

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

Spring 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 The Children's Hospital of Illinois at OSF Saint Francis Medical Center and The University of Illinois College of Medicine. [www.TOUCHHEARTS.org](http://www.TOUCHHEARTS.org)



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## STEP RIGHT UP... BECOME A VIP FOR THE 30TH ANNUAL CHILDREN'S HOSPITAL OF ILLINOIS TELETHON SUNDAY, MAY 31

30 years of "Miracles".... with a Big Top theme. There is much to celebrate this year. We will be honoring and recognizing "Miracle Kids" from the past 30 years! The fundraiser will air on WEEK-TV 25 from 12:00 p.m. to 5:00 p.m. and will be broadcast from two sites – the RiverPlex Recreation and Wellness Center in Peoria and the Holiday Inn on Empire in Bloomington. This is the time of year that we are asking all of you to please stop and consider being a VIP. T.O.U.C.H. has helped to support this event for all 30 years, we have our very own hour, and we would like this to be a record breaking year!

Many people ask, "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. The 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 might be very surprised at how easily this can be done when you ask friends and family to donate to such a great cause. We can even give you some great ideas for fundraisers; such as a neighborhood cookout, movie night, theme party, garage sale, book fair, bake sale, and more. With our new "**On Line Fundraising Tool**" it is easier than ever. Simply e-mail friends and family, and the show of their love and support will amaze you!

Please help us make this year's 30<sup>th</sup> Annual Telethon a huge success, and consider becoming a VIP. Call Gail 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.

# FIRST MELODY VALVE IMPLANT



February 9, 2015, was a very exciting and historical day for the Congenital Heart Center at the Children's Hospital of Illinois. After several years of pursuing approval from the company and the hospital, Dr. Patel successfully inserted the first Melody Valve in the Cath Lab at the Children's Hospital of Illinois. This procedure has never been done in central or downstate Illinois. Currently, there are only 90 centers in the world approved to perform this procedure.

The Melody Transcatheter Pulmonary Valve is a treatment option designed to restore pulmonary valve function and delay the need for surgery. There are many types of heart conditions that affect the pulmonary valve but the most common defects that require a pulmonary conduit are Pulmonary Atresia, Truncus Arteriosus, Tetralogy of Fallot, and Double Outlet Right Ventricle. For many children, a pulmonary conduit (a tube that connects the heart to the lungs) has been put in at the time of their first or second heart surgery. Over time, these conduits may become narrowed due to calcium deposits that build up, or blood may begin to leak backward through a leaking valve. Both of these situations increase the work of the right ventricle.

The Melody valve is an artificial heart valve, made from cow's jugular vein, that has been attached to a wire frame. The valve is then mounted on a flexible tube (catheter with a balloon) much like the ones that are used for diagnostic heart catheterizations. The catheter is then guided through the vein to the heart where it is put in the conduit between the right lower chamber (ventricle) and the lungs. Once the valve is positioned in place, the catheter is removed from the body and the artificial heart valve becomes the new pulmonary valve.

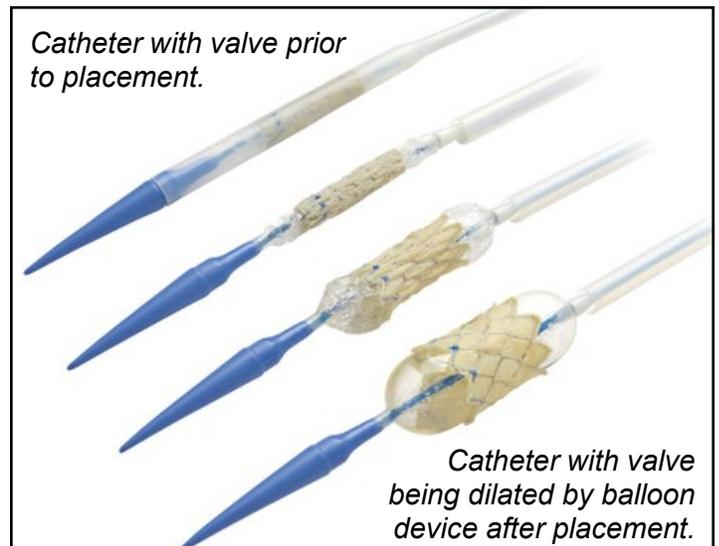
On February 9<sup>th</sup>, 20 year old Jessica Tucker received the first Melody Valve at Children's Hospital. Jessica was born with Pulmonary Atresia and Ventricular Septal Defect, and was taken to the operating room on her first day of life for a shunt. Since then, she has had two other surgeries and several heart catheterizations. The same evening after receiving her valve, Jessica was up walking in the halls and could tell an immediate improvement. She was discharged from the hospital the next day and went back to her college classes two days after the procedure.

Jessica may one day need another heart surgery, but this will certainly delay that day.

Congratulations Jessica and Dr. Patel!



*Close-up view of the melody valve.*



# CONGENITAL HEART DEFECT AWARENESS

## CHD NIGHT WITH THE PEORIA CHIEFS

T.O.U.C.H. has teamed up with the Peoria Chiefs Baseball Team to hold a Congenital Heart Defect Awareness night at the ballpark! This special evening will take place on Friday, June 26, at 7:00 p.m. It's also Superhero Night at Dozer Park, so fans are encouraged to dress in their favorite superhero paraphernalia. Our heart kids are superheroes without any costumes, so there couldn't be a more fitting theme for a night to celebrate "heart kids" of all ages and show the public how amazing they are!



Come out for a night of family fun, including activities, food, baseball, and a CEFCU Fireworks display following the game. Every person with a Congenital Heart Defect will be invited to take part in a High Five Tunnel where the players will "high five" the kids and adults with CHD as they come out onto the field. The Chiefs will take on the Kane County Cougars.



CLASS A  
AFFILIATE

T.O.U.C.H. has purchased a large section of seats for our families and Congenital Heart Center staff to sit together. Tickets are \$10.00 each for those ages 3 and up (2 and under are free). To purchase tickets, please contact Danielle at [danielle.mcnear@yahoo.com](mailto:danielle.mcnear@yahoo.com).

If you purchase tickets and are unable to attend on June 26, you may still use your tickets at any of the following exchange dates: July 7, July 16, August 4, August 19, or September 3.

This will be a great opportunity for our T.O.U.C.H. families to get together and have some fun! It will also help spread awareness of Congenital Heart Defects and the T.O.U.C.H. organization. Keep an eye on the T.O.U.C.H. Facebook page for future updates on this night.

## T.O.U.C.H. BOARD PROVIDES PIZZA AND COOKIES

On February 14, members of the T.O.U.C.H. Board took heart shaped cookies with a CHD awareness message to all patients in the Pediatric Intensive and Intermediate Care Units at Children's Hospital of Illinois. The Board also hosted a pizza luncheon for families on those units the same day.

## CHD VIDEOS



Thanks to everyone who had their pictures taken at the picnic or who submitted pictures! To see the 2015 video, go to YouTube and search "CHD Superheroes 2015". We look forward to putting together another video in 2016. If you have suggestions, please contact Gina at [gmhulett@gmail.com](mailto:gmhulett@gmail.com).

**What did YOU do for CHD Awareness Week? We'd love to hear your stories!  
Please send them to [gmhulett@gmail.com](mailto:gmhulett@gmail.com) if you'd like to share.**

# ADULT CONGENITAL HEART CARE

## NEW STAFF AT CONGENITAL HEART CENTER

With the increase in adult patients, the Congenital Heart Center has been building the Adult Congenital Heart Care staff and services. As part of this effort, Kristi Ryan has recently taken on the role of Advance Practice Nurse for Adult Congenital Cardiology. Kristi's main focus is on cardiac education.

Kristi has had a variety of experiences which she feels are pieces of a puzzle that have come together for this particular position. She began her journey as a traveling nurse in 2000 and was mentored by Carol Koch, a nurse in the Pediatric Intensive Care Unit at Children's Hospital of Illinois. After a move to North Carolina with her husband, Kristi worked at Duke University Hospital managing the Pediatric Cardiac Intensive Care Unit from 2005 to 2007. During this time, she completed her schooling to be an Advance Practice Nurse. She also spent a year working in a pediatric cardiac catheterization lab. She then took an APN position in the Cardiac ICU at Children's Hospital of Dallas.



During her time in Dallas, Kristi kept her eye on Children's Hospital of Illinois. When Carol Koch retired, Kristi returned to Peoria to follow in her mentor's footsteps in the Pediatric Intensive Care Unit at Children's Hospital of Illinois. Then when the new position was created at the Congenital Heart Center, working with Dr. Mark Knepp, Kristi felt it was the final piece of the puzzle. She is excited about her new role in cardiac education and care with adult congenital heart patients.

Kristi is originally from Missouri, and her husband, Matt, is from Washinton, Illinois. They plan to raise their family in the Peoria area. They have an infant son, Zachary, and a preschool age daughter, Samantha. Matt and Kristi enjoy participating in triathlons in their leisure time.

Watch future newsletters for adult congenital articles contributed by Kristi Ryan, APN. Please help welcome Kristi next time you're at the Congenital Heart Center.

## ADULT CONGENITAL HEART ASSOCIATION BLOGS

The ACHA, Adult Congenital Heart Association, hosts a website that is a source of information and support for adults with congenital heart defects as well as for parents of adults and teens with CHD.

One area that many find interesting and helpful is their blog page. Some recent blogs include:

- *Piecing Together My Identity* by Kelly DiMaggio
- *Be Your Own Patient Advocate* by Steve Graham
- *Your Role in Your Healthcare Team* by Christy Sillman
- *CHD During a Job Interview: To Mention or Not to Mention* by Jon Ritchings, Jr.

Check out these blogs and more at [achaheart.org](http://achaheart.org).

# ADULT CHD PATIENT SHARES HER STORY

Elena Gaeta is a 26 year old woman from central Illinois who happened to be born with a Congenital Heart Defect. She volunteers at the T.O.U.C.H. picnics, shares information and encouragement in the Jr. T.O.U.C.H. Facebook group, and works as a camp counselor at a summer camp for kids with Congenital Heart Defects. She is excited to share her story with other CHD families.

“Growing up, I didn’t truly think of myself as different from any other kid until someone pointed out my large scar, which always made me self conscious. As I got older, I realized my heart condition (Single Ventricle Syndrome with Transposition of the Great Arteries and Pulmonary Stenosis) had much bigger impact on my life than I had intended. I couldn't keep it a secret anymore. I like to think that my heart condition has guided me throughout my life. I wanted to work in health care. I wanted to be involved in sports, so I became a trainer instead of the trainee. I wanted to help others live life to it’s fullest potential like I try to do, so I became an athletic trainer, a personal trainer and am currently seeking a master’s degree in occupational therapy. I don’t like to put limitations on myself, and I always want to find a way to be better. I joined a gym and learned a lot about myself mentally and physically. With the help of another personal trainer, I learned how far I could safely push myself. Life is short and there is a lot to see in this world, so I like to travel. I can flip tractor tires, run sprints, rock climb, snorkel, and hike mountains as long as I take my time. I also want to be a confident role model, so I work as a counselor at Camp Odayin, a camp for kids with CHD. I take appreciation in all that I can enjoy in my life and strive to be my best self.”



**Elena also recommends Camp Odayin to other CHD kids and families. She says...**

“Imagine a place where heart kids are free of insecurity from their large scars while wearing a swimsuit, where they can play all day and try new experiences like horseback riding and tubing with a nurse and cardiologist nearby, and where kids can connect with people their own age with special hearts. They can also meet role models such as Miss Minnesota and former NBA player and current Iowa State Cyclones basketball coach, Fred Hoiberg. Memories are made in silly costumes for theme nights, lifetime friendships are formed, and self-confidence rises with each day at camp. Camp Odayin is a very special place for kids with congenital heart defects. I have been a counselor there for two summers and can honestly say I feel more humbled after the experience. What these kids can teach you about life is amazing. After my first day of camp I thought to myself, *Why did I not find out about this camp sooner?!* If you haven't yet checked out Camp Odayin, I urge you to make it a priority on your list of things to do!”

**To find out more about the camp, please visit [www.campodayin.org](http://www.campodayin.org).**

# WHAT CHD TEENS WANT PARENTS TO KNOW

A few of the teens from the Jr. T.O.U.C.H. group that works at the picnic, recently shared some thoughts on what they would like all parents of “heart” teens to know:

- *We know it's difficult to see your heart child go through surgeries and medical procedures, but we want you to know how much we really need your support and care.*
- *After surgery we can be either really loopy or really angry, and we just need you to patiently deal with it. It will only last a little while.*
- *Just because we get mad at you, it doesn't mean we don't love you. It's usually because we are in pain or can't get comfortable.*
- *Sometimes we feel like life just stinks; and more than anything, we need to know that you are there to support us and love us.*

They also have a message for other CHD teens:

- *Stay strong and fight. We know it's hard going through all this, but we also want you to know that your parents will support you and love you. Never lose hope.*



## MEGAN'S LODGE

Megan's Lodge, also known as the T.O.U.C.H. Cabin, has been enjoyed by many families over the past years and will continue to bring joy in years to come. In order to keep the cabin well stocked and looking nice, Amie Love has been making monthly trips to check on the cabin and restock cleaning supplies and essential paper products. Amie is co-chair and treasurer of the T.O.U.C.H. Board, and we are all very thankful for the time and effort Amie has given to the cabin on top of the many other ways she contributes to T.O.U.C.H. As Amie's children continue to grow and life gets busier, she is stepping down from some of the cabin duties. This opens a door for other T.O.U.C.H. families to become involved in helping keep Megan's Lodge in good shape for our families. If you live anywhere near Wildlife Prairie Park and would like to help with the monthly cabin duties, please contact Danielle at [danielle.mcneer@yahoo.com](mailto:danielle.mcneer@yahoo.com). Please help us say “THANK YOU” to Amie Love for her dedication to the upkeep of Megan's Lodge.

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.

# FUNDRAISING EVENT

## RHYTHMS FOR THE HEART – MAY 16, 2015

Rhythms for the Heart is an event to raise funds and awareness of Congenital Heart Defects. The event is being held on May 16, at the Izaak Walton League of America in East Peoria, 1125 Spring Bay Road (Route 26). Doors open at 2:00 p.m., and local bands begin at 2:30 p.m. Food will be served from 2:00 p.m. until 7:00 p.m. (or until gone). Pulled pork meal includes sandwich, potato salad, cole slaw, baked beans, and cookie for \$8.00. Hot dog meal includes 2 hot dogs, chips, and cookie for \$5.00. Lemonade and tea are included in the price of the meal. There will also be a silent auction, raffles, and a bake sale.

### Band line up:

- 2:30 Abe Crowe
- 3:30 Tyler Duckworth
- 4:30 Sarah Marie Dillard
- 5:30 Gilkata
- 6:30 Robin Crowe Band
- 8:00 Doc and Friends



Come out and help us raise awareness of Congenital Heart Defects while enjoying an afternoon/evening of great music!

All proceeds will be donated to the Congenital Heart Center at the Children's Hospital of Illinois. If you would like more information on this event, please contact Danielle McNear at 309-397-7787.

## 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.

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.

- Art and Lynda Hanson in memory of Patti Lyn
- Shelby Fawver in memory of Megan

**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...**

**May 31 Children's Hospital of Illinois Telethon**

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

**June 26 CHD Night with the Peoria Chiefs**

See page 3 for specific details.

**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!

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