

The mission of TOUCH (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. TOUCH 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.



**TOUCH**

**PHONE**

**(309) 655-3453**

**(800) 443-9898**

*As members of the TOUCH 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.*

# Keeping in **TOUCH**

Spring, 2005

**TOUCH Board Members:**

Gail Eaton, Executive Director, Children's Heart Institute of Illinois  
Terra Shelton, Co-Chair (Peoria) 309/693-1778  
Shelly Weaver, Co-Chair (Bartonville) 309/697-5042  
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  
Janine McWhirteryoung, Heartline Chair (Peoria) 309/693-9079  
Lise' Mundwiller, Activity Chair (Dunlap) 309/243-7154  
Gina Hulett (Germantown Hills) (309) 383-4165  
Amy Zbinden (Morton) (309) 263-7704  
Jenn Paulsen (Rockton) (815) 986-8779  
Sally Achterberga (East Peoria) (309) 694-1470

## **The Children's Miracle Network Telethon: Celebrating 20 Years of Caring Sunday, June 5<sup>th</sup>, 2005**

With spring just around the corner it's time for us to start thinking about Children's Miracle Network Champions Broadcast. With this being the 20<sup>th</sup> Anniversary there will be much to celebrate. We will be honoring and recognizing "Miracle Kids" from the past 20years! The fundraiser will air on WEEK-TV 25 from 10a.m. to 5p.m. and be broadcast from two sites - the RiverPlex Recreation and Wellness Center in Peoria and the Eastland Mall in Bloomington. This is the time of year that I am asking all of you to please stop and consider being a VIP. T.O.U.C.H. has helped to support this event for what will be 20 years and we even have our very own hour.

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.... Our T.O.U.C.H. hour is from 3p.m. to 4p.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 would be very surprised how easy this is done when you ask friends and family to donate to such a great cause. We can even give you some great ideas for fund raisers like; A Theme Party, Neighborhood Cookout, Book Fair and lots more.

Please help us to make this year's 20<sup>th</sup> 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!!!

## 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.

Thanks for reading! We look forward to hearing from you or meeting you in person.

**Jeff & Cathy Cunningham**

(& Michael)

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**Touch Website:**

[www.touchhearts.org](http://www.touchhearts.org)

## Thank You Dena Foster

by Gail Eaton

I would like to take this opportunity to thank Dena Foster for all that she has done for T.O.U.C.H. over the past 15 years. Dena has recently resigned from her position as Treasurer and will be turning over all financial reports to Amie Love. Dena and her family have been longtime supporters of the T.O.U.C.H. organization. Over the years there have been many times she and her husband Dave have donated items for our picnic raffles and she has always served as the sweatshirt/t-shirt lady at the picnic. They have served as VIP's for the CMN Telethon and Dena's mother, Charlotte bakes each and every one of those delicious cookies at the picnic each year. Dena sent me a note that I would like to share with all of you:

"Please tell everyone thank you for the years of support that have been shown to me and my family. Sixteen and a half years ago, I thought I would never have the courage to deal with a child with heart problems. You've shown me how to be courageous, especially when I'm a coward at heart. You've all given me strength that I never knew I had and compassion for others who had it much worse then we did. Thanks again for everything! I will never forget any of you. I wish you and your families the best of good health and happiness."

With a daughter now in college and a son in high school her life has taken many new directions. Dena assures me that she and her family will continue to be involved with T.O.U.C.H., just at a different level.

Dena, please know that we appreciate all of your time, commitment, support and belief, in and for T.O.U.C.H. over the years.

*Gail Eaton*



[www.tchin.org](http://www.tchin.org)

You may recall that we announced our affiliation with CHIN (The Congenital Heart Information Network) in the last issue of our newsletter. The network is a fabulous resource for all of us, but it is much more. TOUCH will receive a check in the amount of \$200 from lapel pin and holiday card sales done by CHIN over the internet. We receive this money as a support for our affiliation. Isn't that wonderful??!! Please support CHIN in whatever way you see fit and encourage friends and family to do the same. It helps fund research and a small part comes back to TOUCH. What a great deal!



See page 6 for information on purchasing a Hope Heart from C.H.I.N.

# Jade's Story

*Jade Rice wrote this story for the Young Author's contest at Charter Oak. She is now in fifth grade at Mark Bills Middle School. Her brother Garrett was diagnosed at birth with Tetralogy of Fallot with an absent pulmonary valve.*

When I was five years old, I was in Kindergarten at Charter Oak. I had a little sister named Lexus that stayed at home with my mom. One day when I came home from school, my mom and dad told me that I was going to have a new brother or sister. I was very happy and excited.

When my mom was five months pregnant, we found out that the baby was a boy. I couldn't wait until he came so I could play with him. My family decided to name him Garrett Michael and the only thing left to do was sit and wait for a five year old.



*(left to right) Garret, Jade, Aiden & Lexus Rice*

The day finally arrived for my brother to come. The day was Monday on August 21, 2000. My grandma took me up to the hospital. My mom and dad decided to let me come up to the hospital and wait there until my brother was born. My dad's sister, my Aunt Kim, worked there and she let me make a banner that said, "Welcome Garrett", while I was waiting.

I stayed in the waiting room for what felt like a very long time. The nurse wouldn't let me come into the room while my brother was being born. I was very upset but I was still happy knowing that I would have my little brother soon.

After awhile, my Aunt Stacey, a good friend of my mom and dad, told me it was time to go to her house. I asked her if the baby had come yet and she told me no. I remember that I had seen the nurses and a doctor pushing a cart that had a baby on it and I asked her if that was him. She didn't answer me and we left the hospital. I was very scared because no one would tell me whether my brother had come or not. I didn't know what was happening but I knew it wasn't very good. Later that night, my other aunt, Aunt Kathy came and got me and I spent the night with her. I remember I cried because I couldn't talk to my mom or dad.

The next day, I had to go to school because it was the first day and after school my dad came and picked me up. He told me then that my brother had come but something was wrong with his heart. I don't know what it is called that he has but I do know that he had two holes in his heart and my dad said he was very sick. I got to go up to the hospital then to see my mom but I didn't get to see my brother. I still didn't know what he looked like.

For the next few weeks, my mom was hardly ever home and my dad was home most of the time. The rest of the time I was with my grandma and my other relatives. I asked my dad if my brother had died. I didn't know exactly what that meant but I knew it was very bad. My dad said he didn't but he was very sick. Garrett was seven weeks old when I saw him. He had lots of tubes in his nose. My mom told me that he needed the tube to breathe. Garrett had scars on his chest from him having open heart surgery. He had his eyes open but he didn't make any noise. My mom told me we couldn't hear him cry because of the breathing machine he was on. I brought the banner that I had made the day he was born and I got to hang it in his room.

*Continued on next page*

## **Jade's Story, cont.**

We got to bring Garrett home when he was eleven and a half weeks old. I was so happy that I would get to see my little brother every day. Now that I'm older I know that my little brother went through a lot to get better. My mom took lots of pictures while he was in the hospital and looking at them now it sometimes makes me cry. I'm nine now and know that he had more wrong with him than just the two holes in his heart. I feel lucky and very happy that my brother made it this far. My brother has had two open heart surgeries and my mom and dad said he will probably need one or two more.

Every year, my whole family gets to go to Bradley for a dance marathon to raise money for the Children's Hospital. The Bradley students stay up for 24 hours dancing. We also go to the Children's Miracle Network Telethon and answer phones. The first year we did it, we got to be on T.V. because Garrett was picked to be a Miracle child and we told his story.

My brother, Garrett, is three now and seems like a normal kid. I like to play trucks and cars with him because that is his favorite thing to do. I also read books to him and he always hugs and kisses me. It's sad that my brother had to go through what he did but I am very happy he is here. I also have a new brother named Aiden. Now Garrett gets to be a big brother.

*Jade - Thanks for sharing your story*

**Now Available from C.H.I.N. :**

**(Congenital Heart Information Network)**



The sterling silver "Count Your Blessings" "HopeHeart" was inspired by the idea of changing the world by "opening our hearts."

This beautiful necklace features an artisan-crafted silver heart on black leather cord that incorporates the spirit of the "Hope Ribbon". The back of the heart is inscribed "Count your Blessings 2005".

By purchasing a C.H.I.N. (Congenital Heart Information Network) "HopeHeart" you are assisting others like yourself in getting the help and support they need. At the same time, you are participating in a global effort towards health and unity around a symbol that is meaningful to all people.

Thank you for sharing our message, and enjoy

The cost is \$25.00 per necklace (price includes postage in the U.S.).

Please order at:

**[www.tchin.org/hopeheart](http://www.tchin.org/hopeheart)**

Use T.O.U.C.H. as your affiliate organization on the order form and the proceeds will come back to us.

Thanks so much



# The TOUCH Board Welcomes Sally Achterberg!

Inspired by a soft serve ice cream cone, Haitian 5-year-old Ledy Carm calls her foster American family "The Swirl Family." Ledy is the chocolate ice cream and her foster family, Scott and Sally Achterberg and their two sons Jacob (13) and Heathe (9) are the vanilla.

The Achterbergs are in the process of adopting Ledy, who was brought to Peoria from Haiti through the Haitian Hearts program. At the time, 18-month old Ledy was so weak from the effects of a congenital heart defect that doctors weren't sure whether she would survive the flight to the U.S. She was two years old when she came to live with the Achterbergs and has been part of their family ever since. After multiple heart surgeries, Ledy still has some health issues but she is thriving and melting the hearts of all who meet her.

"Family is number one to us," says Sally Achterberg. Incorporating Ledy into the household was a big decision and has brought many changes. It was hard for Jacob and Heathe at first because they had experienced the death of another Haitian child, says Sally, but now they treat Ledy just like a younger sister.

Sally is a Unit Support Rep for The Children's Hospital, working nights and weekends in the Pediatric Intensive Care Unit and Pediatric Intermediate Care. She acts as an interface between the doctors and nurses by performing all scheduling and ordering of medications so the nurses can focus on performing the more medical parts of their jobs. It has enabled her to fulfill her desire to help heart families while also remaining close to the doctors and nurses that are so integral to Ledy's care. Her job also allows her to work at times when her husband can be home with the children.

Scott Achterberg owns and operates The Achterberg Group, a company specializing in indoor air quality issues. His company sands and refinishes hardwood floors, conducts mold remediation, cleans air ducts, and provides chimney sweep services. His business has been growing in the past 15 years and Scott enjoys the ability to control his work schedule, which has enabled him to tag team with Sally so that their children have at least one parent at home.

The Achterbergs have a long affiliation with OSF St. Francis and Sally brings considerable experience as a new member to the TOUCH board. She has been on the Board of Directors and member of the Development Committee for the Children's Hospital of Illinois, a Children's Miracle Network broadcast chairperson and has been involved in numerous fundraising projects. Her brother and his wife were a foster family for one of the first children brought from Haiti through the Haitian Hearts program and Sally was a liaison between the hospital board and Haitian Hearts. She is very excited to be involved with the new TOUCH cabin under construction at Wildlife Prairie Park.

Since Ledy has come swirling into their midst, the whole family has come to view life differently. Sally observes, "I've learned to take every day one day at a time. I used to joke about that, but I don't take anything for granted anymore...Ledy changed us from the inside out. You learn to really appreciate everything you have. Family time is more important to us than having something extra."

These days, the Achterbergs find themselves trying to spend less on material things and more on family time together - including trips to get an ice cream cone - chocolate AND vanilla.



Ledy

# Stamp to Your Heart's Content



The 2<sup>nd</sup> Annual Stamp to Your Heart's Content event was held in Poplar Grove, IL on Saturday, February 12<sup>th</sup>, 2005. Over 75 people participated in a stamp workshop, homemade card sale, and silent auction. The participants were entertained by returning musical guest, Dr. Bruce Hecht from the Pediatric Cardiology Clinic of Illinois.

Financially, the event was a success! A total of \$2,483 was raised after expenses were paid. A grant of \$1,000 was added to that total from Thrivent Financial.

A 3<sup>rd</sup> Annual Event is being planned for Saturday, February 11<sup>th</sup>, 2006. Save the date and join us as we raise money for Megan's Lodge and raise awareness about congenital heart defects and TOUCH as well!

*Talented demonstrators volunteered to help!*



*Friendly volunteers staffed the homemade card sale!*



*An abundance of wonderful items were donated for the silent auction!*

# RESOURCES...

<http://www.achaheart.org>

The Adult Congenital Heart Association (ACHA) is a nonprofit organization which seeks to improve the quality of life and extend the lives of adults with congenital heart defects. Through education, outreach, advocacy and promotion of research, ACHA serves and supports the more than one million adults with congenital heart defects, their families and the medical community.

## Information and Resources

- \* Important Information: What All ACHD'ers need to know
- \* General information about CHD
- \* ACHD clinics
- \* Other organizations
- \* Internet resources
- \* Books and Articles

## Support

- \* Local support groups
- \* Regional contacts
- \* Message boards
- \* Listservs
- \* Chats
- \* Camps for kids with CHD

## People Connections

- \* CHD Awareness Day
- \* Upcoming events
- \* Photo album
- \* Remembering loved ones

## Message Boards

## Newsletter

Our newsletter, *Heart Matters (formerly The Laurel Wreath)* is published quarterly and contains a combination of medical information, personal stories, and event and support group information. It is mailed to all of our members.

# Child Life Services at The Children's Hospital of Illinois

The staff at the Children's Hospital of Illinois know that families have many questions and concerns surrounding a child's hospitalization. The Child Life Services at the Children's Hospital help meet the needs of families.

*Please call a Child Life Specialist for the following:*

- Any invasive procedure - please call Child Life prior to the start of a procedure. Building rapport is essential to the services provided by a child life specialist.
- Developmentally appropriate teaching about the hospital experience (including pre-operative and pre-procedure teaching)
- Coaching/teaching of developmentally appropriate coping strategies
- Patients that may need medical play opportunities to gain mastery over medical procedures or routine cares (including dressing changes, vitals, breathing treatments, etc.)
- Patients that are in the hospital for more than 4 days may need developmental enhancement, particularly infants and toddlers
- Patients that may have difficulty coping or cooperating with any aspect of hospitalization.
- Selecting developmentally appropriate activities.

*To contact a Child Life Specialist, please call: (309) 655-6935*

## Children's Hospital of Illinois 2004-2005

- May 5, 2005** 6<sup>th</sup> Annual Score Fore Kids Golf Outing in Bloomington/Normal - Join your friends and have a great day of golf at The Den at Fox Creek.
- June 5, 2005** CMN Celebration Telethon - Join us as we celebrate the 20th year as a Children's Miracle Network hospital. Telethon locations include: Bloomington's Eastland Mall and the RiverPlex in Peoria. Watch WEEK-TV 25 beginning Sunday at 10:00 a.m.
- Aug. 12, 2005** Ride the Wake For Kids Sake - The Blue Heron Ski Club skis from St. Louis to Chillicothe, IL. In its 8<sup>th</sup> year, each participant helps to raise money for the Children's Hospital of Illinois through pledges and sponsorships and skis over 100+ miles each.
- Sept. 8, 2005** Thome/Warfield Golf Invitational benefiting the Children's Hospital of Illinois - Golfers gather from all over to play in this signature golf event held at WeaverRidge Golf Club. Guest appearance by Jim Thome highlights each foursome's game of golf.
- Nov./Dec. 2005** CEFCU/CHOI "Brighten A Child's Life" Holiday Greeting Card Promotion - Original artwork by area school children make these cards special. The cards are sold at CEFCU, Peoria and Bloomington merchants and through the Children's Hospital Foundation Office.
- Nov. 11/12 2005** Bradley University Dance Marathon. - A committed group of students organize this 24-hour dance marathon & mini fundraisers leading up to the marathon while bringing the BU students and faculty, Peoria-area community and hospital together as they raise money for Children's Hospital. Event takes place at Bradley's Haussler Hall.

The Children's Heart Institute of Illinois  
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