



A Note from the CEO

Every day 5 families receive the devastating news that their unborn child will have to fight for its life. They have been diagnosed with a potentially fatal birth defect called a congenital diaphragmatic hernia. This means 35 families a week, 133 families a month and 1800 families a year will receive this diagnosis.

I was astounded that in the United States 4.8 families each day would hear that they had to make life and death decisions for their unborn child. When I broke down the statistics and wrote this, I let others at Breath of Hope read what I wrote, they were equally just as shocked. When you break it down to how many per day – it hits home.

This is why we are promoting Congenital Diaphragmatic Hernia Awareness™. There is a definite need for an increase in awareness. Each person who has been affected has always known something needed to be done. We have provided the platform to raise awareness with Congenital Diaphragmatic Hernia Awareness™ Day. ~ Elizabeth

Earthly Angels Corner

Sean was born with LCDH on 1/22/1997. He has short bowel syndrome, severe restrictive lung disease, severe scoliosis, SVC syndrome/stenosis, off and on pulmonary hypertension, is Bi-pap and TPN dependent, as well as oxygen dependent for much of his life. He has had 15 cardiac cath, 7 back surgeries, several central line placements, and several gut surgeries of various kinds. He has spent 4 birthdays, 2 mother's day's, 1 Easter, 1 Thanksgiving, 1 New Years Day and 2 4th of July's in the hospital. But OH he is far more than a few surgeries and a bundle of diagnosis! He is a warrior, a champion, a comic, a love bug, an actor, a magician, an animal lover, a hunter, a smarty pants, a brother, a son, a friend, a knight, and a hero.

When Sean was diagnosed at 33 weeks gestation, we were led to expect a 10% chance that he would survive, let alone be born alive due to massive polyhydramnios. He was born at 38 weeks in Boise, Idaho. He was immediately placed on the oscillator, with surgery to happen when he was stable. 6 days later we were told surgery would

happen the next day... In order to prepare for it they emptied out one of the NICU rooms with 10 other babies in it, and moved him to it and a new oscillator as he was not stable enough to be taken to the OR. That was also the first time he was weighed and measured in preparation for anesthesia. 7 1/2 pounds and 21 inches. The next day we were told surgery would take anywhere from 4 to 13 hours... It took only 5! But there sure was a lot that needed doing! His intestines were up, his stomach, liver, pancreas; his spleen was wrapped around his spine behind his heart. When the surgeon put everything back in his abdomen, his appendix needed to be removed because it ended up behind his stomach. His intestines were badly rotated, so a Ladds bands procedure was performed, and as he was missing the left rim of his diaphragm he had a patch stitched to his ribs.

We were told he would be on a

vent for a minimum of 2 months. 2 weeks later, he was OFF the vent completely! We later found out that it was expected that he would never leave the hospital... He was home in 1 day less than 2 months, less time than they thought he would be on the vent! He even came home nursing part of his feed... We NG'd him for another week, and then pulled the tube and he was completely breast fed for the next 5 weeks. Unfortunately he got really sick, vomiting all night long and when admitted to the hospital for observation and hydration he ended up needing surgery for a malrotated bowel. He lost a large amount of intestine and we nearly lost him. Because of this, he had an ileostomy, and he needed a central line to his heart so that he could receive TPN (nutrition that goes into the blood stream). Again they did not think he would do well, and again he surprised everyone! He came home, and within a couple of weeks was nursing again! Not a lot, but he was taking in 50% of his calories with my milk.

Eventually he did develop an oral aversion and refused milk, solids foods, even water, but at least we had a chance to bond in a way that no one expected he could. At 9 months he had his intestines reattached so he could get rid of the ostomy. At that point he developed severe reflux and oral aversion, and has not been able to eat since then.

The following years we had so many highs and lows... We nearly lost him to sepsis when he was 3, he was in and out of PICU after various surgeries, had to re-learn how to walk 2 different times, had to spend 6 months flat on his back after grow rods were placed, wore a scoliosis brace for several years, had 2 fusion surgeries and 2 months in halo traction. He learned how to crawl, how to walk, how to talk (and he speaks well despite his oral aversion!) he reads beautifully, has an active imagination, and an incredible vocabulary. He has been in 2 musicals, The Frog Prince and The Jungle book, was chosen as Oley Foundation Child of the Year 2006 for his ability to share himself with others, was on the radio last year raising funds for our local Children's Hospital, and brings a smile to so many people in our lives. He is so loved by his doctors, the nurses and staff at the hospital, they look forward to seeing him when they come in the door, even if they know the first words out of his mouth will be GO AWAY! Then he will proceed to tell them some story or other, involving them in his life. He has aspirations of being a big game hunter, a fisherman, a kryptozoologist, a creation scientist, a zoologist, and even an astronaut! And knowing Sean, he will achieve pretty much anything that he puts his mind to. He is so full of life, living, and loving the world around him.

There is so much that Sean has been able to do, despite his "health issues". We had a 3 month family trip earlier this year, driving from Idaho to Wisconsin to Florida, went on a Disney cruise to the Bahamas, then drove back to Ohio, Alabama, and then on home via the Oregon Trail. He got to drive horses on a covered wagon, went down a water slide, walked 2-3 miles in one day at an aquarium when only 4 months earlier he had been on oxygen and was too tired to walk into his doctor's office. Yes, sometimes it takes a bit of work to put plans in place so he can make the most of his life, but he is so good at going with

the flow so to speak... He is a trooper! He has fun at the hospital when he has to be there, having decorated his room with all sorts of fish with macaroni and beads glued on, making posters telling the doctors that he was going to stomp on them if they bugged him, playing jokes on various people who love to play jokes in return. We have had to travel to many different medical centers from Seattle to Denver to Boston in order to get the best care for him, and we always find something to like about each place. Idaho is always home though... We always feel such care from the physicians and staff here. They love him.

His life is a miracle... Survived so much, lives so much, loves so much. We are thankful to God for every moment of every day that He has given Sean to our family, keeps him in our lives. And we look forward to what is coming! Who knows WHAT God has in store, but I am sure it will be as much of a gift as the last 10 1/2 yrs have been.

- by Heidi, Sean's wonderful Mom

Heavenly Angels Corner

Jean, Luke's Mommy, shared this inspirational story a month after he received his wings and we all thought it was such an awesome story. No matter if you are religious or not – no one can deny that these little ones' lives cause a higher power, wiser and stronger than all of us, to intervene in the most amazing ways. Jean in so many ways is our inspiration with all her children!

While I was spending my last hours with Luke, I was trying to keep my wits

about me and trying to think of everything that needed to be done before I could let him go. We had Luke baptized by the Priest on-call at the hospital and then he had to leave but gave me his pager number to call him whenever I needed or wanted him back. Before I could let Luke go, I had to make sure that all my other kids were in one place together. The younger six were with my oldest sister at her house and my older two stayed at our home. They both work full-time and being 18 and 19 and they can stay home by themselves. I wanted to be sure that Ralph and Robert got to my sister's home. I wanted them to all be together when they heard the news.

I wanted a Priest to come in and just say a few words to help Luke on his way to join all the other angels. A friend from my Parish in Owensville was up at the hospital with us and she was trying to get in touch with our Parish Priest. No one in Owensville could find him. She kept trying to find him but she also started calling a few other Priests from neighboring Parishes with no response. The hospital chaplain tried to contact the on-call Priest who had come by earlier to baptize Luke but he had left. For the first time in 12 years, the pager system went on the blink. Heidi (my friend) one of my sisters and some of the nurses in the NICU started calling around looking for a Priest for me, not one could be found. Like a police officer, whenever you need one, there's never one around. One surgeon who had evaluated Luke earlier in the day and gave

me the news that there was nothing more that could be done for Luke and one of Luke's nurses from earlier that day, went out looking for a Priest for me. Both the surgeon and nurse were off for the day.

A few blocks from the hospital there is New Cathedral in St. Louis. The surgeon and nurse went there to find a Priest. (They told me they would "hijack" a Priest for Luke.) They could not find one there. So they came back, meanwhile, my Parish Priest was still nowhere to be found. A Priest from a town down the road called Heidi back but he was on vacation and 200 miles away from St. Louis he did offer to come if I really needed him, he'd start traveling back right away. The on-call Priest was finally contacted, he was at his Parish but he was in the middle of a marriage class and he said he'd come in but he was on the other side of town. My niece had called her mother and my other sister, the Minister from their church would be happy to come in if I wanted, he wasn't Catholic. Not that I would have minded, I wanted a Priest if at all possible. My other sister's husband (who was at the hospital with me) had called their Parish Priest and he was prepared to come into the hospital for me.

While all this was going on, I had five Priests coming, we get news that the same nurse who had gone looking for a Priest earlier, went back to the New Cathedral and was waiting in the parking lot when she saw a Priest heading for his car. She stopped him and she explained to him what was going on. He dropped everything and came to the hospital. So now I had a Priest coming to say a few kind inspirational words to help Luke get those wings of his and fly up to heaven. Ironically, this Priest was not a Priest but a Bishop. Yes, one of the NICU nurses from St. Louis Children's Hospital in St. Louis hijacked a Bishop for a patient. This Bishop was heading to an important meeting and dropped everything to

go with this nurse. She must have been pretty convincing.

Another part of this irony, is that twenty years ago this Bishop was a Parish Priest at the Parish where I grew up. He was the Parish Priest who, twenty years ago, married my husband and me. So Bishop Hermann got to the hospital and he had no idea he was going to help comfort two people whom he had married twenty years earlier. He said some of the most beautiful inspirational words to help my little boy on his way to heaven.

So I started thinking God knew, and still knows, that I was not very happy with Him because of all that went on with Luke so I think God sent me a Bishop to appease me a bit. Not too many people get a "hijacked" Bishop to come to the NICU and say a few inspirational words over their dying son. Even though I still do not have the answer to "WHY?" Luke, I did get a "hijacked" Bishop. So I haven't given up on God yet and I very much doubt I ever will. I'm still very angry with Him and I think it's going to be that way for a long while. I hope I haven't offended anyone with my story but it was just a little something that has kept me going and I wanted to share it. My faith has taken a blow but it's still there and with time it'll come back and probably twice as strong. The one point of this story is I'm working my way back slowly into the world and with all of your love and support and the love and support

from my family and friends, I'll get there.

Jean - Mother of nine!!! Eight Earthly Angels: Ralph, Rob, Nick, Abby, Anna, Clint, Joe, Sophie - One Heavenly Angel- Luke Matthew
6/12/2007-6/12/2007-
FOREVER IN OUR HEARTS!!!!



Donations Received

Nancy Bryant, in Honor of Patrick
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Jenny Thiessen, in Memory of Mia
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Breath of Hope would like to thank all of the amazing people who are on the frontlines, so to say, of the battle with the congenital diaphragmatic hernia birth defect.

They are our unsung heroes.

- The health professionals who take a deep breath and then tell us that our child, born or yet to be born, has this devastating birth defect;
- The surgeons with skilled hands and minds fix the defect as best they can;
- The neonatologists who instinctively try to regulate these not-so-standard babies;
- The nurses who are in there day-in and day-out know our children just as well as we do;
- The genetic counselors who follow-up with us and give the news in the kindest way they can;
- The obstetricians and perinatologists who hold our hands, pat our backs and hope and pray with us;
- The respiratory therapists, the pulmonary doctors, the physical and occupational therapists who help us with these little ones who might just need a bit more to get on-track, their owns or everyone else's.

Without these kinds, caring and dedicated medical professionals trying to save these children and giving us hope when there might be very little, we would be even more alone. Though they know not what we are going through as parents – they are right beside us in so many ways. For that we are thankful. There is no gift greater that they give to us by trying to save our child's life. They work long hours to the point which they probably earn less than minimum wage because they received a called to help.

We should take a moment and reflect upon these amazing angels on earth who shed tears and are frustrated with us but try to maintain their professionalism. While at times we are going off the deep-end because that is just where we are as the parents and families so affected by this birth defect, they see us at our absolute worst, and our absolute best, and we hope that we inspire them and encourage them to continue their valiant efforts.

Breath of Hope sincerely hopes Congenital Diaphragmatic Awareness™ is the stepping stone to more knowledge, more research, more interest in finding a cure or a treatment to save more lives and more help for these health professionals. We hope one day that through the efforts of a small group of determined family members and friends, on that front line – you will feel more empowered and have more in your arsenals to help families. You will not take that deep breath – you will have better statistics and more hope than you have today. Nothing can ever be a 100% guarantee but perhaps one day you can give us better odds.



CONGENITAL DIAPHRAGMATIC HERNIA
AWARENESS DAY™

MARCH 31, 2008

EVERY BREATH THEY TAKE IS OUR BREATH OF HOPE
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