

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

SUMMER, 2006

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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. Dedicates "MEGAN'S LODGE"



Sunday, May 21st, 2006 was a beautiful day to dedicate "Megan's Lodge" at Wildlife Prairie Park. Over 150 people enjoyed a perfect blue sky and gentle breeze while they toured the new T.O.U.C.H. cabin and . It was certainly a celebration of life and a celebration of an incredible act of love.

A short ceremony was held to acknowledge the vision of Mr. William Rutherford and the dream of Megan Fawver. Mr. Rutherford first approached T.O.U.C.H. with this concept in December of 2003. In May of 2004, Megan decided to donate all of her graduation money to the cabin.

(see "Lodge", page 5)



**MEGAN FAWVER
1985 - 2004**

Megan's Lodge is dedicated to the memory of Megan Fawver of Mahomet, IL. Megan was born with a complex congenital heart defect, undergoing her first surgery when she was 2 days old. She would have 5 more during her life. In September 2004 she underwent a heart transplant that was successful but she died of complications on September 13, 2004. Because the cabin was so special to Megan, her family donated all her memorials, almost \$75,000, towards construction of the cabin.

(see "Megan", page 2)

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.

Jeff & Cathy Cunningham

(& Michael)

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Megan *(continued from page 1)*

Megan wanted to see the cabin built as a place for children with heart defects and their families to use, for little or no cost, as a retreat and be close to Children's Hospital and their doctors. Megan's mother, Shelby Fawver explains why the completion of the cabin was so important to Megan and her family:

Megan's life was very full. She had opportunities that so many children like her do not get. We had great insurance to help pay the cost of her hospital stays...the cost was over \$3 million over the 19 years she was with us. We had a lot of family to offer us plenty of opportunities to travel around the country. Megan was very healthy in every other way which enabled us to travel far from her doctors and the hospital. A lot of families are strapped financially due to rising medical costs and some children are just too sick to get too far from their doctors.

Megan donated her high school graduation gift money, over \$6,000, as well, keeping only \$20 for herself to buy a favorite music CD. Megan was an Illinois State Scholar, graduated with high honors and had started as a part-time student at Parkland College. She volunteered at

Carle Foundation Hospital and with the American Heart Association's annual fundraising walk.

Despite her medical problems, or maybe because of them, Megan had an attitude toward life that inspired those who met and knew her. "You only had to know Megan for 10 or 15 minutes to know she was a special person," said one.

"She was happy, an active kid who really wanted to get out there and experience everything. She wasn't a complainer," said another. And Megan's mother Shelby says Megan was wise and mature beyond her teenage years. "She knew she was born very sick and knew her life would not be long...Not one day did she feel sorry for herself. Her dream was not to be anything spectacular but to live a normal life."

Portions of this taken from "Megan's Story" by Fred Kroner, Champagin-Urbana News-Gazette

How to stay in MEGAN'S LODGE

If you are patient of Peoria Pediatric Cardiology then you have the opportunity of a lifetime... stay in Megan's Lodge for a once a year fee of \$50.00. This will entitle you to stay at Megan's Lodge for 1-7 days, and gives you a one year family membership to Wildlife Prairie Park.

The cabin includes the following accommodations:

- Sleeps 8
- Port-a-crib
- Fishing, (you bring the poles)
- Completely furnished

For information on how to rent the cabin at Wildlife Prairie Park,
3826 North Taylor Road,
Hanna City, IL,

Call 309-676-0993

(NOTE: you must bring your own towels, sheets and food).

Megan's Cabin has already had guests. For a testimonial, see page 4

Come Celebrate!

20th Annual T.O.U.C.H. Picnic
Sunday, September 24, 2006

Noon to 5 pm

Wildlife Prairie State Park

(10 miles west of Peoria via I-74, Exit 82 or
via I-474, Exit 3)

Schedule of Events

All TOUCH activities take place at the Train Depot

Noon Registration

Raffle tickets for sale

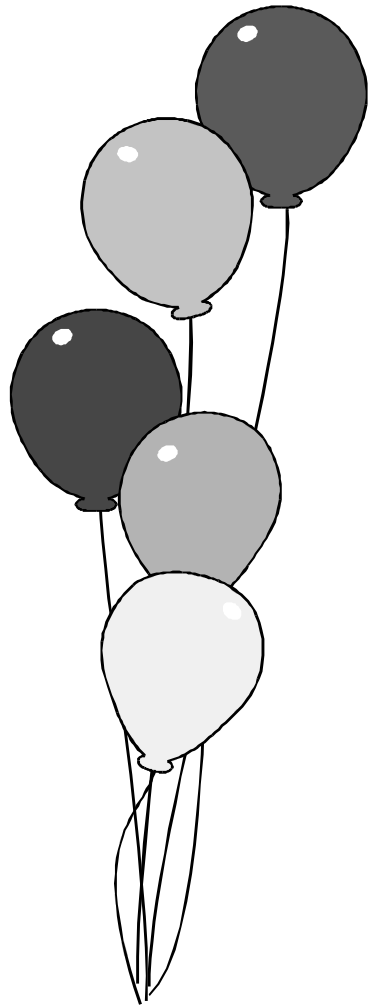
TOUCH Store

2:30 Group Picture at Train Depot**

(orders for pictures will be taken at the picnic and will cost \$12.50 per copy)

3:00 Lunch

4:00 raffle and door prize drawings (including a lap top computer!)



FREE Event!

On-going activities:

Carnival games, Jumping Jacks Moonwalk, crafts for kids, face painting, balloonist, K9 Dog Demonstration, funny car, free train rides, tram rides to tour TOUCH cabin, park naturalist, real fire truck, live music by the band "Fielder", loose change drive

This picnic is sponsored by the Children's Heart Institute of Illinois and
The Organization for Understanding Children's Hearts (T.O.U.C.H.)

It is free to our TOUCH kids and their immediate family. Please RSVP by September 14th.

** Free T-shirts will be given to all of our special "Heart Kids" this year.

In order to receive a t-shirt, you MUST RSVP before September 14th and give us your child's shirt size.

Available sizes are: 6 mos., 12 mos., 18 mos., 2, 4, 5/6, 6/8, 10/12, 14/16,

Adult S, M, L, X-L, 1X, and 2X

♥ ♥ ♥ To RSVP, call 1-800-443-9898 or 309-655-3453 ♥ ♥ ♥

The first visitors to the T.O.U.C.H. cabin, Barb and Jeff Hill, spent a week there with their children Victoria, Joshua and Nathanael. This letter shares their thoughts about their experience.

There is a place of quiet serenity, where sunsets, and sunrises, are painted as if they were a master work of art. The skies mix together deep colors of pink and blue above a picturesque lake. It is here that the birds, crickets, and frogs blend together in a sweet lullaby. This place is located in central Illinois, within traveling distance of your home. It is fondly named "Megan's Lodge," or the TOUCH cabin. The cabin is within Wildlife Prairie State Park, but retains privacy, as it is located in seclusion close to walking trails. We were the first family to stay within its walls, the "explorers," as some have called us. We traveled with great anticipation, knowing that this vacation was a dream come true, beyond our greatest expectations. The cabin's exterior is landscaped exquisitely. One could tell much care had been taken in the selection of flowers, young trees, and shrubs. Breathtaking views can be seen from all areas of the wrap around porch, but our favorite was the back, overlooking the lake. Often we would spend the early mornings and evenings watching the sky, greeting the new day, or watching the stars glisten like diamonds in the sky. It was here that wildlife abounded. Golden colored birds would perch on matching flowers. Rabbits braved meeting us within walking distance, even the baby rabbits. A turtle wandered within several feet, much to the delight of our children. Deer made their home close by as well; we saw a doe and fawn several times while driving to the cabin.

The stay included a membership to the park, and so we were able to see the animals within the main park as well. One night, we saw the elk, in single-file, walk close by the bear enclosure. Our daughter was thrilled to see two baby elk trailing behind the pack. The interior of the cabin felt as if it was "home" to us. It looks as if it belongs in the pages of "Better Homes and Gardens," with its cathedral ceilings and fireplace. A wooden stairway leads up to a loft bedroom. The main floor boasts of a living room, kitchen, bathroom, and bedroom. All rooms have windows in which to see the exquisite views - including the kitchen. The dining room has a picture window that overlooks the lake, and the stone fireplace in the living room is nestled between two windows. The cabin was well equipped. Our family was supplied with everything that we needed, from a pack 'n' play to a George Forman grill. The back porch has a porch swing and rocking chairs in which one may comfortably view the scenery. One night, while in this very spot, our daughter was overheard to say, "I hear the angels singing, mommy." Perhaps this is true - the angels may take great delight in seeing the children who are little heroes come someplace to rest.

-----The Hill Family

--- See page 2 for information about how your family can reserve the cabin!

21st Annual Children's Miracle Network Telethon A Huge Success

by Gail Eaton

A big "thank you" to everyone who helped to make the 21st CMN Telethon a huge success! This year's tote board was **\$2,687,669.00**. The VIP's for the T.O.U.C.H. hour raised \$21,134.79 in advanced pledges, \$6,523.00 during their hour on the telethon, along with the Brady Weaver Benefit check presentation for \$6,000.00. This gave our hour a total of **\$33,657.79**. What a great job!! I would like to recognize and thank the following people:

Joyce and Eric Dietrich
Dan, Trish and Trecker Ralph
Tom and Jay Sanders
Shelly and Brady Weaver
Frank and Sydney Abdnour
Terri, Bob and Elise Punke
Gina and Justin Hulett
Summer and Matt Knobloch
Michelle and Max Bannan
Lori, Jeff and Jacob Kern
Marla and Austin Phillips
Cindy and Mackenzie Miller

Dane and Krystal Barnett
Julie and Christian Witte
Jeff and Michael Cunningham
Terra Boecker and Caroline
Beck and Kaitlyn Wilburn
Sherry, Michael and Elle Wilkinson
Becky Hoffman
Tony and Lucas Zbinden
Leslie Boyer
Angie Graham
Stephanie and Garrett Rice

The telethon is always the first Sunday after Memorial Day so mark your calendars for next year and if you've never been involved, consider joining the T.O.U.C.H. team next year!

"Lodge", *(continued from page 1)*

When Megan died in September, 2004 Megan's family received over \$75,000 from donors as far away as Phoenix, all who had heard about her generosity. The Fawver family gave every penny to build a cabin. Megan's mother, father and sister all shed tears for their daughter but said they felt her presence at the dedication. Yellow (yellow was Megan's favorite color) rose bushes had been planted in front of the cabin last summer and only the day before the ceremony did the roses bloom. We think it was Megan's doing.

Cookie Bannon played her guitar and sang "What a Wonderful World," a fitting choice given the picturesque location of the cabin, which is surrounded by greenery and overlooks a lake.

Following the ceremony, punch and cookies were served while guests enjoyed the view from the rocking chairs and the swing on the front porch. Others were overheard planning a summer get-a-way.

For information on how your family can reserve the cabin, call 309-676-0993





From left to right: Woodland Hall Director Emery Jordan, Woodland Hall Council President Sarah Brillhart, Co-Community Service Chairs Clarissa Allen and Lauren Tedlock, Emily Fawver, Shelby Fawver, Gail Eaton

SIUE Woodland Hall Residents Raise Money For “Megan’s Lodge”

--By Lauren Tedlock

February was Spirit Month at Southern Illinois University Edwardsville’s Woodland Hall. As the 2005-2006 Co-Community Service Chair on the Woodland Hall Council it was my duty to come up with a community service project in addition to the other spirit events occurring throughout the month. I had the idea of raising money for T.O.U.C.H, because I had attended high school with Megan Fawver. After gaining approval from the other council members a “Penny War” fundraiser started in Woodland Hall.

Woodland Hall is divided into eleven wings of about 50 students each. Each wing had a jug at the front desk of the residence hall, in which they collected their money. Each wing placed pennies into their own jug to earn positive points for their wing. Students placed silver coins and bills into the jugs of other wings to give those wings negative points. The wing with the most positive points at the end of the month won an ice cream sundae party. The response to the fundraiser was amazing. One student was quoted as saying, “I’m very competitive and this is for a great cause, so of course I would donate.”

After several hours of counting coins by my fellow Co-Community Service Chair, Clarissa Allen; Woodland Hall Director, Emery Jordan; several Resident Assistants; and myself we had a final tally. Although only one wing of students won an ice cream sundae party, the residents of Woodland Hall raised \$500 for “Megan’s Lodge”.

It was a great privilege for me to be the leader of this project. Megan was a good friend of mine and I am so grateful to my fellow students here at SIUE for raising this money in honor of Megan. I am excited that the cabin will be opening soon for families just like Megan’s to be able to enjoy.

Lauren Tedlock
Co-Community Service Chair
Woodland Hall Council
Southern Illinois University Edwardsville



2007 T.O.U.C.H. Calendars Planned for Holiday Giving

Once again, T.O.U.C.H. will be putting together a calendar featuring pictures of our heart kids. The calendars will be ready by December 1st and will make great presents for family and friends. More information will be sent in a separate mailing soon. Get your digital cameras out and start snapping!



Nolan's Big Brother Has A Cookie Sale

Nolan Decker has a special older brother, Jonathon, now age six. When he was just 5 months old, Jonathon had a surgery for the repair of a coarctation of the aorta. Incredibly, his younger brother Nolan required surgery at three days of age for a critical coarctation of the aorta. This past February Nolan, now 22 months needed to have a surgery to address another problem in his heart. Although only six, Jonathon wanted to do something in honor of his little brother. He and his mother Julie decided that he could sell heart shaped cookies at his school, St. Thomas in Philo, IL. He and his mother baked the cookies and Jonathon sold them on Valentines Day, also National Congenital Heart Defect Awareness Day. When Nolan was admitted on February 22, 2006 the boy's parents, Julie and Bill, presented T.O.U.C.H. with a check for \$324.50.

This is much more than a story of a very sweet little boy selling cookies. This is a story about a big brother who was worried about his little brother and wanted to be able to do something for him. This is a story about his parents, who were dealing with their youngest child needing another surgery and acknowledging that their oldest child was trying to deal with this also. And this is a story about a family who in spite of their own worries wanted to get involved by giving to T.O.U.C.H. so that they could help others. ---Thank you!

Note: The Decker family is happy to report that both boys and their sister Kylie are having a great summer.

4TH Annual Brady Weaver Benefit

The 4th Annual Brady Weaver Benefit was held on Friday, May 12, at the American Legion in Bartonville. Due to the inclement weather, the benefit was moved inside this year, which proved to be a big hit. Once again, we had wonderful food prepared mostly by Brady's Grandma Betty and his great-aunts. We had fantastic items donated for the live auction and silent auction. New this year was the "Kid's Corner". The children had their own area filled with prizes to bid on and games to play.

We had over 500 people attend this year, which is the most to attend Brady's benefit so far. We anticipate the donation to T.O.U.C.H. to be around \$14,000.00. From this money, beds and bedroom furniture for Megan's Lodge were purchased to help furnish the lodge.

Next year's benefit will be held on Friday, May 11th. We are hoping for another record turnout and hoping to see you all there to help us raise funds for T.O.U.C.H.

*Addendum: I would like to take this opportunity to recognize and thank the family and friends of Brady Weaver. What is now known as the "Annual Brady Weaver Benefit" started out as a neighborhood garage sale. There is now an official committee that is made up of friends and family. This very special group of individuals give countless hours of donated time and energy to make this benefit a success. They are dedicated and committed not only because of Brady but because they believe in and want to help T.O.U.C.H. and the Children's Hospital. Over the past three years T.O.U.C.H. has been the recipient of **\$35,000** that has been raised by this remarkable group of friends. They are already planning next year's events. Thank you to Brady, his family and to the wonderful committee members that "believe"!!*

---Gail Eaton

New Twist on Change Drive at T.O.U.C.H. Picnic!

This is a special year for T.O.U.C.H.!!! The board decided that we wanted to do something brand new, so ... this year's loose change drive has a bit of a twist. It involves the doctors, Cookie, and voting by you. Your coins (or paper money) will be your ballot. What happens at the end will be EXTREMELY AMAZING! You definitely will not want to miss it. **Save your change and ask your family and friends to do the same.** Bring your change to the T.O.U.C.H. picnic on Sunday, September 24 and watch the fun!

For more details about the T.O.U.C.H. picnic, see page 3



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at the Children's Hospital of Illinois
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