

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

Winter 2018

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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2018 STELLA WILSON MEMORIAL SCHOLARSHIP APPLICATIONS NOW AVAILABLE

T.O.U.C.H. will be awarding one \$500 scholarship to one eligible student through the Stella Wilson Memorial Scholarship in 2018. Applicants must meet the following eligibility requirements and complete the entire application process by April 1, 2018.

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.

If you have previously applied and not been selected you may re-apply annually!

Application Process:

- Complete the 2018 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 must be received on or before April 1, 2018.

The selection of the recipient will be determined by the Scholarship Committee by June 1, 2018. 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.

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.

Employee Spotlight with Alisa Snedden



1. What do you do at the Congenital Heart Center/CHOI? I like to think I am one of the first friendly faces our families see when they arrive and help them feel comfortable from the beginning. I check patients in and out, assist with scheduling appointments, and ensure our records are correct which also ensures communication with our families is timely and accurate. I also assist our families with any questions or concerns and help them in any way I can.

2. How long have you worked at the Congenital Heart Center/CHOI? I have had the pleasure of working with cardiac patients for 6 years at the Congenital Heart Center. Prior to that, I was blessed to work with Dr. Geiss for 4 years at Illinois Cardiac Surgery.

3. What do you love most about working at the Congenital Heart Center/CHOI? I truly enjoy working at CHC. We are a “family” and to watch our patients grow is a blessing. On a daily basis I see how our patients are living with congenital heart disease. Miracles happen daily in our office and it is amazing to watch this happen.

4. What are your favorite pass times or hobbies? My favorite pass times include gardening, shopping, volunteering at The Center for Prevention of Abuse and spending time with my friends and amazing family. My husband, Craig, and I have 3 children of our own. Bryan, 30, is an electrician and is employed with Oberlander. Austin, 29, lives in Oak Park, Illinois and is a business executive for UPS and Payton is 20. She is currently finishing her last year at I.C.C. and will be starting in the nursing program at OSF this fall.

5. What would you like to say to our heart families? Thank you for allowing me to be a part of your child’s visit. Your strength, courage, smiles and hugs brighten my work day. Every patient that walks through our door truly holds a special place in my heart. Who could ask for anything better...when a child comes through our door and can’t wait to come behind the front desk and hug you...what a way to start your day! Thank you for allowing me to get to know you and your child.

We would like to submit our most heart felt apology to Greg. There was an editor’s error in the last issue of the newsletter. Please know that Greg’s name is Greg Frary. We Love You Greg and all you contribute to our program.



Bullying & CHD

Society as a whole has put an increasing awareness on bullying and cyber bullying.

At the Congenital Heart Center we have also been hearing more scenarios in regards to bullying.

Many parents of children with congenital heart disease have had the heartbreaking occurrence of bullying of their heart children. Sometimes the bullying occurs because: the child looks small and are perceived as different from their peers, perceived as weak or unable to defend themselves, can't keep up with the other children, requires extra equipment or time to do things, is allowed special circumstances and these things can be triggers for bullies. As adults what can we do?

Parents, school staff, and other adults in the community can help kids prevent bullying by talking about it, building a safe school environment, and creating a community-wide bullying prevention strategy.

When adults respond quickly and consistently to bullying behavior they send the message that it is not acceptable. Research shows this can stop bullying behavior over time.

Parents can also be educating their child's teachers. Teachers can also make sure that children with congenital heart disease don't feel different or left out. It is better to choose activities that everyone in the class can take part in equally. Encourage the teachers to be creative with activities that your child may struggle with, such as instead make one or two additional children rest on the bench, act as a referees or hold the tape at the end of the race.

What are the warning signs parents can be looking for? There are many warning signs that may indicate that someone is affected by bullying. Recognizing the warning signs is an important first step in taking action against bullying. Look for changes in the child, be aware that not all children who are bullied exhibit warning signs.

Unexplainable injuries

Lost or destroyed clothing, books, electronics, jewelry

Frequent headaches or stomach aches, feeling sick or faking illnesses

Changes in eating habits, like suddenly skipping meals or binge eating. Kids may come home from school hungry because they do not eat lunch.

Difficulty sleeping or frequent nightmares

Declining grades, loss of interest in schoolwork, or not wanting to go to school

Sudden loss of friends or avoidance of social situations

Feelings of helplessness or decreased self esteem

Self-destructive behaviors such as running away from home, harming themselves, or talking about suicide

If you know someone in serious distress or danger, don't ignore the problem.

If you feel that your child would benefit from speaking with someone at the Congenital Heart Center about this, we would be happy to coordinate that for you.

TRANCATHETER PULMONARY VALVE REPLACEMENT- VALVE REPLACEMENT WITHOUT OPEN HEART SURGERY

Transcatheter pulmonary valve therapy is an alternative to open heart surgery for children and adults who have a failing, surgically placed pulmonary valve. The Melody valve and the Sapien valve fixes the valve function without open-heart surgery. It can also lengthen the amount of time until a patient needs additional open-heart surgery, with the goal of prolonging it as long as possible. The transcatheter pulmonary valve may not replace open-heart surgery as a treatment, but it can help delay the need for surgery and improve quality of life.

The most common congenital heart defects affecting the pulmonary valve include:

Pulmonary Atresia (a condition where the pulmonary valve is abnormal and does not open like it should which results in blood not being able to go to the lungs to pick up oxygen),

Tetralogy of Fallot (a condition which refers to four heart defects that usually occur together; a hole between the right and left pumping chambers of the heart (ventricles), a narrowed path between the heart and the lungs, an artery (aorta) that is connected to the heart closer to the right side of the heart than normal, and a thicker than normal pumping chamber (ventricle) on the right side of the heart),

Double Outlet Right Ventricle (a condition in which both main arteries, one that carries blood to the lungs (pulmonary artery) and one that carries blood to the rest of the body (aorta), are connected to the right lower chamber of the heart (ventricle). Usually, the aorta is connected to the left lower chamber of the heart)

Patients with these congenital heart defects may have had surgery for their pulmonary valve early on in life and some may have had a pulmonary conduit placed (a tube that connects the heart to the lungs).

Over time, mineral deposits may build up on the conduit (calcification), and it may become narrowed and/or leaky. This may happen as the patient outgrows the conduit or as the conduit wears out from the pressures of pumping blood or from calcium build up. Patients may notice they become tired or short of breath with activity, feel too tired, dizzy or weak to do normal activities, have irregular heartbeats, fainting or near fainting episodes.

Depending on the exact nature of the problem, treatment recommendations may consist of balloon dilation, surgical conduit replacement or transcatheter pulmonary valve therapy.

What Is Transcatheter Pulmonary Valve Therapy?

The Melody/Sapien valves are innovative heart valves that allow cardiac interventionalists to repair defective pulmonary valves in children and adults which helps restore blood flow to the lungs. An artificial heart valve attached to a wire, mesh-like tube (stent) is placed on a thin, flexible tube (catheter) with a balloon on the end and guided to the heart through a vein (usually at the top of the leg or a neck vein). It is then put in the conduit between the right lower chamber (ventricle) and the artery that goes from your heart to your lungs. Once in place, the balloon is inflated to open up the valve into position. The catheter is removed from the body, and the artificial heart valve becomes the new pulmonary valve.

The Melody valve is specifically designed to treat either a conduit/homograft or a bioprosthetic valve. It is made from bovine (cow) jugular vein (BJV) valve sutured within a platinum iridium stent frame.

The Sapien XT valve is the First Transcatheter Heart Valve approved for pre-stented transannular patches but can also be used for conduits and valve in valve. It is made up of pericardial leaflets which are sutured inside a cobalt chromium stent frame.

Not every patient is a candidate for the Melody valve or the Sapien valve. A cardiac catheterization is done first to assess the pulmonary valve that is in place, the coronary arteries and the aortic root to make sure there is no compression of the coronaries and no distortion of the aortic root causing leaking of the aortic valve.

After placement of either of the valves, the patient needs to take one baby aspirin by mouth daily for lifetime and observe antibiotic prophylaxis for lifetime. They stay overnight in the hospital, get a portable chest X-ray that night and then another X-ray in radiology the next day in the morning. We also get an echocardiogram the next day to assess the new pulmonary valve. If everything looks good and the patient is stable then they are discharged home. They can go back to routine life, school or work the next day after discharge with the only restrictions being no contact sports, PE or heavy lifting for 6 weeks. No restrictions after that.

OSF Healthcare Children's Hospital of Illinois Congenital Heart Center is the first downstate Illinois hospital and one of only 90 centers in the world to offer Melody/Sapien Valve implantation. Thank you Dr. Priti Patel for making this incredible technology available for our congenital heart patients!

Currently studies are being done with the Harmony Valve. The Harmony TPV may prove to be a less invasive option for approximately 80 percent of patients who currently undergo initial open heart surgical valve replacement.

Melody Valve



Sapien Valve



Harmony Valve



Living with DiGeorge Syndrome

To learn that your child has a heart defect is devastating, but for many of us, the diagnosis doesn't stop there. Many of our heart kiddos are also diagnosed with additional medical issues or syndromes. For our daughter it was 22Q11.2 Deletion Syndrome (aka DiGeorge Syndrome.) Along with this new diagnosis came many medical issues not related to the heart. The genetics team at CHOI made sure that she was being seen by all the appropriate specialists.

She is or was followed by cardiology, endocrinology, pulmonology, infectious disease, GI, genetics, neurology, orthopedic, ophthalmology, ENT, immunology, audiology, hematology, allergist and pediatric surgery. She has needed services that included feeding/speech therapy, occupational therapy, developmental therapy, and physical therapy. For these specialists and services travel is required to Peoria, Bloomington, Springfield, and Chicago.

22Q11.2 Deletion Syndrome has such a wide range of symptoms and it is hard not to get overwhelmed with it all. That is why we found support to be very helpful. Support through family and friends, patient supportive staff, and other families with the same diagnosis are essential to our sanity. I have found support with the International 22Q11.2 Foundation and the Deletion 22Q Support Group on Facebook. Within these groups you can find many answers to questions you may have regarding your child; families that have gone through similar situations; encouraging words; local and international events; and more. She also has recently started to attend a 22Q clinic at Lurie's Children's Hospital in Chicago. We have found that to be both educational and beneficial.

As we prepare for the upcoming school year we have many concerns regarding her IEP. I have found many valuable ideas and information through these support groups. The 22Q Clinic in Chicago has a school information packet that describes your child's diagnosis and all generalized symptoms, breaks down each school year with learning strengths and weaknesses; ideas for the teachers; and additional support for the teacher/school. This is just one example of how finding support regarding your child's diagnosis is helpful.

If you or a loved one has been diagnosed with a syndrome, I highly recommend seeking out support groups within your specific diagnosis. Or reach out to a family that has the same condition. It can be very helpful to you in the good times and in the bad times. By joining a support group you may also help others by sharing your story.

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.

CHD Awareness Night with the Peoria Chiefs

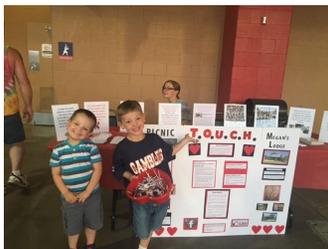
April 21, 2018

It's time for CHD Awareness night with the Peoria Chiefs! We will once again be having our "Dream Team" where 18 of our kiddos can go out onto the field at the beginning of the game with the Peoria Chief players and stand with them during the National Anthem. We will also be doing the High Five Tunnel, which is open to our CHD kiddos and their siblings (and adult CHD patients). For the first time, TOUCH will also be the recipient of the Pitch for Charity event held after the game.

Tickets are \$10.00 ages 3 and up (2 and under are free). TOUCH will receive \$3.00 for every ticket purchased and funds raised will go towards this year's 32nd Annual Picnic.

This has been a wonderful event the last three years and is a great opportunity for our TOUCH families to get together and have some fun! To purchase tickets or for more information, please contact Danielle at danielle.mcnear@yahoo.com.

Keep an eye on the TOUCH Facebook page for future updates on this night.



FUNDRAISING AND DONATIONS

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

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!

- Lorelei Arnold Family & Friends
- Dr. Priti Patel
- Graham Hospital Association & Graham Medical Group—Canton, IL
- Lynda & Art Hanson
- Jenna Grayson & the Mahomet Moms Group

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



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MARK YOUR CALENDAR...

April 1 Scholarship Deadline

Applications are available at www.touchhearts.org.

April 21 T.O.U.C.H. Night with the Peoria Chiefs

Join other families to promote and celebrate CHD Awareness.

September 23 32nd 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!

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