

The mission of T.O.U.C.H. (The Organization for Understanding Children's Hearts) 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 at Peoria.

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Keeping in TOUCH

FALL, 2005

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

Gail Eaton, Executive Director, Children's Heart Institute of Illinois
Gina Hulett, Chair (Germantown Hills) (309) 383-4165
Jenn Paulsen, Vice Chair (Rockton) (815) 986-8779
Amie Love, Treasurer (Washington) (309) 444-5756
Kaye Randell, Recording & Corresponding Secretary (Galesburg) (309) 342-1660
Jeff & Cathy Cunningham, Communications & Publicity (Urbana) (217) 239-1440
Lise' Mundwiller, (Dunlap) (309) 243-7154
Terra (Shelton) Boeker, (Metamora) (309) 693-1778
Shelly Weaver, (Bartonville) (309) 697-5042
Amy Zbinden (Morton) (309) 263-7704
Sally Achterberg (East Peoria) (309) 694-1470
Julie & Adam Carlton (Washington) (309) 886-2163

As members of the T.O.U.C.H. board and fellow parents of a child with congenital heart defects, we encourage you to contact us with your concerns. NO question or concern is too small when your child is involved.

T.O.U.C.H. Picnic, 2005

The 19th Annual T.O.U.C.H. Picnic was held at Wildlife Prairie State Park outside of Peoria on Sunday, September 25. Despite a rainy start to the day, nearly 500 people attended. Because of the wet weather, several activities were moved under the shelter, which made for slightly crowded conditions. That didn't stop the fun, though!



With assistance from volunteers from the Rainbow Girls of Bloomington/Normal and the Kappa Phi Club from Bradley University, families enjoyed crafts, games, face painting, pictures with the Funny Car, a moon walk, and visits with animals. IL State Trooper Cowling led a K-9 demonstration to an entranced audience. There were all kinds of foods, raffle prizes, train rides, and Cookie, of course. Mike Eagan, from W.L. Gore and Associates, Inc. donated two gortex jackets that were given away as door prizes.

Perhaps most important were the opportunities to interact with other families who have been through similar experiences. The picnic is always a wonderful time for families, and especially our heart kids, to get together in a fun environment outside of the hospital. If you haven't attended one of these picnics yet, we hope you'll join us next year for our 20th anniversary picnic!

See pages 3 and 8 for more details and pictures taken at the picnic!



From the Editors:

Readers! 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 the newsletter.

We look forward to hearing from you or meeting you in person.

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T.O.U.C.H. Website:
www.touchhearts.org

New T.O.U.C.H. Board Positions

by Gail Eaton

The board of T.O.U.C.H. wishes to extend a heartfelt thanks to Terra (Shelton) Boeker and Shelly Weaver for serving as Co-Chairmen of the board for the past few years. Through their efforts they have certainly brought about many positive changes and open the door for many more. Both Terra and Shelly will remain on the board but in a different capacity. We would like you to help us welcome Gina Hulett and Jenn Paulsen as they step into their new positions of Chairman and Vice-Chairman. Both Gina and Jenn come to us with prior experience of serving on other community boards but more importantly with a commitment, passion and determination to make T.O.U.C.H. stronger than ever.

Last but certainly not least we wish to thank Janine McWhirter-Young for her years of service and dedication to the board as she steps down from her position. We look forward to an exciting future as we endeavor to find new and challenging ways to serve heart children and their families the very best that we can.

Thank You Terra, Shelly & Janine

The T.O.U.C.H. Board Welcomes Adam & Julie Carlton

When you have a heart baby, your life changes in many ways. You see how precious life is and you re-evaluate your priorities. So it was for Julie and Adam Carlton after the birth of their second child, Elijah.



*Adam & Julie Carlton with
Elijah and Michaela*

Elijah was born with transposition of the great arteries/ASD/VSD and underwent an emergency surgery at three days old to put in a shunt, followed by a corrective surgery at ten days old. The Carltons were warned that he might not make it, but Elijah was strong and made it through. Although he still has a few areas they are keeping an eye on, he has had no problems what so ever. "He is our daily reminder that miracles do happen!" said Julie. "We decided right after Elijah was born we wanted to get more involved with children's heart issues and TOUCH seemed a logical choice."

The experience was a life changing one in other ways. Adam changed jobs and is now an application manager for OSF Health Plans. "I wanted to work for an organization that was making a difference in people's lives" he said.

Julie Carlton is a full time, stay-at-home mom with Elijah (almost 3) and older daughter Michaela, age 5. She and Adam are expecting their third child in mid-April. When she has time, Julie is a birth doula, teaches childbirth classes and

is a psychotherapist specializing in pregnancy & childbirth issues and play therapy with young children.

The Carltons are interested in exploring the idea of a physical support group for heart families and/or a mentoring program to link new families with families who have a child with a similar condition.

Thank you, Julie and Adam, for getting more involved with the T.O.U.C.H. board!

Support for T.O.U.C.H. Picnic Much Appreciated

T.O.U.C.H. would like to extend a heartfelt thank you to those individuals and companies that donated prizes to be raffled off at the T.O.U.C.H. picnic. The raffle always generates a lot of interest and excitement and the proceeds from the raffle will go towards supporting a wonderful picnic next year. We appreciate their generosity and would like to recognize the following individuals and businesses:

- Terry and Leslie Boyer
- Collette Miller and Family
- Maui Jim and Charlene McCollum
- Mike Egan from W.L. Gore & Assoc., Inc.
- Springhill Suites and Chris Whitlatch
- PAR*A*DICE and Becky Mohr
- CEFCU at Valley Park & Joan McWhirter
- Ned Kelly's Steak House and Bill Bikai
- Panera Bread and Katie Pavlacic
- Hampton Inn and Sandy Andrews
- Hotel Pere Marquette and Joel Green
- Walmart in Bloomington
- Kroger's in Bloomington & Normal

In addition to the T.O.U.C.H. Board, many volunteers helped to make our picnic run smoothly. We would especially like to thank the Rainbow Girls from Bloomington/Normal and members of the Kappa Phi Club from Bradley University.

The success of our picnics is dependent on the hard work of individuals and businesses that volunteer their time and resources. We thank you once again for helping us to celebrate our special children and their extraordinary families.

--- *Janine McWhirteryoung*



Start Your Engines!

It wasn't the Indy 500, but Tim Board's Hawaiian Nitro Funny Car raised money for T.O.U.C.H. at the River Valley Drifters 16th Annual Car Show and Cruise on August 13th. Tim Board and his wife Pam helped to raise money for T.O.U.C.H. Many of you will recognize Pam from the Pediatric Cardiology Associates office. She and her husband Tim wanted to do something to help raise money for the cabin project. Tim has been involved with Funny Cars for the past 40 years and decided last winter to build a car that he has put our T.O.U.C.H. logo on. On Saturday night while people cruised the Morton downtown, Tim had his Nitro Funny Car on display and his wife Pam was serving up Hawaiian Nitro Dream Sickle Drinks (ice cream, milk, whipped cream.... yuummmm). Not only did the Board family display this incredible car, have ice cream drinks with all the profits coming our way but they also had very cool Hawaiian Nitro "Need for Speed" T-shirts with our logo on them for sale. Unfortunately a very much needed rain decided to fall that evening and we had to close up shop early, but not before Tim was able to start up that monster engine to the delight of all the onlookers. Tim will be displaying and running his car throughout the state with our T.O.U.C.H. logo proudly displayed. All of us would like to thank Pam and Tim for their wonderful support.

T.O.U.C.H.ing Hearts: One Bracelet at a Time

13-year-old Dane Barnett is a lot like any other teenager. He says for fun he likes to hang out with his friends, go to movies and play basketball. He's a member of Bureau Valley South Junior High School's Scholastic Bowl team, webmaster for the school website and manager for the basketball and volleyball teams.

But unlike most teenage boys, Dane wears a bracelet. And he wants more people to wear a bracelet, too!

His mom Kris is a nurse in the Children's Hospital Peds ICU and Dane says ever since he was born they have raised money for the hospital's Children's Miracle Network telethon through raffles, bake sales and asking for donations. But last year Dane was inspired by his Lance Armstrong bracelet to use the same fundraising idea for the Children's Miracle Network by selling bracelets with their name to raise money. Because CMN is a nationwide organization and getting permissions might have involved a lot of red tape, Children's Heart Institute Executive Director Gail Eaton told Dane he could just sell the silicon bracelets with the T.O.U.C.H. name instead.

Dane got right on the job and found a company that would make 2,000 of the red embossed bracelets for \$1.50 each. After borrowing money from his grandmother to get them made, he has since sold fifteen hundred of them for three dollars each with half going to pay back his grandmother and the other half donated to T.O.U.C.H. He sells the trendy jewelry pieces through local businesses, schools and through his mother at Children's Hospital. He also asks family and friends to help him sell. He keeps track of the funds by simply putting the sales in an envelope.



Dane Barnett

When asked how he raised so much money he says he just "decided on the bracelets and it grew and grew and grew." He also says his heroes are his grandparents and his doctors. And he helps raise money because he wanted to give back to the hospital and help other kids. "It's not even close to what they've given me," he says gratefully.

Dane is the son of Kevin and Kris Barnett and lives in Buda, about an hour north of Peoria. He was born with a heart defect consisting of Dextrocardia and double inlet single ventricle. He had surgeries at one, two and ten years old and had a pacemaker installed when he was 3 years old. He says he's done with the surgeries, only has to take a baby aspirin a day for medications and has no limitations because of his defect.

To buy a bracelet, email k.barnett@mchsi.com or write to Dane at 224 North St., Buda, IL 61314. They are \$3 each.

Brady Weaver Benefit

By Gail Eaton

Brady Weaver, his family and friends are **all** a source of true inspiration. Brady was born July 19, 1999 with Hypoplastic Left Heart Syndrome. He has had five cardiac catheterizations and six cardiac surgeries. Brady will be entering first grade this year at Hollis School in Bartonville, Illinois. His mother Shelly and his dad Greg have been true supporters of T.O.U.C.H. and the Children's Hospital of Illinois since Brady's birth. What started out as a neighborhood garage sale to help raise money for both T.O.U.C.H. and the hospital has exploded into an annual benefit.



The 3rd Annual Brady Weaver Benefit was held Friday, May 13, 2005 at the Bartonville American Legion pavilion and attended by over 400 people. The evening included karaoke, a wandering magician, clowns, games for the children, a lemonade stand, bake sale, great food live music by Mid-Life Crisis, a live auction and phenomenal prizes. One lucky guest took home a magnificent 42" Samsung plasma television along with a DVD/VCR combination.

A special presentation to Brady was made possible thanks to the generous donation from Doc and Mari Halliday. Brady (along with his family) was brought to tears when he was presented with an autographed D. Brown jersey and poster. Brady is such an Illinois bas-

ketball fan that the committee sported bright orange and blue shirts with Brady's photo on the back promoting his love for the Illinois basketball team. Whenever I think about how this family and their friends have taken a neighborhood garage sale to the extreme, I am simply amazed.

Committee members include **Dave and Cindy Carlock, Joe and Angie Menefee, Jackie and Randy Sweeter, Dave and Terry Miller, Jason and Kim Wolland, Brad and Sharon Wood, Bill and Betty Wood, Katie Sales, Terry O'Malley, Linda Bruce and of course Brady's parents.**

It also needs to be said that many more people helped out the night of the benefit, as well as the 80 individuals and companies who donated items. All in all, the committee worked extremely hard and their efforts did not go unnoticed when the final numbers were tallied. Brady's benefit brought in an amazing \$19,600 this year and T.O.U.C.H. has been the recipient of \$14,000 that will go towards the "Megan's Lodge" fund. If you know the Weavers or any of their amazing friends please give them a special thank you because they are already hard at working planning next years benefit which is scheduled for May 19, 2006.

On behalf of T.O.U.C.H.....Thank you Brady, family and friends!!!



Don't forget to let us know if you are moving!

Help us keep our mailing list current by sending your new address to:

Gail Eaton

The Children's Heart Institute of Illinois

at the Children's Hospital of Illinois

530 NE Glen Oak Avenue

Peoria, Illinois 61637

T.O.U.C.H. Interest Survey

Hi, my name is Gina Hulett, and I am the mom of two children with congenital heart defects and one "normal" child. I've been a member of the T.O.U.C.H. board for a few years and have recently moved into the position of chairman. Our executive board has made it a goal for this year to get more people involved in T.O.U.C.H.. We need your help gathering information so we can provide more of you with opportunities to be an active part of T.O.U.C.H.. If you were not at the picnic, or did not complete a form, please take the time to fill out the information below and mail this form to me as soon as possible at:

Gina Hulett, 1345 Countryside Court, Metamora, IL 61548.

Your Heart Child(ren)'s Name(s) First _____ Last _____

Mother's Name _____ E-mail Address _____

Street Address _____ Phone # _____

City _____ State _____ Zip Code _____

Father's Name _____ E-mail Address _____

Street Address (if different from above) _____ Phone # _____

City _____ State _____ Zip Code _____

Please indicate any areas where you might like to get more involved with T.O.U.C.H.

_____ Helping plan the annual T.O.U.C.H. picnic

_____ Helping with the T.O.U.C.H. newsletter

_____ Fundraising for T.O.U.C.H.

_____ Participating in community advocacy for T.O.U.C.H.

_____ Mentoring other parents of heart children

_____ Stuffing T.O.U.C.H. packets and bags, etc.

_____ Helping organize a resource library for the Peds ICU

_____ Participating in a support group

_____ Helping put together a T.O.U.C.H. calendar

_____ Submitting your child's picture for, and purchasing, a T.O.U.C.H. calendar

_____ Soliciting material donations for the T.O.U.C.H. cabin (Do you have any particular connections to help us obtain appliances, furnishings, fixtures, etc.?) _____

_____ Helping with construction of the T.O.U.C.H. cabin (Do you have particular skills that you could lend, such as carpentry, plumbing, etc.?) _____

_____ Answering phones for the T.O.U.C.H. hour of the Children's Miracle Network Telethon in June (you are also asked to raise \$500 in advance)

**Please return this survey to Gina Hulett, 1345 Countryside Court, Metamora, IL 61548.
Thank you for your help!**

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