

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

Spring 2020

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](http://www.TOUCHHEARTS.org)



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## Congenital Heart Defect Awareness T.O.U.C.H. SYMPOSIUM

**Saturday, February 8, 2020, 8:00 a.m. to 1:00 p.m.**

The Organization for Understanding Congenital Hearts (TOUCH) and the Congenital Heart center (CHC) at OSF Healthcare Children's Hospital of Illinois have joined together to host our 3rd Congenital Heart Defect (CHD) Awareness Symposium for patients, parents, caregivers and families impacted by congenital heart defects.

This year's symposium will focus on the emotional implications of living with CHD for both the patients and their support systems. We will have patient and family stories enriched by panel discussions. We will also touch on transition care to adulthood.

The cost for the symposium is \$10 per person or \$30 for three or more people in the same family. Seating is limited, so participants must pre-register. The content is recommended for participants who are 12 years of age and older. There will be no childcare at the event. Continental breakfast and lunch will be provided.

The event will be held at the Jump Trading Simulation & Education Center, 1306 N Berkeley Ave., Peoria.

**Please register at [jumpsimulation.org/CHC-TOUCH](http://jumpsimulation.org/CHC-TOUCH)**

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.

# **2020 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 2020. Applicants must meet the following eligibility requirements and complete the entire application process by April 8, 2020.

## **Eligibility Requirements:**

- Have a congenital heart defect or acquired heart disease.
- Must be a patient of the Congenital Heart Center at OSF Children's Hospital.
- 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 2020 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 other (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 Ave, Suite 301  
Peoria, IL 61603

**All applications and supporting documents must be received on or before April 8, 2020.** The selection of the recipient will be determined by the Scholarship Committee by June 1, 2020. All decisions are final and are not subject to dispute or appeal. Supporting documentation will not be returned. For questions regarding the Stella Wilson Memorial Scholarship Program, contact Danielle McNear at [Danielle.A.McNear@osfhealthcare.org](mailto:Danielle.A.McNear@osfhealthcare.org) or 309-655-2853 at or Kristen Anderson at [Kristen.E.Anderson@osfhealthcare.org](mailto:Kristen.E.Anderson@osfhealthcare.org) or 309-655-3419.

**You are invited to attend a free Parent 2 Parent Support Group for parents/ caregivers of young children with special needs–**

**When: 1st Monday of the Month Time: 6:00 pm – 7:00 pm**

**Place: Easter Seals 507 E. Armstrong Ave. Peoria, IL 61603**

**RSVP: Call or Text Erica (309) 360-9743**

## **Heart of Illinois CHD WALK**

We are excited announce that we will be having a walk to raise community awareness and celebrate the heart heroes who live in our community. With the support of TOUCH money will be raised to support the OSF Healthcare Congenital Heart Center and the Adult Congenital Heart Association. Put **May 31, 2020** on your calendar!! The walk will be held at Keller Station Shopping Center in Peoria, IL at 2 pm. There will be fun for the whole family at the expo! Watch for more information to be a team captain and create your own team!!! Information will be on the TOUCH Website. Feel free to also email [Kristi.n.ryan@osfhealthcare.org](mailto:Kristi.n.ryan@osfhealthcare.org) for more information.

## **TAKE ME OUT TO THE BALL GAME CHD WITH THE PEORIA CHIEFS!**

Keep an eye on the T.O.U.C.H. Facebook and website page for future information and a date to raise awareness and celebrate CHD with the Peoria Chiefs!

Tickets will be \$10.00 ages 3 and up (2 and under are free). T.O.U.C.H. will receive a small donation for every ticket purchased and funds raised will go towards this year's 34th Annual Picnic.

This has been a wonderful event the past six years and is a great opportunity for our T.O.U.C.H. families to get together and have some fun!



When tickets are available for purchase tickets or for more information, please contact Danielle at 309-397-7787 (call or text) or at [danielle.mcneer@yahoo.com](mailto:danielle.mcneer@yahoo.com).

## **T.O.U.C.H. Facebook Groups**

Just a reminder that there are 3 T.O.U.C.H. Facebook groups for patients and families to join:

- T.O.U.C.H. Heart Parents– This group is open for parents of congenital heart patients to offer support and encouragement to each other.
- Jr.T.O.U.C.H.-This group was designed for younger adult patients to connect and support one another.
- T.O.U.C.H. Bereavement Support:- A new way for our bereaved parents to connect and support one another.

These groups are all in addition to the main T.O.U.C.H. Facebook page which is under the name: The Organization for Understanding Congenital Hearts.

# ADULT CONGENITAL HEART CARE



## **KRISTI'S KORNER** by Kristi Ryan, Nurse Practitioner for Adult Congenital at OSF HealthCare Children's Hospital of Illinois

Happy New Year! As we ring in the new year we will hear everyone talking about their resolutions and goals. As I see patients in clinic, I try not to pick on any patient too much, but to focus on one or two things to work on that will improve their overall health.

Whether you have a congenital heart defect (CHD), are a parent of a child with CHD or neither assuring that you have a balance of healthy lifestyle choices will not only help you live longer but you will also feel better. I'd like to challenge you to pick one

item to focus on now and if you have many areas that could be improved then maybe you can pick one for each month of 2020. In one year, you can think back to how you feel after making these changes.

Here are some small things that you can do to reach goals leading to better health for 2020:

### **Nutrition/Diet:**

- Increase the amount of water you are drinking. You should drink at least 8- 8oz glasses of water! Try to avoid feeling thirsty.
- Limit soda and other sugary drinks to a treat. Soda should not be drank daily and certainly not several times per day. If you drink multiple caffeinated and sugary sodas a day you should decrease these slowly to avoid withdrawal symptoms. Also, it's a good idea to ask your cardiologists if you should have these at all.
- Eat a balanced diet. How many servings of fruit & vegetables do you eat? No matter what type of diet or eating style you follow be sure to include some vegetables and protein. If you are looking at starting a new diet or supplements be sure to ask your cardiologist if there is any concern regarding your heart or interactions with your medications.
- Keep a journal of what you eat for a day, week or month. I like using an app to track my food on occasion to give me an idea how much I'm eating and what the breakdown of carbohydrates, protein, fat is compared to what is recommended. (I like MyFitness Pal)

### **Activity Level:**

- How much are you moving now? It is recommended that you gradually increase amount and intensity of activity over time. Don't go crazy here and try to make up for lost time... you will get burnt out and changes won't stick.
- I recommend an activity tracker. There are lots of different trackers ranging from \$10-\$1,000. If this motivates you I recommend getting one of these. It can stimulate the competitive side as you can challenge yourself to move more than yesterday (or last week) or you can compete against friends and family. i.e. Fitbit, Apple Watch, etc. The American Heart Association (AHA) recommends at least 150 minutes per week of moderate- intensity aerobic activity or 75 minutes per week of vigorous aerobic activity, or a combination of both, preferably spread throughout the week.
- At least 2 days of muscle-strengthening activity is also recommended. i.e. resistance or weights. I enjoy doing home workouts with free weights, I use the BeachBody on Demand app which has an annual membership fee of \$99. There are many others that are great and at the beginning of the year there are lots of great deals to join a gym or hire a personal trainer.
- If you have a significant CHD you should ask your cardiologist what your restrictions are or if they have recommendations for what activity is good for you. If you haven't exercised because you are not sure what your limitations are because of your heart, be sure to have this conversation. Often times, exercise will actually help your heart and you may be doing more damage by not doing anything.

### **Spiritual life:**

- No matter your spiritual beliefs, having time for meditation and/or prayer is so good for everyone's mental health.
- Finding a good book that helps you to focus on your beliefs or whatever area you feel is important is great. I struggle finding time to dedicate to this but have found if I set small goals like 10-15 minutes I am more successful.
- There are some great apps that teach and guide meditation that can significantly help anxiety. OSF Healthcare offers a free app called SilverCloud that can be linked to your primary care provider (PCP) if they are with OSF.

### **Sleep:**

- So many things to fit into a single day. My favorite of all of these is sleep! It really is super important to get a good night sleep. The recommendation for healthy adults is seven hours of sleep
- Try to stick to a sleep schedule. Don't vary your sleeping time significantly from weekends to week days.
- Pay attention to what you are eating and drinking towards the end of the day. Avoid caffeine after dinner time. Also avoiding a big meal within 2 hours of going to sleep is helpful.
- Create a restful environment. You should be sleeping in your bed and limit TVs and electronics close to bedtime. Did you know that melatonin is a natural hormone that our bodies produce to make us sleepy and fall asleep? The blue lights on cell phones, tablets and TV actually suppress the production on Melatonin. If you need quite time to help your brain relax, pick up a book.
- Sleep apnea can cause you to feel unrested and especially have an afternoon slump requiring daily naps. Sleep apnea is actually more common in people with CHD. If you have been told that you snore or gasp for air while sleeping then you should talk with your PCP or cardiologist.

OK, so admittedly that was way more information than I planned to write this newsletter. I know that there are many of these areas that I will be working on in 2020. I encourage you to pick out just one or two and see if it helps you feel better. I'm guessing you have heard most (if not all) of the suggestions in the past but what better time to remind you than now! I'd love to hear if anyone is trying these or has other suggestions. Drop me an email if you get a chance!

If you have any comments, questions or thoughts about this article or ideas for future topics please feel free to reach out to me at [Kristi.n.ryan@osfhealthcare.org](mailto:Kristi.n.ryan@osfhealthcare.org)

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 five 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.

**\*\*Cabin availability is filling quickly, so book your stay today!**

# TOUCH Community Outreach Update

## Bookfest

This October, T.O.U.C.H. hosted a table at Peoria Bookfest 2019 in order to spread awareness about congenital heart defects. Our table provided the opportunity for attendees to create a card for a heart patient. The response from our community was overwhelming as they created an amazing 80 cards! Many people took the time to draw a special picture inside, write well-wishes, and even pen a joke. Our TOUCH board members were able to meet some other families who received care at OSF Children's Hospital of Illinois, as well as a couple heart families. With such a successful event this year, we look forward to next year's event. Mark your calendars for Peoria Bookfest 2020 on October 24<sup>th</sup>. If you would like to help make card kits for the next event, contact Meredith Rensberry at [rensberryx4@gmail.com](mailto:rensberryx4@gmail.com) for details.



## Drive For Miracles

This year marked the 18th Annual Drive for Miracles Radiothon and T.O.U.C.H. is honored to have been a part of this exciting event helping to raise funds for the Children's Hospital of Illinois. T.O.U.C.H. has always been one of the top fundraising hours and we are proud to be apart of the radiothon. Thank you to all who called in and donated and those who volunteered during the T.O.U.C.H. hour.



## FUNDRAISING AND DONATIONS

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!

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

- Marshall County Motorcycle Club

### 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](http://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!**

# CONGENITAL HEART CENTER

Recently I had the opportunity to sit down with our new manager, Carolyn Henricks, to ask her a few questions to introduce her to our TOUCH families.

**I understand that the Congenital Heart Center is not new to you? Tell me a little bit about why this is a little like “coming home” to you?**

34 years ago our first son Drew was born with a VSD. Since he was a 31 week old preemie, he was followed pretty closely at the CHC until his VSD closed at 11 month of age. Then, 7 years later, our son Dylan, now 27, was born with Tetralogy of Fallot and Pulmonary Atresia. Like many parents, we did not know that CHDs are the most common birth defects and occur in almost 1% of births. As many of you know it feels like your world is suddenly turned upside down. The Congenital Heart Center and the staff here became a very familiar place for us and many times was the voice of wisdom and calmness to our questions.



**Tell us a little bit about what you have spent your career doing?**

I have been a nurse for 38 years. I was actually working in open heart surgery when Dylan was born but quickly knew, after receiving care here at the Children’s Hospital of Illinois, that I wanted to work in the PICU which I did in 1994. It was such a gift to work with families who also had children with Congenital Heart Disease. Since that time, I have also worked in the Emergency Department, for the Children’s Service Line, and in Quality and Safety. I am thrilled to again be working with this patient population that I am so passionate about.

**What would you like our heart families to know about you?**

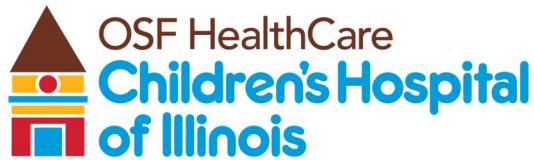
I am truly excited to work in the clinic setting with our patients and families. We are like family here and I hope that you feel that when you visit our office. I really do want to hear your feedback or suggestions of how we can better serve you, your family and your child.

**What are your favorite pass times or hobbies?**

I have been married to my husband Gary for 36 years. We have been blessed with 4 children. Three of them are married and we have 6 grandchildren! Because three of our children live in three different states much of our time is spent traveling to DC, Louisville, and Grand Rapids visiting them. We also love to spend time at our parent’s cabin in the Lake of the Ozarks and enjoy fishing and boating.

**What would you like to read about in the newsletter? We welcome your ideas! Please send them to [kristen.e.anderson@osfhealthcare.org](mailto:kristen.e.anderson@osfhealthcare.org) if you’d like to share.**

The Congenital Heart Center at



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## MARK YOUR CALENDAR...

**February 8**                      **Congenital Heart Defect Awareness Symposium**  
Speakers will be addressing issues that are of interest to many T.O.U.C.H. families.

**April 8**                              **Scholarship Deadline**  
Applications are available at [www.touchhearts.org](http://www.touchhearts.org).

**May 31**                              **Heart of Illinois CHD Walk**  
Join us for the 1st walk to promote Congenital Heart Disease.

**June 29**                              **T.O.U.C.H. Night with the Peoria Chiefs**  
Join other families to promote and celebrate CHD Awareness.

## 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](mailto:kristen.e.anderson@osfhealthcare.org)