



Quarterly

NEWSLETTER

Special points of interest:

- Little Hearts moved November 2005
- February 14th CHD Awareness Day
- 10th Annual Picnic Sunday June 4th
- Stephanie Swabski and Rose Palmer of Connecticut joined Little Hearts Board of Directors in 2006
- Dr. Gil Wernovsky of CHOP has joined our Medical Advisory Board
- Newsletter online—go to SERVICES page of littlehearts.org

Question for LITTLE HEARTS? Email us at INFO@littlehearts.org

WE MOVED in 2005!

Since 1998, the Little Hearts office has been based out of the home of one of our members. While it worked over the years, the time has come for Little Hearts to move out and get “her” own place!

In November of 2005, Little Hearts moved to its first professional office located in the center of town.

Now, whenever orders are to be filled, we no longer have to go down to the basement to get the items. Whenever we have appointments, we no longer have to meet at a local coffee shop. Whenever we receive a midnight fax, no one will be woken up. Whenever we print up our newsletters (which we do ourselves to keep printing costs down), we will no longer keep those awake who were trying to sleep.

Little Hearts has been around since 1998 and we’re here to stay and the best way to help with our future was to find us a new home. We already have people in town volunteering their time and helping with the administrative tasks and helping us with orders and newsletter mailing! Many thanks to all our supporters in making this day possible for the Little Hearts “family”! We wouldn’t be here without your support. If you would like to volunteer in any way for Little Hearts, please contact us.



Welcome to our new office!

To our little grandson, Jacob

Thirty three years ago we had a little son
We named him Jeff and had lots of fun
We camped, played sports, joined scouts and then
Our little son who we loved so much became a man

Time flew by and all of a sudden he was married
Three years later our grandson they carried
How excited we were about the little guy
Then we found out he had a heart defect and we began to cry

Our grandson was born and surgery he had
On that “special day” we were so happy and sad
But with a lot of prayer we all made it through
With God in your life you all will too

We love our little grandson
He’s such a special little boy
And everyone who sees him
He just brings so much joy

Just keep your faith and hope and pray everyday
And someday you’ll see everything will be OK
A child is a blessing from heaven above
And to all of the families at “Little Hearts”
We’ll keep you in our prayers and send you our love

Written by Kathy ten Bosch of Michigan proud grandma to Jacob Jonathon ten Bosch born 2005



Jacob

Inside this issue:

Delaney’s story	2
Giuliana’s story	2
Donations	3-6
Emilyn’s story	6
Connor’s story	7
Murphy’s story	7
Story by Jeffrey	7
My little brother	8

January 2006 Quarterly Newsletter

Giuliana's story (VSD)



Giuliana

My daughter Giuliana was born with a Ventricular Septal Defect (VSD). I did not know much about congenital heart defects until I started reading about it. She had a significant (loud) murmur which anyone would be able to hear with a stethoscope. Being in the medical field, I would always listen to her heart to see if it went away. We were told by our pediatrician that we needed to see a pediatric cardiologist. Now it was starting to get a little scary. At her first visit she had her first EKG and an echocardiogram. The cardiologist then showed us the defect which was small and told us it may close on its own. She would now have to see him every six months. Well, she did and no change. At the age of four and a half we went for her yearly. At this time, the aortic

valve was starting to stretch and it was time to get her little heart fixed. So we were referred to a cardiothoracic surgeon. We were seen within a couple of weeks and surgery shortly thereafter. The surgery was performed at CCMC and what a wonderful experience it was. The entire staff there was wonderful. I did not know how to thank them enough for all they did for my little princess. My daughter had her surgery on a Tuesday morning and we were home on Friday afternoon. She was a trooper and we could not believe how fast she was recovering. She is my miracle daughter. Giuliana is a very special person and I want to thank Little Hearts for all that they have done for me.

Story by Giuliana's dad, Max

Delaney's story (COA, VSDs)

One evening after Delaney was born, I noticed she was a little sweaty and fussy. I took her into our air conditioned bedroom but she didn't get any cooler and started to breath funny. I noticed she would let out a small moan on every exhale and she became sleepy and stopped fussing. I called our pediatrician explaining the symptoms when Delaney began to turn blue. The voice on the other end of the line urged me to hang up and call 911. The ambulance responded within two minutes, grabbed Delaney and escorted us out. We arrived at the emergency room to find a team of doctors ready for her. It was a scene out of a movie. The doctor on duty knew almost immediately what was wrong and started to explain. To be honest, all I heard was, "Wha wha wha...extremely ill...wha wha wha...severe heart condition."

I just sat in disbelief, watching them stabilize her for the helicopter ride to CCMC. My husband and I drove which was the longest car ride of our lives. We cried and prayed the whole time. This wasn't fair! We took good care of ourselves. How could this have happened?

When she was brought in, they escorted us into this room. Doctors and nurses were all around her working vigorously. I was helpless as I watched my weak little five day old baby girl just lay there on that big table, arms out to the side and almost lifeless. I was sobbing. One of the doctors leaned over to me and said, "mom, you did the right thing by calling when you did. If you had waited until the morning, she wouldn't have made it." I then asked, "Can you fix it? Can you make her better?" He replied, hands clenched, "we hope so." Doctors aren't supposed to say "we hope so"! They are supposed to say, "yes, no problem". I knew all I could do was trust the team of specialists and keep praying.

After days of testing, they diagnosed her with Coarctation of the Aorta and two large Ventricular Septal Defects. After ten days in the PICU, she had open heart surgery and did very well and two and half weeks later, we were home. Since then, we have had no problems. She is the most content and smiley little baby I have ever seen. It is almost like she knows she has been given a second chance in life. We are truly blessed.

Story by Delaney's mom, Erin

Have a story you'd
like to share?
Contact us at
INFO@littlehearts.org
or by mail it to
P.O. Box 171,
Cromwell, CT
06416



Delaney

Volume 7, Issue 1

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David Matthew Choi
"miracle one"

Many thanks from all of us at Little Hearts for your support. Your donations help us with our mission in providing support and hope to many!



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Volume 7, Issue 1

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Grazzini sisters

Emilyn's story (TOF)



Emilyn

Emilyn was born April 21, 2003. The day after she was born, they told us that she had a heart murmur but not to worry. She looked perfect so I put this out of my mind and enjoyed my precious gift. When she was two days old, the doctors decided to call in a pediatric cardiologist to look at her. We will never forget the moment when this

stranger came into the hospital room and told us that our sweet perfect looking baby had Tetralogy of Fallot (TOF) and that she would require open heart surgery.

Thankfully, she didn't need surgery right away and we were able to take her home so she could gain weight before her repair. When she was

three and a half month old, we were told it was time. We knew this day would come yet we were panicked. We were terrified of the outcome.

It is amazing what the medical world can do for our "heart children".

by Emilyn's mom, Stephanie

Volume 7, Issue 1

Conor's story (TAPVR)

Conor was born by c-section on January 26, 2000. Being our second child, we were looking forward to enjoying our new baby and assuming we were "veteran" parents. Well, we were in for the shock of our lives.

After Conor was born, he was having difficulty breathing so there was the thought that he had pneumonia. After working on him for an hour, the neonatologist called in a pediatric cardiologist. Conor was then

diagnosed with TAPVR and was intubated and transferred to Columbia Presbyterian of New York. When he was only twenty hours old, he had open heart surgery. His repair was more complicated than anticipated and his recovery was very, very difficult. His lungs were what they called "very wet" and the miracle of chest tubes assisted in "drying" them out.

These five years have been such a learning experience for

the entire family. Conor has been in and out of the hospital for various respiratory and pulmonary issues, however, nothing seems to slow him down. He is an amazing kid. We consider ourselves blessed to have been touched by his doctors, nurses, family, friends and Little Hearts. Only parents of "heart children" can understand what it is like. For that, we thank you.

By Conor's mom, Bridget



Conor

Read more stories
online at
www.littlehearts.org

Murphy's story (TGA)

On September 13, 2004 we were the proud parents of a bouncing baby boy. However, shortly after his birth, Murphy was quickly whisked off to "special care" NICU because he was having trouble breathing. We were absolutely stunned to find out that he had Transposition of the Great Arteries (TGA).

Within two hours, he had a balloon atrial septostomy and two days later he had an arterial switch. The latter of which was one of the longest days of our lives! We were beside ourselves with worry but ten days later we were home.

Murphy had reflux until about six months of age. He is now

walking, self-feeding, jabbering constantly and eats everything healthy in sight. He also hits the milestones right on schedule. We go for EKGs and echocardiograms regularly. He is doing great and has never looked back!

by Murphy's mom, Kathleen



Murphy

Story by Jeffrey (HLHS)

Hello, my name is Jeffrey and I have a heart defect. HLHS is my heart defect.

I'm 9 years old and I'm in the 4th grade. I have a lot of friends. I do the one mile run every year and this year I came in 36 out of 46 kids. Yeah! I love beating other kids and they didn't even have a heart defect. Ok, enough

with the other kids and back to me.

Once at the picnic, a grown up came up to me and said, "You know, if you were not here, we would not be at this place right now." They even said, "You were the one who started these picnics. If you were not here, no one would be at the picnic today having

fun". I liked it when this grown up said this to me. And, the one who helped me so I could be at the picnics and for kids to have fun, is the one and only, Dr. Jonas.

Jeffrey was born June 6, 1996 with Hypoplastic Left Heart Syndrome. His story is online at www.littlehearts.org



Jeffrey



Providing hope since 1998

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My little brother was born with a heart defect



Me and my brother

Hello, my name is Matthew and I'm twelve years old. My little brother has a heart defect called Hypoplastic Left Heart Syndrome. When he had his first surgery, I didn't understand what was going on. I was only 3 ½ or 4 years old then. When time went by, I understood that my baby brother was a miracle. I learned that he almost died when he was a baby. In fourth grade, we learned about the circulatory system and I did a poster on his heart. All the other kids in my class did a poster on the heart's normal circulation.

Now, I sometimes forget that he has a heart defect because of his ability to run and play like the other kids. He also acts like a little brother sometimes and drives me crazy. Sometimes, he just knows how to bug me. But, that's his job as a little brother, isn't it?

But, we do what brothers do now and we have fun. Our favorite thing in the winter is to sled down this big hill. We have to walk up the hill a lot and whenever he gets tired just a little bit, he stops for a breather. But, I have to admit, I get tired too and I stop for a breather too. My brother is terrific.

Any other siblings want to share their story? Email LITTLE HEARTS at INFO@littlehearts.org or phone toll free 866-435-HOPE