDING** with **DEDICATED PEDIATRIC AMBULATORY CLINIC SPACE!** This state of the art facility will be located on the OSF HealthCare Saint Francis Medical Center Campus allowing for one stop pediatric care.

CONGRATULATIONS LOGAN WORRICK

Winner of the 2017 Stella Wilson Memorial Scholarship

On behalf of T.O.U.C.H. and the Stella Wilson Memorial Scholarship committee we would like to congratulate Logan Worrick as this year's recipient.

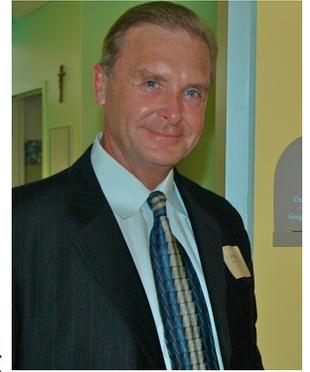
Logan has voiced his appreciation by saying: "I am very honored to be your selection as the recipient of the Stella Wilson Memorial Scholarship, and it is with great thanks and appreciation that I accept the scholarship. This scholarship is very dear to my heart, not only because I am a heart patient, but also because I fully understand the meaning and the commemoration that put this scholarship into being".



This year we had the largest number of applicants to date and am sure that it was a difficult decision for the committee. The committee is formed by the Wilson family and includes family and friends from around the country. No one has a connection to the Congenital Heart Center or to T.O.U.C.H.

Congratulation Logan and good luck with your aspirations.....follow your dream!

STAFF SPOTLIGHT, with Greg Frary



1. What do you do at the Congenital Heart Center? I am a sonographer in the CHC performing transthoracic and fetal echocardiograms.
2. How long have you worked at the Congenital Heart Center? This is my fortieth year doing echos at CHO!
3. What do you love most about working at the Congenital Heart Center? I love interacting with children, their families, and the amazing staff. It keeps me motivated and challenged, as well as feeling “young at heart”.
4. What are your favorite pass times or hobbies? Outside of work, I keep busy doing photography/videography, and interacting with our four grandchildren.
5. What would you like to say to our heart families? Every day, I continue to be in awe of your love, dedication, and hard work to make your lives and those of your families the best they can be.

I am thankful that God has allowed me to be a part of this great mission that the Sisters started here in Peoria so many years ago. Any success that I have had is due to Him. I also thank the giants of this program on whose shoulders I stand, such as Drs. Bill Albers, and Dale Geiss without whom my career and this program would not have been the same.

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.

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 with a congenital heart defect as well as honoring the memory of a loved one. Donating can also be a great way to “pay it forward” after experiencing the picnic for many years.

ADULT CONGENITAL HEART CARE

KRISTI'S KORNER



ACHA National Conference

In June Jodi Reid, the adult congenital care coordinator, and myself had the opportunity to attend the 8th National Conference hosted by the Adult Congenital Heart Association (ACHA). The theme was “Changing the Landscape of Congenital Heart Disease” and was targeted to patients, their families and providers specializing in the care of adults with congenital heart disease. The mission of the ACHA is to improve and extend the lives of the millions born with heart defects through education, advocacy and promoting research. I felt the conference really had a balance of topics that hit all of these areas.

The opening sessions provided an overview about the history of congenital heart disease, where we are now, and what the future has in store. One of my favorite slides was one presented by Dr. Karen Stout out of Seattle, WA where she talked about the varying exercise capacity in patients with Tetralogy of Fallot. She referenced a patient that rides his bike to clinic every year which is quite impressive, especially when he comes from Albuquerque, NM (>1500 mile ride). There was also a patient that presented her perspective of the importance of being informed, especially during high risk times like when you face surgery, when you relocate, and when you face major life changes.

Throughout the conference, sessions were offered that targeted patients/families, medical professionals and research specific. There were several sessions that discussed the single ventricle patient that has had the Fontan procedure, current outcomes and the importance of long term follow-up including screening for changes in the liver. I also found the topic of neurocognitive problems in ACHD interesting as a continuation of all of the discussion regarding neurodevelopment outcomes within our pediatric cardiac kids. Presentations on advanced therapies such as ventricular assist devices (VADs) and what the evolution of these will look like were exciting and amazing.

There is so much research and new technology that I'm not sure any of us know what the future of ACHD holds. In addition to the medical aspect of ACHD there was a focus for patients and their families on the impact of congenital heart disease in the other areas of life. Topics included exercise, diet/nutrition, dating with CHD, family planning, employment, insurance and disability. I had a special interest in listening to the discussions on family planning. Patients and medical experts presented information about supporting women with CHD to safely plan pregnancy and delivery as well as other options. They discussed adoption as an option as well as surrogacy. There was lots of enlightening information that provoked good discussion and left quite an impression.

The closing session and final wrap up was an inspiring note to leave on. The new president and CEO, Mark Roeder spoke about his plans and what the vision of the ACHA board looks like. They are really focusing on spreading the message about ACHA and importance of public awareness regarding congenital heart disease. There was lots of discussion about the many patients that had heart surgery as a baby or child and have been lost to follow up because it was believed they were “fixed”. There is opportunity to prevent bad events if we can get these patients back for a check-up but this means lots of outreach and advocacy. “Advocacy” was the buzz word used throughout that final session.

Some of the recommendations they gave for how you can be an advocate:

- Increase awareness through social media: like the Facebook page and share posts from them.
- Visit the ACHA website at achaheart.org. to learn more about advocacy.
- Share your story.
- Become an activist and seek opportunities to have your voice heard with local congressmen. They also talked about going to DC to advocate. ACHA has a group that goes every year, more info on achaheart.org
- Attend a Congenital Heart Walk. There is one in Chicago and St. Louis. Wouldn't it be great to have a Peoria one? (contact me or T.O.U.C.H. if you are interested in starting this or find out more on achaheart.org).

As you can see it was a busy week with lots of great topics. The speakers were inspiring and enlightening. I encourage each adult congenital heart patient to at least visit the ACHA website. The national conferences are held every couple of years. The website also offers monthly on-line presentations for patients which are recorded and available for you to watch.

If you have any topics that you would like to read about in future newsletters please email me.

Kristi.n.ryan@osfhealthcare.org

WHY IS BLOOD DONTATION SO IMPORTANT

A little over a year ago, I was hospitalized with a serious infection. While everyone was worried about my heart, a duodenal ulcer began to bleed and quickly became a dire situation. Over the course of a few days, I was given over 40 units of blood products. Thanks to generous donors, these blood products were available for transfusions that essentially saved my life and, for that, I will forever be grateful.

Blood products have a shelf life and an expiration date so consistent donation is vital and necessary to keep the supply adequate. Red blood cells must be transfused within 42 days and platelets must be transfused within 5 days. Blood supply is much like a cell phone battery in the respect it needs to be constantly re-charged. At this current time, there is critical shortage of our local blood supply. The American Red Cross needs to collect 14,000 blood donations every day and serves patients at approximately 2,600 hospitals across the country. It is important to remember that one donation can help multiple individuals.

Blood transfusions can involve whole blood or various blood parts. Whole blood contains red cells, white cells, and platelets suspended in plasma. Each part has its own function. Red cells carry oxygen from the lungs to your body's tissue and take carbon dioxide back to the lungs to be exhaled. Platelets interact with the clotting proteins to help stop and prevent bleeding. There are also different blood types. Type O is the most common and as a result, often in high demand and low in supply. Type O negative is the universal type needed for emergency transfusions.

It is important to have blood accessible in the event of an emergency. Some transfusions are planned like scheduled surgeries and some are emergency situations such as car accidents, internal bleeding, etc. A donor can donate to a general blood bank or they can donate for a specific event.

For example, all of the children at OSF HealthCare Children's Hospital under the age of 3 years, having open heart surgery will have Fresh Whole Blood on hold. Fresh Whole Blood is collected within 48 hours of surgery and contains all blood elements including blood clotting factors and platelets. Our local Red Cross has a select group of donors that they use specifically for our heart kids and our neonatal population. Prospective donors with matching blood types are contacted by the American Red Cross once a child is scheduled for surgery. At 6 am the day before surgery donors are required to be at the American Red Cross donation center in Peoria for blood collection. This process takes about 1 hour. The blood must be collected early in the morning to allow time for necessary testing prior to releasing it for patient use the following morning.

Like me, you will probably never meet the people who gave you, your child or your loved one the gift of life through blood donation. The donations are anonymous. However, you can make a difference in someone's life by becoming a general donor or a designated Fresh Whole Blood donor.

For more information please contact the American Red Cross at (309) 674-7171 and encourage all of your friends and family to answer the call to donate and help out our community!

The Congenital Heart Center at



NON-PROFIT ORG.
U.S. POSTAGE
PAID
PEORIA, ILLINOIS 61637
PERMIT NO. 552

530 NE Glen Oak Ave.
Peoria, Illinois 61603

MARK YOUR CALENDAR...

September 18 BMW Golf Classic

Help Raise money for Children's Hospital of Illinois at the Country Club of Peoria.

September 23 NICU Small Wonders Walk

Join other NICU families at Eastside Center for a day of fun activities.

September 24 31st Annual T.O.U.C.H. Picnic

Join other heart families at Wildlife Prairie Park for a day of fun activities.

November 27– December 8 12 Days of Giving & Radiothon

Join other families to promote and celebrate Children's Hospital of Illinois

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.com