

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

WINTER 2013

The Organization for Understanding Children's 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



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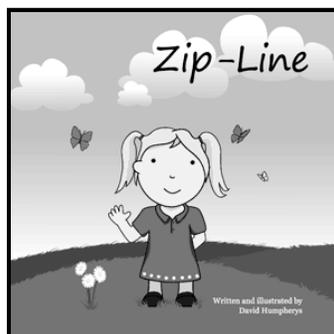
Amy Zbinden
Morton

CONGENITAL HEART DEFECT AWARENESS

Congenital Heart Defect Awareness Week was recently celebrated throughout the world from February 7 to February 14. Individuals, local support groups, national and local organizations, and congenital cardiology centers concentrated efforts to educate the public about Congenital Heart Defects.

The week may be past, but each and every day is an opportunity to spread more awareness. Here are a few simple things you can do to help. First, share your journey with others so they can better understand. Second, encourage families who are expecting to have their newborns screened with a simple test called pulse oximetry screening before they leave the hospital. This is a quick, non-invasive way to measure the oxygen levels in a person's blood which can lead to prompt diagnosis of critical congenital heart defects. Finally, share a book to help children talk about their scar in a positive way.

Zip-Line is a charming children's book written and illustrated by the father of a baby girl who had open heart surgery at 6 months of age.



This heart warming rhyme book whimsically explains the answer to the question "How did that line get there?". The book sets a model for children to be comfortable with themselves, their scar, and the surgery that they were too young to remember.

Visit www.ziplinebook.com for more information.

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.

CONNECTING PARENTS

On December 6, 2012, T.O.U.C.H. sponsored its first parent lunch on the 4th floor of the Milestone building. We invited parents from the Pediatric Intensive Care Unit (PICU) as well as the Pediatric Intermediate Care (PIC). Twelve parents joined us in the Child Activity Room for lunch, support, conversation, and camaraderie.

Parents started trickling in at noon and it was a little quiet at first. They weren't sure who we were or what we are about. After a simple explanation and sharing a little of our journeys the ice was broken and conversations flowed. The parents asked us questions about our children and our experiences. Parents had the opportunity to learn more about the people they see regularly in the units. They shared stories about their children and were able to support each other.

Our board agrees that it is beneficial for the parents to talk and get to know each other. By making connections with other parents in the units, they may feel less stress and more connectedness while their child is staying at Children's Hospital of Illinois. It is our hope that some of those connections will continue to grow even after families leave the hospital to return home.

Our plan is to have a meal (changing days and times) monthly and try to reach out to even more families. Plans have been made for another luncheon on February 9. To aid in our effectiveness, T.O.U.C.H. Board members will be taking part in Parent Mentor Training through Children's Hospital in February. This training will help the board members be more prepared for issues that may arise during conversation. It will also help provide access to further resources which may be of benefit to the families who attend.

As parents who share the experience of raising children with medical challenges, we know that connections with other parents in similar situations is invaluable. We each have stories to share that may touch someone else and open doors for more communication. If the story of one parent can help even one other parent feel that they are understood and they are not alone, then we are fulfilling an important part our mission.

Do you have a story to share? We encourage you to share your stories with those you come in contact with. We would love to hear your stories as well. Share your story with us on the T.O.U.C.H. Facebook page or by contacting us through www.touchhearts.org.

MEET THE HEART KIDS

For the past two picnics, a group of T.O.U.C.H. board members' kids have gotten together to form a Jr.T.O.U.C.H. group to help plan picnic activities for preteens and teens. One of their ideas was to interview heart kids at the picnic so that they can start getting to know each other better and share their experiences. The goal is to introduce a few "heart kids" in each newsletter. Please take a few minutes to meet the first few...

Arabela is 6 years old and lives in Tremont. She has had 6 heart surgeries. Her favorite things about the hospital were eating and watching movies. Her least favorite things were shots and pacemaker adjustments. In her free time, Arabela loves to play with her friends.

Vidal is 9 years old and lives in Germantown Hills. He has had 4 heart surgeries. His favorite thing about the hospital was eating potato chips. His least favorite thing about the hospital was "doing nothing". In his free time, Vidal enjoys playing football.

Hannah is 10 years old and lives in Rockton. She has had 3 heart surgeries. Her favorite things about the hospital were the Spotted Cow and the nurses. Her least favorite thing was being separated from her puppy. In her free time, Hannah likes to play with her dog and watch movies.

Jonathan is 13 years old and lives in Peoria. He has had 4 heart surgeries. What he most liked about the hospital was TV. What he disliked the most was needles. In his free time, Jonathan enjoys playing video games.

Anna is 16 years old and lives in Quincy. She has had 5 heart surgeries. Her favorite things about the hospital were TV and internet. The thing she most disliked was the pain. In her free time, Anna likes to dance and participate in her school color guard.

Elena is 23 years old and lives in Spring Valley. She has had 3 heart surgeries. What she liked most about the hospital was the awesome nursing staff. What she liked least was missing some of the beautiful days of summer. Elena is a college graduate who enjoys yoga, hiking, and taking pictures.

May we introduce you or your child? Contact us with your information through the website at www.touchhearts.org.

FUNDRAISING EFFORTS

Picnic Donations and Sponsors

The annual picnic would not be possible without the generous donations and sponsorships of numerous businesses and individuals. T.O.U.C.H. is very grateful for all of the financial support in 2012!!

It is now time to start soliciting for the 2013 picnic. If you have any personal contacts with businesses, organizations, or individuals who might be interested in helping support the picnic with monetary donations, raffle items, or sponsorships, please contact the T.O.U.C.H. board through the website at www.touchhearts.org.

DuPont 2012 Employee Reunion

Bill Wince, a midnight supervisor in the El Paso DuPont plant, came up with the idea of a reunion for employees and retirees. Deb Winegar, another employee, pulled together a planning committee and expanded on the idea of a reunion. Because they were grateful for the jobs they had, they decided to help others by combining a benefit with their reunion. The event included golf, bags tournaments, dinner, and raffles.



Deb Winegar presented a check to T.O.U.C.H. for \$3670. Gail Eaton, Congenital Heart Center, and Justin Hulett, heart kid, accepted the check for T.O.U.C.H.

The first year recipient of the benefit was Autism/MS and the second year recipient was St. Jude. The most recent benefit was held to raise funds for T.O.U.C.H. The 65 employees and retirees who attended the event raised \$1835 for T.O.U.C.H. and DuPont matched their amount for a total donation of \$3670.

Deb and her committee plan to continue the El Paso DuPont reunion benefit to honor Bill's wish and to give back to their communities.

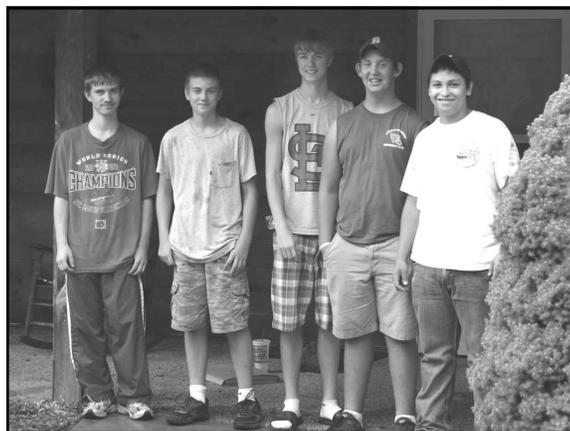
The T.O.U.C.H. board wishes to express our sincere thanks to the DuPont employees and retirees!!

MEGAN'S LODGE

The T.O.U.C.H. Board of Directors would like to extend our sincere thanks to Jeremy McCoy, his family, and his friends for their outstanding work at the cabin. It's because of acts of kindness from those like Jeremy that we are able to maintain Megan's Lodge for so many of our families to enjoy. The Board would like to share Jeremy's story with all of our T.O.U.C.H. families.

My name is Jeremy McCoy and I'm in Boy Scout Troop 5 out of Decatur, Illinois. When I was born, I had a heart defect called Tetralogy of Fallot. I had open heart surgery at OSF Children's Hospital to repair the defect. Then I had another surgery to remove cartilage a while later. Currently I am working on getting the highest rank in Boy Scouts, Eagle Scout. To become an Eagle Scout you have to pass many requirements. One requirement is to plan and execute a service project to give back to the community. When I started thinking about who to do the project for, OSF Children's Hospital was the clear choice. The T.O.U.C.H. cabin was the perfect place for a project, because I could help other families that are currently suffering the same problems my family did. A few of my fellow scouts went to the cabin in June and did some yard work and repairs on the cabin. I also built two benches to add to the cabin. I'd like to thank T.O.U.C.H. for helping me set up the project and get one step closer to becoming an Eagle Scout. This was a great way for me to give back to the people who have done so much to help me live the life I can today.

**Thank you, Jeremy
and BSA Troop 5!**



If you would like to book a stay at Megan's Lodge, please contact Wildlife Prairie State Park at 309-676-0998. The cabin is located inside the park just west of Peoria. The current cost for a stay is \$85, 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.

T.O.U.C.H. BOARD LEADERSHIP

There has recently been a change in leadership of the T.O.U.C.H. board. Gina Hulett and Terra Boeker have stepped down from positions of chairperson and secretary after several years of service. Please take a few moments to meet our new leaders.

My name is Angela Ludlum and I am the current co-chair of T.O.U.C.H. I am mom to Gabriel, an active five year old with congenital heart defects. We have been involved as a heart family with Children's Hospital of Illinois for three and a half years. After I was informed of our son's heart condition, just prior to our adoption of him, I was given the phone number of another mother whose son had the same defect. I immediately called her and we talked for over an hour. Her information and support was invaluable for us on this journey.

I was informed about T.O.U.C.H. when we began to bring Gabe to the Children's Hospital for his first procedures. The information they gave was very helpful, but even more support came when we started attending the annual picnics and getting to know other heart families. It was so great to see the heart kids interacting and having fun in a normal atmosphere. No one thinks about being sick on that day and it is something we look forward to every year.

I was very excited to join the board for T.O.U.C.H. and to be a part of helping other families in the cardiac community. I feel that the mission of T.O.U.C.H. is important to so many families so the opportunity to help chair the board seemed like a good chance to continue my commitment to T.O.U.C.H.

Amie Love, veteran member and treasurer of the T.O.U.C.H. board, has agreed to continue as treasurer while she also partners with Angela as co-chair.

Tracy Bond is currently serving as the secretary of the T.O.U.C.H. board. Tracy has been on the board for a year and a half. She is mom to two boys, one of whom was born with congenital heart defects and has had several surgeries. Tracy lives in Chillicothe but was raised in Nebraska. She enjoys cheering on the Huskers during football season. When she is not busy raising her boys, she likes to volunteer at their schools and likes to read. Tracy is also passionate about the mission of T.O.U.C.H. and is excited to be a part of the leadership team where she can make a difference for other families.

Thank you Gina and Terra . . .

T.O.U.C.H. would like to send out a special “thank you” to Gina Hulett for her years of service as the Chairperson of our T.O.U.C.H. board. Gina has served in this capacity since the fall of 2005. She has been instrumental in overseeing all of our board responsibilities and functions. Gina is the mother of three boys, two of which have heart defects and have gone through numerous surgeries. Although she is stepping down as chairperson she will remain on the board as an active member. She will continue to oversee our website, help with the newsletter and of course continue her involvement with our annual picnic. We also want to thank Terra Boeker for her service as Secretary of our T.O.U.C.H. board for several years. Terra is the mother of two girls, one of which has heart defects and has had numerous surgeries. While Terra is stepping down as secretary, she will remain active on the board. From all of us at T.O.U.C.H. we would like to send out a big “thank you” for all that you have done for each of us and all of our kids.

Check us out and LIKE us on FACEBOOK!

Search on T.O.U.C.H.

Like our page.

Keep up to date on information and events!

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

In Memory of Linda Little

Joseph and Kathleen Kleinkort

Janice Holder

Rose Harms

David and Lynn Glover

Jerry and Ramona Carlton

Clinton Power Station Employees Club

Delta Kappa Gamma

In Honor of Jonathon and Nolan Decker

Don and Jan Morton

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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Children's Hospital of Illinois & OSF Saint Francis Foundation CALENDAR OF FUNDRAISING EVENTS

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| February 16 | Children's Fashion Show, Luncheon & Concert with Julie K
for Children's Hospital of Illinois - Embassy Suites, East Peoria |
| April 27 | MJC Fishing Tournament
Proceeds benefit OSF Saint Francis Foundation and designated to
Simulation Center |
| April 27 | Fight to the Finish
Presented by Children's Hospital of Illinois H.O.P.E.
Jubilee State Park |
| May 2 | Score Fore Kids Golf Outing
for Children's Hospital of Illinois - The Den at Fox Creek, Bloomington |
| June 2 | 28th Children's Miracle Network Annual Telethon
for Children's Hospital of Illinois - Peoria Riverplex & Bloomington Parke Hotel |

For more information, please visit www.childrenshospitalofillinoisfoundation.org.