

The Awareness Articles

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Awareness to be Continued

By Elizabeth

Breath of Hope has been diligently networking with hospitals and other non-profit organizations out there for several months. We now are a member of the Center for Non-profit Excellence based in Charlottesville, Virginia and this has many benefits from courses in grant writing to local contacts that can share their services and experiences. There is also a listing of Corporations and Foundations that offer grants to non-profit organizations which Breath of Hope has numerous applications pending.

In July, Breath of Hope was awarded a \$25,000 grant to assist in starting a Scholarship Endowment and also award \$10,000 in scholarships for the 2009-2010 academic year. We will be assembling a scholarship committee in the coming months. We are also seeking other grants to help with this Endowment and continue to grow the organization to being self-sufficient.

Our website will also be revamped with more information; we have hired a website developer to take www.breathofhopeinc.com to a new level for those out there seeking information on congenital diaphragmatic hernia, awareness of this devastating birth defect. Breath of Hope now has their own branded Carepages for families to keep their friends

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Helmeted Warrior

By Roberta

I know every family of a child born with a birth defect is given special strength and divine guidance to ride the roller coaster of the unknown and experience the joy of knowing these precious gifts from God. I know because I am the grandmother of one of these wonderful children. And I know our journey was filled with beautiful breaths of joy amid the confusion and mere terror. So I am telling about our family's experience not in boasting, but in witnessing to others just starting the journey that the road is frightening, but God has chosen them for a blessed experience.

In April 2005, Jake and Kelly, my son and daughter-in-law, found out that, Kennedy Grace, the baby girl they were expecting, had a birth defect called a congenital diaphragmatic hernia. The abbreviation for this condition is CDH. This means there was a hole in her diaphragm, and her stomach, intestines and spleen had migrated up into her chest cavity. The specialist is Evansville said statistically the survival rate was 50%, but, and I can see her face now as she shook her head and said, "There is really not much hope." We feel she was preparing us for the option of abortion. The miraculous thing was, while the doctor was telling us this, a still ultra-sound picture of our little girl was frozen on the screen. In this picture, Kennedy was pointing one finger up. It was as if she was pointing to our hope.

The next morning as I was driving to school, I was pleading with God for a ray of hope. When I got to school, I typed the words "diaphragmatic hernia" in the search engine of my computer. The first site that came up was, "realhopeforcdh.com". This

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'Kennedy' means 'helmeted
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CDH fighter."*

Beyond the Grief

By Elizabeth

My journey with congenital diaphragmatic hernia started in July 1999 when our unborn daughter was diagnosed at 22 weeks. Truly, there are no words that describe the day we heard of CDH for the first time and then being a researcher searching for accurate information was virtually impossible. She was delivered and treated at the University of Virginia Medical Center on November 2, 2008 and gave us a wild ride. As with most CDH babies she had her own agenda and if they pushed her too hard – she pushed right back.

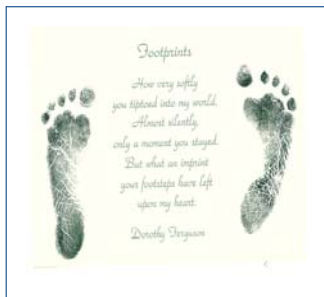
" The emotions you go through after your child is in critical care or dies are raw and can cause you to react as you never would."

After setting the record for hours on ECMO (32 days) at UVA she was placed on a machine for hemophiltration CVVH. She was the first at UVA on this machine. Details are covered in her story at: but on December 10, 1999 she decided that wings would be more fun than feet. No parent should have to bury their child and for the year after her death I prayed that all infant death would stop. God didn't listen to me. Other families were also diagnosed and I also learned that it can not be stopped completely because it was not in my control. The emotions you go through after your child is in critical care or dies are raw and can cause you to react as you never would. You are surprised with your reactions and you feel like you are not quite sane at times. It is important families and parents know those emotions are perfectly normal. Many nurses and doctors know our reactions are purely normal and not to take them personally.

It takes a good two years to heal and recovery is throughout your life. Parents of surviving children of CDH (Earthly Angels we call them) also suffer grief and survivor's guilt. They wonder why their child survived as we wonder why ours didn't. They struggle daily with some on-going health concerns of their child and sometimes waiting for another shoe to drop and a diagnosis that need further follow-up. We struggle with the ache in our hearts of missing our angel. I have noticed many of us together seem to help one another through tough times and celebrate the good times.

In the years, I recovered – my heart has healed and we had a beautiful baby boy in 2002. He brought our smiles back. We always miss our daughter but are no longer in the hallows of grief. I am writing this so that those who are in the early stages know

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Cecilia's Footprints

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and family updated on their child's condition and health. Our goal is to not only educate the public but other non-profits out there on congenital diaphragmatic hernia because each time one person is informed they may just tell another.

We are also going to be organizing our volunteers and the Congenital Diaphragmatic Hernia Awareness® Day Campaign for 2009. Our goal is to have all fifty states governors sign Proclamations so that we can then move to the next level of having the President of the United States issue a perpetual day of Awareness on March 31.

If anyone wants to volunteer or offer their special services or talents to Breath of Hope, please feel free to contact us. We also need more stories from members and would love to have an article for this publication from a doctor, nurse or anyone out there who feels they can share their own experience with CDH.



Helmeted Warrior *from page 1*

website was our link to support from other couples who had CDH babies. They found hope in Gainesville, Florida, where there is a doctor and staff that specialize in saving CDH babies. Instead of the 50% survival rate, this doctor gave a 90-95% survival rate.

We knew we had to go to Gainesville, Florida to have Kennedy, but we didn't know how. Jake and Kelly are young, without much financial cushion. We knew this was too big for us. God had to lead our way. Immediately our Christian family began sending an outpouring of love and support. Numerous fundraisers were organized.

I began researching housing options. I also found a church email address from our denomination's website. I began communicating with the secretary of Gethsemane Lutheran Church in Gainesville. I made all the arrangements online without knowing anything about the city and where things were. That was not our concern because God knew. We found an apartment in a gated facility that we could afford, thanks to the monetary support of our community. This facility was managed by an evangelist's wife, who immediately started praying for Kennedy. When we arrived in Gainesville, one month before Kennedy's due date, we discovered that our apartment was just a few blocks away from Kelly's doctor and just up the road from Gethsemane Lutheran church.

All through this roller coaster ride, God has shown us that He is concerned about all aspects of our lives. Kelly and I stayed in Gainesville from August first until it was time for Kennedy's arrival. Then Jake, two other sets of grandparents and our pastor came to support Kelly and Jake when Kennedy was born on August 24. Kennedy was in the hospital a little over two months. She underwent two surgeries and there were many frustrating moments during this time, but she is doing well now. She is almost three years old now and loves baby dolls, bubbles, singing and dancing, and her heroes are Dora the Explorer and Bob the Tomato.

Jake and Kelly brought Kennedy Grace, our miracle baby, home to Indiana on October 28th. During this adventure, God was in control. God provided us with not only a safe place to stay, but a place that was enjoyable and friendly and covered in prayer. God provided us with a church. It wasn't just a church; it was a garden of refuge named Gethsemane.

Oh, and another miracle I wanted to mention is Kennedy's name. Jake and Kelly chose the name Kennedy because they liked it and it went well with Grace, which was chosen because she is a gift of God's Grace. Well, after research we found out that "Kennedy" means "helmeted warrior"—how perfect for a CDH fighter. I tease her parents and tell them they just think they named her, God really did.

We met people who became like family during our stay in Florida and even gave me a mission while I was down there. Knowing there would be many hours of sitting in a waiting room, I knew I would need something to occupy my time. I took yarn and a crochet hook. I began making booties. Now there is a limited number of booties one little baby girl can use, so I began giving booties to the parents of other babies in the neonatal intensive care unit. With the booties I included a message of prayer for the babies that received the booties. Kelly started calling me the "Bootie Grandma". Making booties gave my anxious fingers something to do and it gave us a way to reach out to other frightened parents. One day my crocheting pastime intrigued a number of young mothers. We had a little crochet class. There was bonding and laughter and friendship in the midst of such unnatural circumstances.

I don't know why, but we didn't find Breath of Hope until after Kennedy was home. But God took care of our needs. Breath of Hope is a godsend and Kelly depends on her friends at BOH for support everyday. Knowing other parents and sharing stories continues to give Jake and Kelly and the rest of the family hope as Kennedy continues to deal with the challenges of being a CDH miracle.

I also want to stress that, yes, we brought our miracle home, but my admiration goes out for those who are given a different journey. We met little Aiden. He was born about a month after Kennedy, what a precious little fighter. We bonded with his family and wept when after we were home for a short time we got notice that Aiden's time on earth was over. Yet, that little boy touched so many hearts and his short time with us is irreplaceable. We know that all life is a gift from God and even 99 years is a fleeting moment in the scheme of the universe, but to have been created and loved and to have brought joy to others is what any of us hope for. Every CDH child does this, each in his or her own special way. We learn through this experience not to take life for granted. Enjoy every second of it and treasure our memories.

Each year I write a Christmas poem that reflects something important in my family's life during the past year. Of course the 2005 Christmas poem was inspired by Kennedy Grace. I want to share it with you because I feel it expresses a lesson all CDH miracles teach us.

(Please go to page 4 to see this wonderful poem.)



Kennedy Grace

"We can't change the cards we're dealt, just how to play the hand."

– Randy Pausch

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that there is hope. There were days I didn't feel I had the energy or desire to move forward. There were days and moments I felt I couldn't survive the pain. There were moments I wanted not to continue. Those days are part of me but they are in the past.

I have learned more compassion, understanding and acceptance from my experience with CDH and I have researched it and continue to research and read and learn. I have learned that I don't like pity and neither do these families affected by CDH. There is nothing to pity – these babies are

remarkable and amazing fighters and they come from families that are of strong wills and determination. You admire their fights against CDH and you admire these families and their friends who are in awe of these small babies that astound us. Even when they decide wings are more fun than feet – we know that their spirits never die because they are within all of us.

Poems & Quotes of Inspiration

Christmas Grace

Christmas Grace came in the night,
In the dark,
Under a star-lit sky.
It is the Gift of Ultimate Love
Given to us because--
Because of His Love.
When no hope is seen,
When desperation consumes our being,
When all seems dark,
Grace is there.
It illuminates our hearts with Hope.
It warms our quivering souls with His Comfort.
This Hope ignites Faith.
This Faith reveals His miracles!
Our lives glow in the eternal light of this Gift--
Christmas Grace!

This was written for Kennedy Grace who, by her precious life, is witness to this Gift of Christmas Grace.

With lots of love and Angel Kisses.....from your Angel

I was sitting here in Heaven and having a wonderful day,
I started thinking about you and all the things I didn't get
a chance to say;

I don't want you to worry about me and please don't
shed any tears,
Because I will wait for you in heaven if it take a hundred
years;

Everything you have on Earth I have in heaven too!
My first day here my body became brand new;

It is really pretty here and I love my new home,
Although your heart is broken because my body is gone;

My love will always be there as you go along the way,
Just take a peek inside your Heart there is where I'll stay;

Know that I loved my family and all my friends too,
My thoughts will be with each of you your whole life
through.

"Some things that are worth dying for are also worth living for." –The Bucket List

"Sometimes finding the power within ourselves can be struggle and can bring with it much pain but once we get beyond that and allow the revolutionary insight to penetrate our souls we emerge so much more beautiful....kind of like a caterpillar turning into a butterfly." – Theresa, Donny's Mommy
