INAUGURAL LITTLE HEARTS GOLF OUTING

Little Hearts invites you to join us for the Inaugural Little Hearts Golf Outing on Monday, June 21, 2010 at The Apawamis Club in Rye, NY. All skill levels of golfers are welcome to participate in the 18-hole scramble. Fee is $375 per person or $1460 for a foursome. Includes lunch, greens fees, cart rental, dinner, prizes and refreshments. Want to donate or advertise? Sponsorship opportunities start at just $300.00. We have many sponsorship packages available.

Visit the NEWS page of our website and print off the Registration and Sponsorship Packages forms. Please contact Kelly Molloy at 203-462-7527 or via email at kmolloy@rc.com for more information.

PICNIC T-SHIRT ARTWORK CONTEST

With the picnic around the corner, it’s that time to ask your kids to do their magic and draw a picture for the front of the picnic t-shirt. The theme is our picnic and if they want to write something, ask them to use "Little Hearts 14th Annual Picnic". No limit to the colors used. Mail in your child’s artwork by Feb 28th. Mail artwork to the address below.

Inside this issue:

Donations 2009  2-7
Your support is truly appreciated!

Ashlyn, Brandon,  7-8
Jaxon & Ruby’s
Stories

Share the HOPE—send in your “heart child’s story today!

Tetralogy of Fallot —Bailey/triplet
born 2009—Minnesota

HLHS—Madi
born 2008—Indiana

Tetralogy of Fallot, PA
Tristan, born 2007—AL

Dilated Cardiomyopathy
Elise, born 2008—NY

HLHS—David/twin
born 2005—MA

2009 Picnic t-shirt
Artwork Winner
Volume II, Issue I

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Lisa Terranova

Eleanor Terry
Judy Tessier
Erin Tevlin
Kirk Thomas
Bryn Thompson
Mary Tohn
Kysle Tolson
Joanne Tomko
Greg Travers
Rob Tudor
Tullys Cafe, Inc.
Andrew Turpin
Erin Twomey
Dr. Joseph P. Tynan School
Fund
Denise Uga
John Vahey
Quirine van Oldenboorn
Amber Vasquez
Christopher Veneto
Helen Veneto
Deborah Verge
Adeline Victoer
Terri Lynn Villa
Desai Vishal
Patricia Voner
Adam Walsh
Kristen Walsh
Lisa Ward
Paul Watson
Robert Watson
Kathy Watt
Christine Wayman
William Weddleton
Wendy Weinberg
Gerald Wellman

Shef Wesraka

Evan West
Margaret West
Courtney Wheeler
Lisa Willet
Jim Willis
Melissa Willis
Maria Willis
Matt Womer
Jaccqueline Wong
Joshua Woodruff
Jason Wright
Catherine Yim
Julia Zaino

KYLA JONES GOLF
OUTING
Robert & Nancy Jones

SCHOOL FUNDRAISERS
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MA
Eastplain School
N. Massapequa NY
Ramepo High School
Franklin Lakes NJ
Sowams Elementary School
Barrington RI
Thiells Elementary School
Thiells NY
Toms River Intermediate
School
North Toms River

NJ
Ashlyn’s story (Double Outlet Right Ventricle) by her mother, Carly—FLORIDA

I had Ashlyn on Thursday 9/18/08. She was just fine, eating well and alert. When we went to be released on Friday, they wanted to keep her because she was running a fever. They ran blood work on her and a culture to see what was causing the fever. She stayed in the room with me until I went home on Saturday.

Around 2:30 am on Sunday morning (9/21), the NICU at the hospital called to tell me that Ashlyn was having trouble breathing, they had put her on oxygen and taken an x-ray of her heart. The x-ray showed that her heart was enlarged and they wanted to send her to All Children’s Hospital in St. Petersburg, FL. She made the trip very well, and once we arrived she was settled.

Ashlyn was diagnosed with Double Outlet Right Ventricle (DORV). They gave her medicine to keep her PDA open and then monitored it closing to decide if she was going to have surgery right away or go home to grow. Ashlyn spent ten days in the NICU, then came home for almost three weeks, before having surgery at about six weeks old (10/27/08). The surgeon’s office was surprised she had been sent home, telling us most arterial switch (surgery type she had) do not come home before having surgery. Ashlyn never really fit the symptoms of DORV, she ate well, gained weight well and wasn’t real sleepy, nor did she look blue. She came home eleven days after surgery.

Ashlyn continues to grow each day. She is now gaining weight and is developing normally. She is also medicine free; they took her off after a month because of how well she was doing. Ashlyn has a small hole around her VSD patch that they continue to monitor.

Brandon’s story (Aortic Stenosis) by his mother, Aimee—NEW JERSEY

I gave birth to Brandon February 27th 2009. He cried right away had pink skin and he seemed perfectly healthy. He was born at 2:01 AM, so shortly after giving birth I went to sleep, and he was taken to the regular newborn nursery. The next morning a nurse came in and told me that they found a murmur that may or may not be something. I was hopeful that it was an innocent murmur like so many children have and would turn out to be nothing. I didn’t get to see or hold my baby at all that whole day because they wanted to monitor him and do tests in the special care nursery. Later that evening my worst fears came true when the cardiologist came in and told me that she thought my son had Aortic Stenosis.

Brandon was then immediately transported via helicopter to CHOP. I had to wait a whole extra day before they would discharge me. Luckily my husband was able to drive there the same night and be with him. He stayed there for the eight days. On his seventh day there he had balloon valvuloplasty in order to make his condition less severe. Although he will never be healed his gradient is much lower then it was at birth.

He is growing and doing extremely well. He looks and acts like a normal baby, and you would never know he has a problem by looking at him. Our cardiologist said he will most likely need another balloon valvuloplasty or a valve replacement surgery in the future. We are hoping that he never needs another procedure done and that if he does it isn’t until he is an adult and can better understand what he has. Everyone at CHOP was truly amazing and we are grateful that they took such good care of our son.
Ruby’s story (HLHS) by her mother, Samantha—GEORGIA

Our story begins like so many others with the memorable pause during the ultrasound and the devastating news that our new baby will have HLHS. Being prenatally diagnosed was a blessing in disguise. Although it was so hard to carry her knowing what she faced immediately after birth, my family and I are so thankful to have been prepared. Ruby’s big brother was a preemie so our first mission was just to carry her as close to term as possible. My labor was induced at 37 weeks because she had stopped growing. She was born January 21, 2009. Many prayers were said for her as she was flown 3 hours after birth to Egleston Children’s Hospital.

She faced her first stage surgery at only 4 pounds and did very well. Dr. Kirshbom was her incredibly talented and caring surgeon. We left the hospital for the comforts of home on February 7th. We were terrified to take care of her so far from the monitors and security of the hospital. She had two heart caths to do angioplasty and then a stint was placed into her 4mm shunt before she was big enough for her Glenn procedure. Before her Glenn, it seemed like we spent every few days or so in the E.R. but we always seemed to get there just in time. We know that God and her guardian angels are taking great care of her and all of the other special heart babies we have met. And thanks to the awesome care and love she has received from our family, community and all of her health care providers (home health care, cardiologist, nurses, surgeons, etc.) her life is so much happier than I ever imagined it to be.

She has a fighting spirit and a happy smile that expresses overwhelming joy from just being alive. Since her Glenn in late May everything seems so much more “normal” and relaxed. She loves staring at her brother, playing with her toys and exploring the new world around her. We try not to dwell on what discomforts she might face down the road because of her special heart. Instead we thank God for every wonderful day that we are enjoying with her. She is without a doubt living a wholehearted life! And we love her and are so proud of our little miracle Ruby Anne.

Jaxon’s story (Tetralogy of Fallot) by his mother, Tracey—KANSAS

Jaxon was born on Sept. 24, 2005 at 2:41 AM, at about the same time hurricane Rita made landfall. That right there should’ve told us what life would be like with him! It was an uneventful pregnancy, and for the most part, an uneventful delivery. He was pink and healthy, but he had a heart murmur. The doctors and nurses figured it would go away in a few days. When it didn’t, we were referred to a pediatric cardiologist. One month later, we found out that Jaxon had been born with a congenital heart defect. Soon words like Tetralogy of Fallot, echocardiogram, and open-heart surgery became regular words in our vocabulary.

He did very well, no blue spells or anything out of the ordinary. He wasn’t as active as our other two children were. He had his surgery done on June 21, 2006. He made a quick recovery, coming out of ICU within 3 days and going home 2 days later.

Jaxon has taught us so much... from completely trusting God, to how to live each day to its fullest. After all, today is the only guarantee. He will probably need a pulmonary valve replacement in the future, but as of now he is as playful and active as any other little boy his age. He is such a blessing to all who know him!

Ashlyn, Bailey, Brandon, David, Elise, Jaxon, Madi, Ruby and Tristan are just a few stories added to the STORIES page of our website in 2009. We hear from so many expectant parents telling us how our stories gave them the hope after learning of their babies diagnosis. Would you like to share your child and hope with many online (over 10,000 hits a day)! Email us at INFO@littlehearts.org or mail it Little Hearts, Inc. P.O. Box 171, Cromwell CT 06416 today!