



Quarterly

# NEWSLETTER

## Abnormal Brain Development in Newborns with CHD

### Mark your Calendar:

**February 14th** – CHD Awareness Day

*Suggestions & flyers, visit our website*

**April 2008** – Picnic registration form mailed out

*Members traveled from 13 states last year to attend. Hotel and other information will be online in April.*

**June 1st** – 12th

Annual Picnic *A great way for your heart child to meet another*

**NEWSLETTER ONLINE** – go to **SERVICES** page of [www.littlehearts.org](http://www.littlehearts.org)

*Share our newsletter with family, friends and your favorite PC and surgeon!*

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*Have a question for LITTLE HEARTS?*  
*Email us at*  
**INFO@littlehearts.org**

Phone us Toll Free  
**866-435-HOPE**

**MAILING ADDRESS:**  
P.O. Box 171  
Cromwell, CT 06416

In the New England Journal of Medicine, an article was recently published regarding abnormal brain development in newborns with a congenital heart defect. Researchers studied 41 newborns with a congenital heart defect—29 who had TGA and 12 who had single ventricle physiology—with the use of a MRI and other tests before cardiac surgery. They were compared with 16 infants without a CHD, who were matched for gestational age and the study found that 13 of the infants with a CHD (32%), had white matter injuries, compared with none of 16 without a CHD. The conclusion of their study was “Term newborns with congenital heart disease have widespread brain abnormalities before they undergo cardiac surgery. The imaging findings in such newborns are similar to those in premature newborns and may reflect abnormal brain development in utero.” One implication of this study may be that delays seen in some of our heart kids may not solely be the result of surgery.

This study was published in the New England Journal of Medicine—Volume 357:1928-1938 on November 8, 2007. To read more about this study, go to the STORIES page of our website. We’ve linked it under the heading of “Medical News”.

We share news and other informational type of articles to members through our NEWS email group. If you aren’t subscribed and wish to be on these mailings, email us at [INFO@littlehearts.org](mailto:INFO@littlehearts.org).

## Sharing HOPE Nationwide

Our website gets over 5,000 hits a day with the stories being one of the favorites. Together we’re making a difference! If you want to help and share the hope with others, email or mail in your heart child’s story and photo so we can add it to the STORIES page of our website—[www.littlehearts.org](http://www.littlehearts.org). We’re sharing in this newsletter just a few of the member’s stories that were sent to us last year.



*Kyle doesn’t need a story—this photo says it all!*

*He was born 1990 with HLHS.*

*Here he is after getting his driver’s license in 2007!*

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### Donations to LITTLE HEARTS in 2007 by members, family and friends

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*Happy  
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Birthday  
Little  
Hearts!*

*Thank you to all  
of our  
supporters in  
making this  
possible!*

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### Donations to LITTLE HEARTS in 2007 by members, family and friends

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## January 2008 Quarterly Newsletter

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### **Benjamin's story (AVSD, Down Syndrome) by his parents, Laurie & Ernie—Connecticut**

On May 13, 2005, our son Benjamin was born at Hartford Hospital. He was quickly diagnosed with Down Syndrome along with Atrioventricular Septal Defect (AVSD). He was quickly rushed off to the NICU where he remained for a week before he was sent home to be monitored closely by a visiting nurse and countless doctor visits.

After numerous hospital stays which almost immediately followed, he had open heart surgery at CCMC at the age of 15 weeks on August 29, 2005 to repair the defect. He stayed in the Pediatric ICU for one week following surgery and was then sent home. While this was an extremely agonizing time for us, we were grateful that there was a surgery available to repair this defect. In the months that followed, we noticed a huge difference in his appetite and he started to gain weight consistently. We felt relieved that the surgery was behind us and we finally felt like things had taken a turn for the better.

Unfortunately, on December 12, 2005 we found ourselves back in the hospital with Benjamin, this time being diagnosed with Infantile Spasms (a type of seizure). After another week long hospital stay, we were discharged. For the next seven weeks we had a visiting nurse coming to the house to administer injections of medications into his thighs to control the seizures. This was an absolute nightmare time for us, as it came out of nowhere and we were not at all prepared for it. Our poor baby had already been through so much. Luckily, the treatment and the prayers worked and the seizures have resolved. His neurologist says that his recovery was nothing short of miraculous.

Despite all of the medical hurdles that he has had to overcome, and all of the medical issues and challenges that are still ahead of us, we thank God everyday for the gift of our Benjamin. He has brought such incredible joy into our lives and it is hard to remember a time when he was not with us. Throughout our entire ordeal, people have repeatedly said to us that "God gives special kids to special parents". I used to think that they were just trying to make us feel better, but now I really think that it is true. For all of us with children with heart and other problems maybe God chose us to be their parents because he knew we had big hearts full of love to give to our extra special children.



### **Aubrey's story (HLHS) by her mother, Angelina—Pennsylvania**

Princess Aubrey was born on January 16, 2004 with Hypoplastic Left Heart Syndrome (HLHS). We found out when I was five months pregnant at a routine sonogram that something wasn't right. Specialists at West Penn and Allegheny Hospitals in Pittsburgh confirmed HLHS. We were devastated but knew she deserved her chance.

We researched HLHS when we got home and knew ahead of time what kind of help would be offered to our Princess. When we went to Allegheny Hospital, the Pediatric Cardiologists started to give us our options but we already knew that there was only one answer. The life inside of me that had a strong heartbeat and radiated will and stength and kicked with gusto would be strong enough to make it through her surgeries. We knew she could do it.

At three days old, she had her Norwood, during the process of putting her on the heart/lung bypass for the second time during that surgery due a large leak in her aorta, Aubrey had an embolic stroke. The stroke led to seizures and she has had Chylous Effusions with each open heart surgery. Aubrey completed her third surgery on August 11, 2006.

Today, she is a bouncing, thriving Princess going on 4 years old. Despite the front left side of her brain being non-functioning, she shows no lasting affects from the stroke or seizures. She is a miracle and the strongest woman that I will ever know!



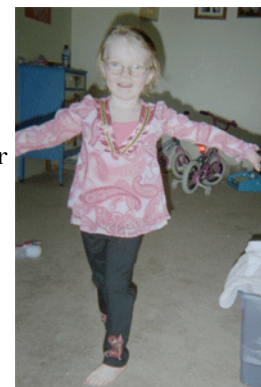
## January 2008 Quarterly Newsletter

### **Raychel's story (VSD, PDA, DCRV) by her mother, Arica—Michigan**

Shortly after Raychel was born, I was told she had two heart defects, VSD and PDA. Fortunately, the PDA closed up on its own, but the VSD never did and caused a condition called Double Chambered Right Ventricle (DCRV) where the muscle in the right ventricle of her heart started to thicken. Raychel's cardiologist told me she would need surgery if the muscle became too thickened.

The dreaded day came on September 12, 2007. I brought Raychel to Helen DeVos Children's Hospital and Congenital Heart Center in Grand Rapids, MI the morning of 9/10 for a cardiac catheterization that showed the muscle so thickened, it was nearly completely blocking off the right ventricle in her heart and causing it to pump at an alarming pressure of 86. She was in danger of a heart attack.

Her surgery on September 12th took approximately 5 hours and it was the longest 5 hours of my life. At about 1pm, my baby girl was brought upstairs from surgery to the PICU to recover. She was hooked up to at least 10 machines, a multitude of tubes, and had a 6-inch-long incision down her chest. She was gagging on the anesthesia and gasping to breathe on her own. She opened her eyes occasionally and looked at me while gripping my hand and crying in pain. I felt so helpless to do anything for her. I cried, seeing her in that condition. Two days later, Raychel was released from the hospital. She was still weak, of course, and on medication, but is recovering well. Her sternum is wrapped in wire and clips to help it grow back together.



This past October, my little girl had a minor setback when she passed out twice while playing with me and her sister. She was taken to the hospital and kept overnight, hooked up to a heart monitor. The next morning the doctor performed an ECHO on her and it was found that a blood vessel leading to her heart had become dislocated as a result of her open heart surgery and was no longer in its proper location. Her doctor assured me it was nothing to be concerned about but definitely to watch. She was sent home later that day, wearing a portable heart monitor.

### **Sebastian's story (Pulmonary Atresia w/IVS) by his mother, Marcy - New Hampshire**

My pregnancy with Sebastian was such a wonderful experience. I was the happiest pregnant woman I knew! Sebastian was born via c-section (due to being in a breech position) at 39 weeks. He was beautiful. He scored 9/9 on his Apgar tests and had the lungs of a champion when he joined the world. He was born very early in the morning and it was evening before the truth of his defect was discovered. His nurse came in and took him for a hearing test. Until then we had all been resting in a dimly lit room, Sebastian in his bassinet. The nurse immediately came back in to tell us he was a little blue but not to worry, that this was typical of c-section babies who don't always get all the fluid out of their lungs. But we soon discovered it was not that.

The pediatrician on call came in and told me they were fairly certain that Sebastian had a heart defect but they didn't know anymore and were awaiting doctors from Boston Children's Hospital to come get him. It was definitely a horrible blow to what had been, just moments before, a new happy family. Once in Boston, he was diagnosed with Pulmonary Atresia with Intact Ventricular Septum. His first surgery occurred on September 11, 2001. And while the whole world was obsessed with what was occurring in our country, my whole world was enduring his first open heart surgery and showed us that strength isn't about size!



He completed all the steps in his 3-step Fontan surgery and is doing beautifully. He amazes me everyday with his sweetness and his humor and of course his strength. It wasn't an easy road seeing such a fighter in such a tiny body. It's hard to see the things they must go through and the road to recovery they must face but I always told myself, "If he can go through it, I can do whatever he needs to help him to survive." And, for this, he is my hero.

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### **Brianna's story (TAPVR) by her mother, Jeannine - Connecticut**

On Friday, October 13, 2006 I realized I hadn't felt my baby move for several hours. I went to lunch with my mother, husband, and brother and was getting really nervous. I thought a big meal would get the baby moving, but still nothing. I called my doctor and she told me to meet her at the hospital. Within minutes of arriving, a team of doctors assembled and performed a c-section. The baby's heart rate was erratic. I could tell something was wrong, but I remember thinking, "well, they're getting her/him out so they'll fix whatever it is."

Nothing could have prepared my husband or me for the next several days and weeks. Brianna was born at 5:05 PM that Friday. She weighed 6lbs 9.5 ounces. I saw her so briefly before they whisked her off to be intubated and worked on. She was gray in color but I thought all newborns looked like that. She was just so cute crying! I couldn't stop thinking of her while I recovered from the surgery wishing I could hold her and look into her eyes. The next time I saw her she was intubated. That night she was transported to Yale New Haven Hospital. Saying goodbye to her was excruciating! I felt as if someone was ripping my heart out of my chest.

At first, they thought it was her lungs so she was on ECMO for two days. At three days old, she was diagnosed with TAPVR and operated on that night. The surgery took 8-9 hours. It was even more complicated than the doctors predicted. She was brought up to the PICU and we remained there with her every day for 56 days! I didn't hold my baby girl until she was 24 days old and she was covered with chest tubes, IVs, central line, etc. It was a living nightmare. She finally came home at exactly two months old but unfortunately ended up on a helicopter with me by her side back to the hospital on New Years Eve day. The effusion in her chest re-accumulated. I always say she wanted an exciting first New Years! She was intubated at exactly 2007, just after I was told by one of the nurses to call our priest or minister. We were there for another two weeks before Brianna was well enough to come home.



All of this time, her Dad and I never doubted her strength and will to live! She always looked so alert. I nicknamed her "Tiger" in the hospital and she more than lived up to this name. She's the strongest little baby I've ever known! She teaches me what love is every day. I just don't know what I'd do without her. She is my life. I still pray for her health every single day. I will never take it for granted. We are forever grateful to the brilliant nurses and doctors who cared for our miracle baby. Also, we couldn't have survived this ordeal without the love and support of our family and friends.

### **Kimberly's story (DILV) —Georgia**

Kimberly has recently shared her story in an inspirational book titled, "In a Heartbeat." She was born in 1960 and has had three open heart surgeries as a child - two BT Shunts and a bidirectional Glenn. A copy of her book can be purchased online at [www.KimsHeartbeat.com](http://www.KimsHeartbeat.com)



### **Financial assistance to "heart" families based in NH**

For members living in New Hampshire looking for financial assistance, please contact the Kara Catherine Duclos Foundation at 603-520-7033 or visit them online at [www.friendsofkara.org](http://www.friendsofkara.org). We've added this resource to our Listing of Resources on the CHD FACTS page of [www.littlehearts.org](http://www.littlehearts.org).

### **Little Hearts 2008 Calendar**

Our 2008 photo calendar is now available. This year, we have 114 photos of children born with a heart defect. Order online on our PRODUCTS page or mail in your order to LITTLE HEARTS, INC. P.O. Box 171, Cromwell, CT 06416. Cost per calendar is \$22.00 which includes postage & handling.

