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

SPRING 2010

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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25 YEARS OF MIRACLES

25th Annual Children's Miracle Network Telethon
Sunday, June 6, 2010

This is the time of the year that I am asking all of you to please stop and consider being a VIP Phone Volunteer for the T.O.U.C.H. hour during the Children's Miracle Network Telethon. This will be the 25th Anniversary and is sure to be a special celebration of miracles. Not only will we be celebrating 25 years of miracles but we will be celebrating the upcoming opening of "The new Children's Hospital of Illinois."

Read more about the Milestone Project in the next issue of Keeping in T.O.U.C.H.

This year's fundraiser will air on WEEK-TV from 10:00am to 5:00pm from two sites – the RiverPlex Recreation and Wellness Center in Peoria and the Parke Hotel and Conference Center in Bloomington. With your efforts, Children's Hospital has been able to provide specialized care and support services for our patients and families.

Just a couple of the miracles that will be celebrated this year are our very own cardiac kids (sorry guys but you will always be my kids) Arthur Hanley and Zachary Messersmith.

Read more about Arthur and Zachary on page 2!

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.

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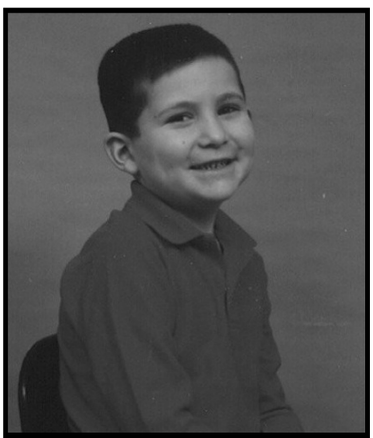
25 YEARS OF MIRACLES–
Meet Arthur & Zachary

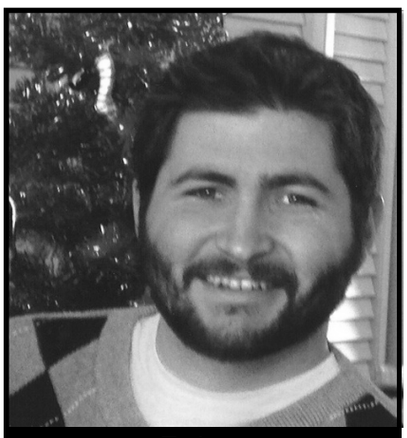
Arthur and mom at Children's Hospital in 1988.

Arthur was born in 1987 with Tetralogy of Fallot and underwent his first surgery at about six weeks of age. He has since had surgeries in 1988, 1994 and 2003. In addition he has had multiple cardiac catheterizations. Arthur was an avid baseball player all through high school and recently graduated from the University of Illinois with a bachelor's degree in Mechanical Engineering. He is currently the Resident Director at the Newman Center at the University of Illinois while pursuing his MBA.



Zachary
1989

Zachary was born in 1984 with a complex heart defect consisting of L Transposition of the Great Vessels and Pulmonary Atresia. He had his first surgery at 1 day of age. At the age of four he had his mitral valve replaced and a pulmonary artery conduit placed and spent more then a month in the hospital. Zach was one of the miracle kids for the T.O.U.C.H. hour in 1989. He has done well since then and was the recipient of many awards in high school among them the Honor Five recipient at Princeville High School. Zachary went on to graduate Cum Laude from Illinois State University with a degree in Political Science and works for the Senate Republicans in communications. On December 8, 2009 Zach had three valves replaced during a fourteen hour surgery by Dr. Geiss and Dr. Fortuna. He spent eight days in the hospital and is now fully recovered and back to work in Springfield.



Zachary
2010

Keep reading to find out how you can help celebrate the Children's Hospital Telethon's 25th Anniversary!

Just for KIDS!

This new feature will include activities, information and features designed especially for kids.

KIDS– send in your favorite recipes, games or special interests!

ANNOUNCING... T.O.U.C.H. JR!

Hi my name is Caroline Shelton. You might have met me at the TOUCH picnic. My friend Grace Paulsen and I are starting a TOUCH Jr. committee.

I am 10 years old and have a complex heart defect called unbalanced atrial-ventricular canal defect with a permanent pacemaker. Grace is also 10, but she does not have a heart defect. Her little sister Hannah does. Grace and I met when our moms became friends through TOUCH. We have been going to the TOUCH picnic together for a long time.

This past year we told our moms that the picnic wasn't as much fun anymore; that there wasn't anything for kids our age to do there. This was hard to do because our moms help plan the picnic.

Our moms asked us what we wanted to do at the picnic. Well, we had a long list of ideas. But our moms said it was too late to get everything organized. Instead, we decided to start TOUCH Jr. for kids our age. Our goal is to help our moms plan the picnic each year with ideas of things older kids can do.

TOUCH Jr. is for kids 3rd grade through high school. If we have enough high school students join, we plan to divide into two sub-committees. You don't have to have a heart defect. You could be a brother or sister of someone with a defect. TOUCH Jr. will meet three times each year: June, July and August. If you can't come to the meetings in Peoria, you can email your ideas to us.

If you are interested in joining TOUCH Jr., please email me at cps0729@mtco.com or call me at 309-383-2575. Our first meeting will be June 14th at 6:00 PM at Peds Cardiology.

Preteen perspectives

Children between the ages of nine and twelve years old, often known as preteens, experience unique challenges during these years. Hormones are causing rapid changes in physical and emotional development. Preteens face issues of body awareness, self image, and social identity. They are learning and growing at a rate that can be overwhelming and exhausting. When medical concerns are a normal part of a child's life, the preteen years can be especially trying. Preteens may become more curious about the specifics of their medical conditions and the implications for their daily lives and futures. They may become more aware of their differences when comparing themselves with their peers. Parents can help their children through these times by encouraging questions and discussion. Honesty from adults and some sense of independence and control in regards to their medical condition can be empowering for preteens. For more guidance on how to help children cope with medical conditions at different developmental levels, visit www.childrenshospitalofil.org and click on *child life* under the *patients and families* tab.

CONGRATULATIONS, DR. STEPHEN BASH!

The W. D. Boyce Councils of the Boy Scouts of America in celebration of their 100th anniversary recently announced something that we TOUCH families have known for years...**DR. BASH IS A HERO!**

He will be honored by the Council as a person who has used the principles of scouting to become heroes. Here is just an excerpt from his nomination essay.

Dr. Bash is a pediatric cardiologist at the Children's Hospital of Illinois, which he helped open in 1986. He specializes in cardiac catheterization and interventions in children and adults with congenital heart disease. Dr. Bash has dedicated himself to treating patients who are born with a defect or malformation in one or more structures of the heart or blood vessels.

His profession is a powerful demonstration of scouting values. Every day, Dr. Bash meets with parents and discusses how he is going to help their child, who will have a heart condition for the rest of his/her life. In a short time, he has to demonstrate he is a courteous, kind, trustworthy and optimistic individual. It is unimaginable to most people to hand over their sick child to a complete stranger. Dr. Bash exudes the fortitude and bravery needed for people to trust him with their children. It is an intense situation when the life and heart of a child is in his hands. Dr. Bash's demanding profession can put him under unimaginable pressure, yet he deals with it on a daily basis.

Dr. Bash exemplifies a direct relationship between his life in Scouting and his life now, as a pediatric cardiologist, Vigil Scout, and grand-father of two Scouts. When Dr. Bash became medical director of Camp Ingersoll for five years, he integrated his medical career with Scouting and performed a service for Scouts as a gesture of gratitude for the foundation Scouting instilled in him. He attributes his self-sufficient and disciplined nature to being "the small guy" in a physically rigorous, but supportive Scouting class. He was taught to never give up, which is a powerful philosophy, whether it is referring to the inconspicuous aspects of life or the moment when a doctor is put on the line to save a life.

In his endeavors, Dr. Bash advises others to keep their problems in perspective. He says whenever you think your issues are too difficult to deal with, take a waltz through any hospital and look at the people, particularly the children, and, suddenly, you'll find your problems really aren't that bad.

CHECK OUT THE NEW DOC AT MEGAN'S LODGE!

HELP CELEBRATE 25 Years of Miracles!

Won't you please consider being a VIP this year to help celebrate not only these two young men but also all of our children and young adults?

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. The T.O.U.C.H. hour is from 3 - 4 pm. 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 ideas for fund raisers like: A Theme Party, Neighborhood Cookout, Movie Night and lots more.

Please help make this year's 25th 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. Thank you so much!!

Adult Congenital Heart Association

Is your heart child approaching adulthood? Adulthood brings a new set of challenges for those living with congenital heart issues. The Adult Congenital Heart Association can help you and your child navigate through some of those challenges. The A.C.H.A. provides helpful information and offers free educational webinars presented by professionals. To visit the A.C.H.A. website, follow the link on the T.O.U.C.H. website at www.touchhearts.org.

The Congenital Heart Information Network

As parents of heart children, we are often seeking the latest information pertaining to congenital heart conditions. A wealth of information is accessible through the internet. Unfortunately, every website or source is not completely reliable and can lead to misguided worries or reassurances. T.O.U.C.H. is an affiliate member of The Congenital Heart Information Network, which is a source of invaluable assistance for families like ours. C.H.I.N. is a national organization that provides reliable information, support services, financial assistance and resources to families of children with congenital heart defects and acquired heart disease, adults with congenital heart defects, and the professionals who work with them. If you are looking for a reliable website to help answer your questions, we recommend visiting www.tchin.org.

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! Julie Witte

4516 N. Rosemead Drive ~ Peoria, IL 61614 ~ (309) 693-0511 ~ kj_witte@comcast.net

HELP PASS the Congenital Heart Futures Act!

Senator Dick Durbin recently led the bipartisan charge to introduce the **Congenital Heart Futures Act** in both houses of Congress. Up until now there has been virtually no federal investment to address the research and education needs of the 1.8 million Americans now living with congenital heart disease. What can we, as families touched by congenital heart disease, do to help advance this groundbreaking legislation? Like any piece of legislation, the Congenital Heart Futures Act has to get majority support in both the House and Senate in order to be passed. Please email your Senators and Congressmen today to ask them to become a co-sponsor of this legislation. It just takes a minute–please visit **www.tchin.org** to join the efforts.

HEART HEALTHY RECIPE

Almond Crusted Pork with Honey Mustard Dipping Sauce

From EatingWell.com

INGREDIENTS

1 cup coarse dry breadcrumbs, preferably whole-wheat

1/2 cup sliced almonds

1 teaspoon garlic powder

1/2 teaspoon kosher salt

1/4 teaspoon freshly ground pepper

1 large egg white, beaten

1 pound pork tenderloin, trimmed and cut diagonally into 1/2-inch-thick slices

DIPPING SAUCE

1/4 cup honey 2 tablespoons Dijon mustard

2 tablespoons reduced-sodium soy sauce

DIRECTIONS

1. Preheat oven to 425°F. Set a wire rack on a baking sheet and coat it with cooking spray.
2. Place breadcrumbs, almonds, garlic powder, salt and pepper in a food processor; pulse until the almonds are coarsely chopped. Transfer the mixture to a shallow dish.
3. Place egg white in another shallow dish. Dip both sides of each pork slice in egg white, then evenly coat with the almond mixture. (Discard any remaining egg white and almond mixture.) Place the pork on the prepared rack and coat on both sides with cooking spray.
4. Bake the pork until golden brown and no longer pink in the center, 16 to 18 minutes.
5. Meanwhile, whisk honey, soy sauce and mustard in a small bowl. Serve the pork with the honey-mustard sauce.

Per serving: 299 calories; 7 g fat (1 g sat, 4 g mono); 74 mg cholesterol; 30 g carbohydrates; 29 g protein; 3 g fiber; 561 mg sodium; 562 mg potassium. **Nutrition Bonus**: Potassium & Zinc (16% daily value).
2 Carbohydrate Serving **Exchanges:** 1 starch, 1 other carbohydrate, 3 lean meat

MEGAN'S LODGE UPDATE

Be sure and make your reservation for Megan's Lodge early!!! Wildlife Prairie State Park will officially re-open on February 28th. We have already taken many reservations for this coming year. We are continuing to ask families to not make more then 2 reservations per year so that we can allow those that have never stayed at the cabin to be able to do so. The cost is $60 per stay whether you stay 1 night or 7 nights. This gives you one year Family Pass to the park (valued at $50), and the remaining $10 is used for a cleaning fee. We feel fortunate that we have been able to keep the cost to a minimum, and will do our best to continue to do so. Everyone's efforts to help leave the cabin the way they found it, is key. If during your stay you see some weeds that need to be pulled or a window that needs to be washed, please help out and do so.

A new addition this year is an all cedar deck that sits out over the waters edge. Construction on the deck started last fall. The deck and stairs leading down to it will be completed by late spring. To make your reservation, please call Wildlife Prairie Park at 309-767-0998.

IT'S FINALLY SPRING! "PLAY BALL....."

The spring baseball season is right around the corner…..is your child ready? Are **YOU** ready?

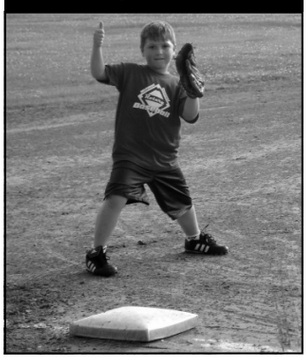
If your child was diagnosed with a heart problem, and has gone through the trauma of having a pacemaker surgically implanted, any sport can cause anxiety, especially for the parent(s). Tensions rise when your child wants to take part and participate in everything they can, but you don't want to put them in danger unnecessarily.

If your child gets hit with the ball in or around the heart area, there could be serious issues. However, you don't have to force your child to stop playing the sport he or she loves…there are protective devices obtainable to help offer protection.

Heart/chest protectors are available, and should be worn by ANY/ALL children, whether they were born with a congenital heart defect or not. Heart/chest protectors come in a variety of styles and are readily available at most sporting goods stores. Talk to your physician or sporting goods expert to find out which guard is best for your child.

No part of your body deserves more care and attention than your heart. Be smart…be heart smart, and…**PLAY BALL!**

TOUCH kiddo Logan Worrick gives the thumbs up after a great hit!



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The Children's Heart Institute of Illinois
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Peoria, Illinois 61637

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

May 1 – June 16 Walmart Campaign
Donate to Children's Miracle Network when you checkout at Walmart & Sam's Clubs during the 6 week balloon campaign.

May 6 COUNTRY'S Score Fore Kids Golf Outing
The Den at Fox Creek, Bloomington

June 6 Children's Miracle Network Telethon – 25th Anniversary –
Watch WEEK-TV 25 – Sunday at 10:00am-5:00pm.
Peoria – Riverplex Bloomington – Parke Hotel & Conference Center

For more information, please contact Shauna Skowronski- Children's Hospital and OSF Saint Francis Foundation at (309) 566-5674.