The Awareness Articles

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2009 Congenital Diaphragmatic Hernia Awareness Day

By Elizabeth

November 4, 2008 has passed and we now have new Governors elected so now we can embark on the challenge of 2009 Congenital Diaphragmatic Hernia Awareness Day™! We ask anyone who wishes to; please contact us at cdhawareness@breathofhopeinc.com for a sample letter and proclamation again this year. The letter has the technical information that is needed for this request but also has an area for you to insert your story of CDH. Breath of Hope only asks that you tell us when you send this letter to your Governor and the outcome to be scanned or photographed and emailed to us. You keep the Proclamation, which can be used any way you would like. We just want confirmation that your state has issued it. Our goal for 2009 is to have all 50 states in the United States proclaim March 31, 2009 as Congenital Diaphragmatic Hernia Awareness Day™.

This is at a cost of under $2.00 to mail this to your Governor and we will be happy to provide you with your Governor's name and address. We say $2.00 regular mail if you are also mailing photos or other information to your Governor.

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Inside This Issue

"One baby every twelve hours will die of complications due to CDH." – Breath of Hope, Inc statistics

Our Little Blessed One

By Ann

In January 2003, when I was 16 weeks pregnant with our first child, our son, Bennett, was diagnosed with congenital diaphragmatic hernia (CDH). This was something that neither I nor my husband, Mike, had ever heard about. I had decided, because I was 35, to have a level 2 ultrasound done to see if there were any potential abnormalities or downs syndrome. The ultrasound showed that Bennett's stomach was in his chest cavity near his heart. Mike and I were also told that based on the ultrasound measurements, Bennett had signs of downs syndrome. This was the first of many devastating days to come. Before leaving the hospital that day, an amniocentesis was done.

Over the next 2 weeks, while waiting for the amniocentesis results, Mike and I did as much research as possible on CDH. But, I never found any type of support group like Breath of Hope. There was one website that my in-laws (a doctor and nurse) found, but they told me not to go to it because so much of their information and stories were about babies that did not survive and they felt it was not in my best interest to read those stories so early in our research. The Doctor who gave us the diagnosis also told us that we only had a 50% chance that our son would be born alive and, if he was born, that he would need surgery

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We also ask for any family, friends, nurses, doctors, therapists – anyone at all to also help us in this effort to having all fifty states in this nation proclaim Awareness for this birth defect that has affected over 100,000 people in the United States alone. Five families every day will be told that their unborn or just born baby has CDH. One baby every twelve hours will die of complications due to CDH. At the rate of 1 in 2000 pregnancies in the United States alone being diagnosed with CDH – this is equal to or more frequent than spina bifida, cystic fibrosis and Downs Syndrome. More people have heard of these birth defects than congenital diaphragmatic hernia. If you are not in the United States we also will try to help you with your local or area governments in your country to issue a Congenital Diaphragmatic Hernia Awareness day of 31 March 2009. This does make an impact; it brings attention to this devastating birth defect that has been overlooked for so long. From Awareness, brings about funding for research and knowledge and education. All it takes is one letter and perhaps an hour of time.

"Live your life from your heart. Share from your heart. And your story will touch and heal people's souls." --Melody Beattie

Miracles Among Us

Amanda, proud aunt to Gus

I can pinpoint the day and the hour my life changed, November 19, 2007 at 11:09 AM Pacific. My father sent me a text message that simply said, "Call me asap." My sister and her husband were weeks away from the due date of their first child, a son- our first nephew, grandson and great-grandson. The many aunts, uncles and grandparents were eagerly awaiting his birth. I was both excited and anxious when I received the message thinking the beautiful, perfect baby boy must be coming early.

I stepped out of my office to make the call and got the heartbreaking and terrifying news. Little Gus had been diagnosed that day with a Congenital Diaphragmatic Hernia. I kept shaking my head, "no" denying that there could be something wrong with the child we'd been awaiting for three years. Jill and Tyler so badly wanted to be parents. Gus had been a miracle since conception, somehow finding his own way, though they'd tried numerous fertility treatments. Jill discovered she was pregnant only days before beginning a new round of treatments. This was the baby of our hearts, how could something go so terribly wrong?
I spoke to both my mother and father in the next half hour. I spoke to my sister Lynn. I called my best friend. My mind couldn't encompass the fear and disbelief. During the next day or so, I worried and prayed and cried. My heart ached that I was 2000 miles away and could not comfort Jill and Tyler.

Gus – portrait smile!

Two days after the diagnosis, the day before Thanksgiving, Gus was born at Barnes Jewish Hospital in St. Louis, Missouri. Jill and Tyler barely had a chance to say hello before he was hurried away to our family's soon to be "home away from home," St. Louis Children's Hospital. On Thanksgiving Day, I flew from Las Vegas to St. Louis to be with my family and to meet my nephew. I spent the seven hours and two flights giving myself stern lectures to be strong. Jill and Tyler didn't need someone to cry, they needed strong shoulders to lean on, encouraging words and positive attitudes. When I arrived at the hospital, I found my sister and brother-in-law, stronger than I'd ever seen two people. Both wore a look we would become very familiar with over the coming months – fierce determination and strength.

Family members continued to arrive and a couple of hours later we made our way across the hospital to meet Gus. I didn't know how he'd appear. I knew he'd be connected to monitors and machines, perhaps be pale, tiny and weak. (Jill asked that we not research the condition prior to his birth as she'd seen too many grim stories and didn't want us to absorb that fear...she had enough for all of us.) When I entered the room though, I was heartened to see how beautiful and perfect he was. The machines surrounded him, but he moved his tiny feet and hands, fighting the sedatives they had given to keep him still and calm. He tried to breathe over the ventilator and just a glance showed his fight and determination.

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immediately after birth with only a 60% chance of survival. We found, through research, that survival rates after surgery ranged from 60%-90% - it all depended on how severe of a hernia each baby had. The amniocentesis results came back with no chromosomal abnormalities, so we moved forward to find the best hospital, doctors, and surgeons near our home in Northern Illinois. We had learned about Dr. Kays in Florida, but wanted to exhaust all options in our area first. Learning about Dr. Kays approach to treatment armed us with vital information we wanted to hear from the Doctors we ultimately chose to treat our son.

At 20 weeks, we went to see a Doctor from Evanston Hospital's Maternal Fetal Medicine group to have a follow-up ultrasound done and to get a second opinion. This Doctor was wonderful and, based on what he saw that early in the pregnancy, he felt he could give Bennett a 70% to 80% chance of survival. Then at 24 weeks, I went to visit the hospital and meet with the surgeon. His approach was very much like Dr. Kays, so we knew we were going to be giving our baby the best chance we could.

Bennett showing his Turquoise Tongue!

Before receiving the CDH diagnosis, we had not picked out a name – we only knew that if we had a son, his middle name would be Michael after his Father. We both wanted a name that would not be common because we both always had another Mike or Ann in our classes all through school, but also wanted something that he wouldn't always have to spell because he'd always have to spell his last name. After finding out that we were having a boy, I liked Aiden and Mike liked the name Cameron. I quickly learned that Aiden was becoming a popular name, so we decided not to use it. Then a woman at my work was having a boy before me and she was naming him Cameron Michael – so we put that name at the bottom of our list. I went online to compile a list of baby names. As I was going over the list, which included the origin and meaning of each name, I stopped at Bennett because its meaning was "Little Blessed One" and we knew that Michael meant "Who Is Like God". I knew at that moment that I needed to give my son a name that would be strong because he needed to be a fighter from the start. I also liked the name Garrett which means "Spear Rule".

When I was 34 weeks, I started to go into labor – the non-stress test performed that day didn't show anything to be very concerned about. On June 6, 2003, one week later, I was going in for my first weekly checkup and my contractions were very strong. During that 1-1/2 hour drive, Mike and I realized we hadn't decided on a name and had a gut feeling that our son would be born that day. Mike liked Bennett and I liked Garrett, but Mike didn't want to give the baby a name until we saw him. At the Doctor's office, I was told that I was 4-1/2 cm dilated, fully effaced, and my cervix was very thin. Mike and I had learned the week prior that our son was in a breach position. I was rushed to Labor and Delivery for an emergency c-section. Bennett was born just over 2 hours after we entered the hospital that day weighing 5 lbs 7 ozs.

Because of the CDH, a team of Neonatologists were in the delivery room ready to intubate Bennett immediately after he was born. We never were able to hear a cry or any sound from him after he was delivered – the tubes were placed in his throat and nose within a minute after birth. The Doctors and Nurses cleaned him up and put him on a transport cart to take him to the ISCU (Infant Special Care Unit). They stopped only long enough for Mike and I to touch his tiny hand - he grasped his Father's finger. Mike followed Bennett to the ISCU. In recovery, Mike came to me and said, "He looks more like a Bennett than a Garrett – I think we should name him Bennett." We both agreed that he was truly our "Little Blessed One".

"I was going over the list, which included the origin and meaning of each name, I stopped at Bennett because its meaning was "Little Blessed One" and we knew that Michael meant "Who Is Like God"." – Ann, Bennett's Mom

Over the next 5 weeks Mike and I went to the hospital almost daily to visit Bennett. His surgery was performed when he was 2 weeks old. During those first weeks he was put on different ventilators, paralyzing drugs so that his breathing would be controlled, and many other drugs to make him comfortable and pain free. His oxygen requirement was anywhere from 35% to 70%. After his surgery he had one really bad day where his oxygen requirement went up to 87%. Once the paralyzing drugs were stopped, Bennett started to get better. At 3 weeks old he was fed breast milk for the first time through his nasal tube and we were able to finally hold him. At 4 weeks old Bennett was extubated and started bottle feedings - it was at this time that we finally heard his voice. This happened on the evening of July 4th – the Nurse called us at home to tell us the good news and let us hear his tiny, hoarse voice while he cried. What a night of joy and celebration we had. The next morning, we went to see Bennett with such joy in our hearts, but this became the day that we call "Blue Baby Day". Bennett stopped breathing for a few minutes after being suctioned – but it seemed like an eternity. We were paralyzed to our seats as we watched our ever-caring Nurse, Gina, work by herself to get Bennett breathing on his own again (the other Nurse had just left for her lunch break). At exactly 5 weeks old Bennett was released from the hospital.

When Bennett went in for a 1 year checkup with his Surgeon, x-rays showed that his diaphragm had weakened and was covering the lower portion of his left lung. Over the next 6 months, we had numerous visits with his Surgeon and a Pulmonary Specialist to determine what the best course of treatment would be. Because x-rays were showing that the diaphragm was getting worse, it was decided that surgery would be the only way to give Bennett the best chance at full use of his lung.

In January 2005, we took Bennett to Children's Memorial Hospital in Chicago. The surgery lasted about 2 hours. Diagnostic tests done during the surgery showed that there were no nerve endings in the left diaphragm and it was explained to us that it was no longer a functioning muscle – its only purpose was now to be a barrier between the chest and abdominal cavities. The Surgeon had pleated his diaphragm to tighten it, but he could not guarantee how long it would last – that he could not guarantee this would be Bennett's last surgery.

When we took Bennett to his Surgeon for his 2 year checkup in June 2005, x-rays showed once again that his diaphragm was weakening. The diaphragm was covering some of the lower portion of his left lung, but it was not impairing his breathing. It was explained to us that as Bennett's body grows, the diaphragm is stretched to accommodate the growth. But, since there are no nerve endings to "exercise" the muscle, it will weaken after each growth spurt and will always be a concern with regard to his lung functionality. We saw the Pulmonary Specialist twice between June and December 2005 and lung sounds were good, so no surgeries were deemed necessary.

We next saw Bennett's Surgeon for his 3 year checkup in July 2006. This time x-rays showed a large amount of bowel and intestines over his lower left lung. We were told that surgery needed to be performed within the next 2 months. When I called to schedule the surgery, the first date open was August 22, 2006 – the second anniversary of my Father's death. We were all nervous about having Bennett undergo surgery on that date, but we felt that it was going to be a special day because his Pa Pa would be watching very closely over him.

The surgery was supposed to take about 2-3 hours. As we sat in the hospital, we got a call from a Surgical Nurse an hour into the surgery to say that it had taken that long to get through scar tissue to finally see what was going on inside, that a small section of his left lung had adhered to the tissue and was no longer viable so it was removed, and that Bennett's diaphragm had completely disintegrated – that it looked like a thin web of tissue over his bowel. Because of this, we were told that a full Gortex patch would need to be used and that they could not estimate how much longer the surgery would take – possibly another 2-4 hours. We were devastated and I broke down in tears while other families of children in surgery watched. We quickly moved into a private room so that they did not see my pain. Once we collected ourselves, we gave our cell phone numbers to the waiting room attendant and left the hospital. We called our parents to tell them the news and went to a nearby bar for a much needed drink and change of scenery.

About 5 hours after Bennett first went into surgery, we got the call that everything was complete and Bennett had done very well. When we got to Bennett's room in the PICU, he was awake with very wide eyes. He looked at us and realized he couldn't speak or sit up with the tube in his mouth – a single tear rolled down the side of his face. He, and we, quickly learned to ask and answer yes and no questions because he could nod his head. Over the next 3 days, Bennett got better, was extubated, and moved to a regular room. But, he was pretty much refusing to eat and kept complaining about stomach pain. We all thought it was hunger pains because he hadn't eaten since the night before surgery and we also decided to start backing off of pain meds to try and trigger some desire to eat. I was only able to get small amounts of applesauce, crackers, and water in him. The second night out of the PICU was really bad; he was up crying pretty much all night long. The Surgeon came to the hospital the next morning, a Sunday, and when he reviewed Bennett's last x-rays (taken about 36 hours prior, just before leaving the PICU) he saw that bowel and intestines were over a significant portion of his lower left lung. The resident Surgeon's had thought that was just bowel moving into the slack left in the patch for Bennett's growth. Another x-ray was done immediately and he had bowel and intestines all over his left chest up to his collar bone. He was immediately prepped for surgery.

This time the surgery lasted about 4 hours – they entered through both his chest and abdomen because they had to pull the intestines and bowel back down as well as reattach the patch. When the Surgeon finally came out to talk with us – he told us that this second surgery was a God send. That Bennett's diaphragm was almost fully intact – a small hole had torn open near his rib and allowed bowel to escape. But, his body had created a thin membrane layer to try and keep the bowel down and protect his lung. When they attached the patch, it caused too much pressure and the bowel broke through. In the Surgeon's words, "Bennett is better off now than he was after the first surgery." We spent almost another week in the hospital before being released to go home.

We've had follow-up x-rays done with his Surgeon the summer's of 2007 and 2008 and everything looks "perfect". The Surgeon said that if someone looked at Bennett's x-ray now and didn't know his history, they'd never know what he's been through.

We cannot say enough about how wonderful the Surgeons, Neonatologists, and Nurses are at Evanston and Children's Memorial Hospitals. Thanks to the miracles that can now be performed by these individuals through research and medicine – our son is a healthy 5 year old. 15 years ago our son (and other CDH babies) would never have made it out of the hospital after birth, now Bennett has the opportunity to live life to the fullest.

Miracles Among Us from Page 2

Bless us, oh Lord

And these Children, thy gifts. You gave us in trust angels without wings. Evidence of Grace. The miracles whom you've placed in the arms of us fortunate few.

Over the following days, we spent hours in the room getting to know the newest member of our family. When he continued to struggle with the ventilator, I began to whisper to him often, "Gus, fight the war, not the battle." He needed to conserve strength for the journey ahead, but he was just so stubborn. His mother's and father's tenacity was firmly embedded in his DNA. Once Jill was released from the hospital, she, Tyler and I moved into temporary housing suggested by the hospital's staff. I hope I was a help and distraction to them by getting a fan for our room, things to eat and reading material and by giving Jill someone else to focus on (she seemed to enjoy scolding me for my lack of a jacket...St. Louis weather in November is a bit different from that of Las Vegas.) That night as we lay in the large room pretending to sleep, Jill received a call from the hospital- Gus wasn't doing well. His oxygen level was dropping and his doctor had been called in. I didn't realize my heart could break any further, but after she hung up, as she lay crying quietly, I heard Tyler whispering and soothing her, and I knew a heart can break again and again and again.

Gus bounced back a bit the next day, giving us all a bit of a breather. I stayed in St. Louis until the following Tuesday and then had to fly back to Las Vegas to return to work. When I said goodbye to Gus, I could barley choke back the tears enough to tell him that I loved him and would always be with him (in fact I can't choke back the tears writing this eleven months later.) Once I returned to Las Vegas, I lived for the CaringBridge website, hoping for updates and soaking up the prayers and love from entries left by family, friends and even strangers who'd heard his story. Jill and Tyler kept their positive attitudes and humor, giving us comfort, though I know there were so many times when they struggled to find anything good to say about their days in the NICU.

He spent almost two weeks on ECMO life support. Jill and Tyler struggled with this decision, having been given odds on the outcome that no parents should ever hear. They prayed and struggled through six surgeries and the countless hours waiting for updates and consultations. Through all this, they were never able to hold their precious baby. On December 25th, they were able to hold Gus for the first time. What a gift to them and to the family who ached for their empty arms. Our family decided collectively not to have a celebration of Christmas until Gus was home with us to celebrate too. This gift on such a special day gave us strength to keep on.

As the days turned to weeks and the weeks to months, Gus took us on many dips and peaks as he played driver on his own roller coaster. He'd start to fade and the family would be called in, many driving several hours to be at his side...he's seem to enjoy the attention and adoration and bounce back. And finally, there seemed to be more good days than bad. Tyler had to go back to work after the first of the year, another trial for him and Jill. We prayed for Jill on the days she spent alone in a hospital more than two and a half hours from home. We prayed for Tyler as he worked another hour still farther from the hospital, not being able to see his son daily.

During the three months Gus spent in the hospital, we were blessed by the support of countless family and friends. Strangers donated booties and hats, blankets and gifts. The nurses and doctors became friends and cheerleaders. The cafeteria became a well memorized dining room, with taco salad days being the highlight of the week's meals. And finally, finally, the day arrived to take Gus the two hours home, to bring him at last to the nursery so lovingly prepared. Gus came home on February 11, 2008 to a family who will never take his smiles and his health for granted.

Gus is still a sucker for attention, a ham for the camera and a shining light in our lives. Today he's on the verge of walking, sounding like he won't start with words, but full sentences and a curious ball of energy and fun. We still worry what the future may hold, but have learned that Gus can handle so much more than we can imagine. God sent us this miracle for which we daily give thanks. Praise be to God, from whom all good things come. The miracles whom you've placed in the arms of us fortunate few.

Denise is a Mom of two angels; Ryan was born undiagnosed with congenital diaphragmatic hernia. Jesse Rose (Jan 16 2000) was her angel before Ryan and was diagnosed with anencephaly in utero. Denise not only understands being diagnosed prior to your child's birth but also the shock of discovery of a devastating birth defect after a babe's birth. After Ryan died, she met others who were making there own graphics with pictures of there babies. She found groups that would teach how to create graphics. Denise offers her talents to parents and even has made websites and graphics for families. She creates the most beautiful web pages for parents to memorialize their children but not able to do these things for themselves.

She said of the CDH Quilt she created: "The quilt is a special page that commemorates the lives of congenital diaphragmatic hernia children both angels and earthly angels. I do this to honor my friends who have gone through the same journey. I love to have all babies with CDH to come together from all corners of the globe, in one place for the whole world to see just how many children are affected with this horrible defect."

This makes an impact and brings awareness. There was an actual Quilt for HIV/AIDS laid out in Washington D.C. which impacted the world to the awareness of that disease. Please have your child added to this amazing creation so we can make the same impact!

Angel Ryan's CDH Quilt by Denise

Just a note that the cdh quilt has been updated if you filled out the form please go to the quilt http://www.freewebs.com/angelryandesigns/cdhquilt.htm and look to make sure it is on there the way you want it or if it needs correcting e-mail me here angelboy@sbtek.net

If you want your child added please fill the form out on this page http://www.freewebs.com/angelryandesigns/menu.htm

Donations Received – Thank You!

Gloria Knots In Memory of William Ethan Morgan
James & Barbara Scott In Memory of William Ethan Morgan
Roger and Tu Phuong Jennings In Memory of William Ethan Morgan
John S. Morgan In Memory of his Nephew, William Ethan Morgan
Bob and Donna Gasper In Memory of their Grandson, Jordan Luning
Leroy & Wylanda Steinkuhler for Congenital Diaphragmatic Hernia Research
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Anna Rainbow Chalker & Daniel Smith In Memory of William Ethan Morgan
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Argiro & James Morgan In Memory of their grandson, William Ethan Morgan
Barbara Laverty In Memory of William Ethan Morgan
Michael & Kelli Kopple In Honor of their son, Chad Michael
WALMART, Charlottesville, Virginia – Community Grant for United Way Day of Caring
Quincy Farm & Home Distributing in Honor of Cadan Christopher
Andrea & Darryl Kirkpatrick In Memory of William Ethan Morgan
Yohanna & Richard Oetting for All CDH Babies & their Angel Christen Emmanuel
Elizabeth & Brian Propst In Memory of Cecilia Winn Propst
Elizabeth & Brian Propst In Honor and Memory of all CDH Children

Benefit for Tiffany's son Cadan Christopher & CDH Awareness! Going Turquoise in October!

To donate, you can visit our website at www.cdhawareness.com
You can send a check or money order to:
Breath of Hope
PO Box 6627
Charlottesville, Virginia 22906
To donate your time you may email us at cdhawareness@breathofhopeinc.com we always can use your time or help with projects. Or if you have goods or services you think we may need, please contact us! Our toll free number is 888-264-2340

United Way Laurence E. Richardson

DAY OF CARING

United Way
Thomas Jefferson Area

United Way

On September 17, 2008, Breath of Hope participated in the United Way Laurence E. Richardson Day of Caring – this is the Thomas Jefferson Area's United Way. Every year in September they coordinate volunteers – thousands of them to help other nonprofits complete projects that otherwise would not get done. Volunteers help with everything from painting at local elementary schools, to landscaping to office work.

Breath of Hope's project was to assemble 500 Infant Handprint Kits, 450 which are donated to the University of Virginia Children's Medical Center NICU and 50 which we will use for our Expectant Parent Packages. Nine amazing volunteers came excited and a few of them already knew of congenital diaphragmatic hernia! 500 kits were assembled beautifully in three short hours!

Please thank the volunteers from the University of Virginia Health Services Supply Chain Management: Trina West, Rose Tolliver, Barbara Strain, Trish Shifflett, Pat Shifflett, Thomas Shannon (who retired that week!), Mary Morris, Charlotte Jenkins and Merge Early. They were absolutely wonderful! They even asked if we would ask for them next year! And thank you to the Doubletree Hotel in Charlottesville, Virginia for the space to assemble these!

www.breathofhopeinc.com

Breath of Hope