



NEWSLETTER

Issue No.2

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September 2007

A Note from the CEO

. Breath of Hope received the Determination Letter from the Department of the Treasurer dated July 25, 2007 stating that we are a **501c3 Public Charity** and donations are 100% deductible as of **May 17, 2004** in accordance to law.

Stacy Everett and I have known one another for 8 years. We shared our loss of our children to Congenital Diaphragmatic Hernia, our obsessive search for new information on medical reports, treatments or anything; on how can we save others from the path we had to walk in life. We also shared the hammering out of all the paperwork to form BoH as a Public Charity. My husband calls her my evil twin. We say we are sisters with different mothers.

Congenital Diaphragmatic Hernia Awareness Day™ came to her and we researched it and thus it is born from seed of an idea we hope will bring awareness, more research and a united group of determined parents that will make this not only a Day for our States, our Country but the World. March 31, 2008 will be a Day for Congenital Diaphragmatic Hernia Awareness™. ***Isn't it about time?***
~Elizabeth Doyle-Propst

Heavenly Angels and Earth Bound Angels Unite

*Graham and James; an Angel
story.....*



*Graham 8 Months with
James' Footprint*

Graham was born March 31, 2003, after a normal pregnancy and delivery, at a whopping 8lb 14oz; with a right side Congenital

Diaphragmatic Hernia (CDH). His survival depended on some extreme measures, including a heart-lung bypass machine called ECMO. His first round on ECMO was relatively routine, he was taken off in 5 days and we breathed a sigh of relief that we were now on our way to getting better and going home. It was apparent within a day that Graham's troubles had barely begun. His lungs, though big for a CDH baby were severely damaged. They tried the oscillating vent, so many chest tubes I couldn't keep track. His chest kept filling with air; his lungs were full of holes....

On April 17, the decision was made to put him back on ECMO, but before they did that, his surgeon needed to open him up and see if that right lung had any chance of healing. They did the surgery in the ICU. I had to listen to parents complaining about

not being able to go see their children because the ICU had become an OR for 5 hours. We were told before this surgery that a second round on ECMO was extremely dangerous, that his chances for survival were now slim. His surgeon told us that they were prepared to put him on the lung transplant list and also that he'd never saved a CDH baby with a lung transplant. Just a day before this, another CDH baby passed away during his second round on ECMO.

While the team worked on Graham, my husband and I talked about what kind of funeral we would give our son, we prayed that some of Graham's organs would be good enough to donate and help another child. We prepared ourselves for being 'Those poor people who lost their baby'.

He came through the surgery and the ECMO cannulation but with no guarantees; his lung looked a little better than they'd expected but his chances still slim. The wait began again. We stopped accepting visitors except for our parents; we gave few details to anyone.

On Saturday, April 19, while sitting by Graham's bed I saw a baby being wheeled by, saw the ECMO, the nurse didn't need to tell me that the baby had CDH. She told me the parents were in Albany, mom had a c-section and would be a couple days; dad would come the next day.

Sunday morning, I was eating breakfast in the waiting room and a man walked in and collapsed on the floor, his head in his hands. I knew who he was. I said 'I know how you feel' and he replied 'I'm sorry, but there is no way you could know how this feels'. He was stunned to hear that I'd been going through it for three weeks. His name was Rob, his son James Joseph. We talked for a while. I told him to send his wife my way as soon as she arrived, if she was up to it.

Monday morning I saw a woman in the waiting room, holding her little bottles and pumping equipment, waiting for a room to open up so she could pump. Again, I knew instantly who she was. I introduced myself and as we began talking I felt an instant connection, like I'd known her all my life. She had a 4 year old son back in New York and wasn't going to be able to stay in Boston; she'd come as often as she could. I

told her that I'd be keeping an eye on Baby James while she was gone. James was smaller than Graham, only about 5 pounds, on ECMO, had some bleeding in his brain. Like me, Lollie didn't know anything was wrong until her son was born.

For the next couple weeks, my routine of sitting by Graham's side was broken up a little by sitting by James' side. When Lollie was able to be there we'd share every detail of our sons' conditions. Graham came off ECMO on May 1st but continued to have complication after complication. Every day we got bad news. There was heart failure, kidney failure, seizures and infections of every imaginable kind. I couldn't get the thought out of my head that I probably wouldn't hold my son until they put him in my arms to die. Baby James wasn't doing well either, so small, and with a serious bleed in his brain.

On May 7th my husband and I got to the ICU to find Lollie and Rob and their sisters looking worse than usual. I knew before they told me. James was losing the battle, his lungs too small, his brain badly damaged. It was time to let him go. There was lots of hugging and crying; these people we'd only just met but felt like family.

The nurses brought Lollie some paint and clay to make molds of James' hands and feet. Lollie sat and watched as her sisters and I painted James' little hands and feet and made T-shirts and posters. I put a footprint in the middle of a piece of paper, wrote around it "To Graham, Love James", ran

across the ICU and put it at the end of Graham's bed. When my husband and I left the hospital that afternoon James was still alive.

When we walked into the ICU the next morning, the first thing I did was look at the names on the census board, James' name was gone and my heart just sank. One of our surgeons, Dr. Mike, ran over to us when he saw the looks on our faces, he told us that James had passed soon after we'd left. He then tried to reassure us that Graham was still holding on and that there was no bad news to report; ***there would never be bad news again.*** From that day on things got better for Graham by leaps and bounds. He made amazing progress every day. His kidney function improved, his heart got stronger, his infections cleared up, his lungs were healing.

On May 9th he came off the oscillating vent. May 15th I held him for the first time. May 30th we left the ICU. Another 6 weeks of getting him stronger and healthier and we brought Graham home on July 11th 2003.

Some think I'm crazy, but I know that it was no coincidence that Graham's amazing recovery started the day that James went to Heaven. James body may have been weak, but once his strong spirit was set free, he went right to work helping Graham fight for his life; and win. James was there for every victory, for every tube removed, for every infection cleared, for Graham's first breath without a machine. Every milestone that Graham has reached over that past

two years has been a victory for James Joseph I know that Graham never walks alone, that James is by his side. I continue to share Graham's progress with Lollie and family always wanting to know how Graham is doing.

Baby James' footprint has never left the head of Graham's bed. It followed him when we left the ICU, and when we finally brought Graham home. It's there right now. I have a picture in my head of Graham's college dorm room. On the wall over his bed is a piece of paper, now framed, with a baby's footprint in the middle: 'To Graham, Love James'.

Written by Cristin, Graham's Mommy



Graham, age 2 still with James' Footprint

NILMDTS

Now I Lay Me Down to Sleep is a NPO where professional photographers donate their services and materials to capture parents with their precious children in critical care or who become angels..

www.nowilaymedowntosleep.org

RECEIVED DONATIONS

Joanne Kales Trontz, in honor of Michael

Christie Brooks, in memory of Madison

Margaret Ko, in honor of Ines Jennifer Evans, in memory of Grace

Anne Mank, in honor of Abby

Leanne Carmona, in honor of Rylea

Victoria Jensen, in honor of Jack

Jennifer Luning, in memory of Jordan

Victoria Jensen, in honor of Jack

Jean Ashner, in memory of Luke

Karen Myers, in memory of Kaleigh Marie & William Logan

Holly and Jonathan Centurino, in honor of Blair

Stacy Harding, in memory of Nicholas

Elizabeth Doyle-Propst, in memory of Joseph

Elizabeth Doyle-Propst & Brian Propst, in honor and memory of ALL CDH babies & children and their families

To Donate:

Paypal to
breathofhopeinc@gmail.com

Or mail to:
Breath of Hope, Inc.
PO Box 6627
Charlottesville VA
22906
*(Please send in US
Currency our Bank Fees
for conversion are
exorbitant.)*

SPECIAL THANKS TO THE FOLLOWING

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Bridgeport, Connecticut
for our Brochures!

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Plymouth, Minnesota
for this Newsletter!

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M.P.H. University of Virginia Children's Hospital
Division Chief, Neonatology
Charlottesville Virginia
for review of our materials.

Members who have helped:

Stacy, Nicholas' Mom

Jennifer, Jordan's Mom

Carole, Joseph's Mom

Melissa, Bennett-Chadlen's Mom

Rick and Nancy, Patrick's Mom and Dad

Marsha, Zach's Mom

Terri, Ava's Mommy

Catherine, Sofia's Mommy

Bethany, Brody's Mommy

Holly, Blair's Mommy

Kara, Adam's Mommy

Ilianna, Danté's Mommy

Please contact us to be added to our mailing list or to opt out of our mailings at:
boh@breathofhopeinc.com

Real Integrity is doing the right thing, knowing that nobody's going to know if you did it or not. – Oprah Winfrey



CONGENITAL DIAPHRAGMATIC HERNIA
AWARENESS DAY™

MARCH 31, 2008

EVERY BREATH THEY TAKE IS OUR BREATH OF HOPE

WWW.BREATHOFHOPEINC.COM

On July 31, 2007 Breath of Hope, Incorporated launched ***Congenital Diaphragmatic Hernia Awareness Day™***. Each Board Member used the letter template created by Stacy Harding to be sent to their respective State Governor. This is a grass roots effort to have each State, Commonwealth and Republic in our nation to recognize March 31, 2008 as Congenital Diaphragmatic Awareness Day™. Enclosed in this Newsletter is the Awareness Ribbon you can wear or display and when someone asks, you can tell them about Congenital Diaphragmatic Hernia. You can tell them about your child, grandchild or a child you know of that was affected by this birth defect.

How many of you who have child that was diagnosed with this devastating birth defect knew what it was? After finding out what CDH was and how deadly it could be, how many did you tell that said, "Oh, my uncle had a hernia that is an easy fix." Your uncle did not have a Diaphragmatic Hernia. There is a reason the diaphragm separates the lungs and heart from everything else in the body. When these babies are developing it inhibits lung growth. Vital source of life is the ability to breathe! It is frustrating explaining it to a public out there that has little or no knowledge.

For those health professionals out there, with ***AWARENESS*** of this birth defect would come perhaps more funding for research and more advancement so that more of the cases you work on every day will become the best case scenario. People would realize how many are affected by this and how frustrating a condition it can be on health professionals that try every day on the front lines of NICUs, doctors offices and clinics to help families. One Mom told me, she uses it as her test on Nurses and EMTs. When she tells them her son survived one and they go white in the face she knows they had that "experience" of a CDH patient taking that dramatic turn for the worst.

For all of us – what can we do? Write your Governor requesting that **March 31, 2008** be designated as ***Congenital Diaphragmatic Hernia Awareness Day™***. If you need a guideline contact at Breath of Hope and we will send you the sample documents: a letter, a Sample Proclamation and a Brochure. In these documents you can express why you believe CDH should have an Awareness Day and how this has had an affect upon your life, your child's life or your family and friends. If you are outside the United States, let us know how we can help you spread this in your Country too! breathofhopeinc@yahoo.com

What will happen if we don't have awareness? Parents will be diagnosed and be as dumfounded as we all were. They will have to research for the resources out there, hospitals out there, treatments out there and choices to how to treat their unborn child. Without it, doctors will still be frustrated with the lack of research and funding that they are faced with every day. Without awareness, it will still be a "rare birth defect" which occurs just as often as Spina Bifida and Cystic Fibrosis. Without awareness it will not be acknowledged by the general public.

We want awareness. We want the general public to be educated. We want parents who are diagnosed to be aware prior to diagnoses and that there is ***a Breath of Hope***.