



The Hemispherectomy Foundation Brain Matters Newsletter

Monthly E-News

July 2009

On Our Website



Read [stories of hope](#) about our families on hemifoundation.org

Our Mission

To Encourage and Support impacted families by connecting them with other families who have had a hemispherectomy or similar surgery.

To Work together with medical professionals to fund research into the cause of the diseases that lead to intractable epilepsy, hemispherectomy, and the surgery itself.

To Raise Money for camp fees, scholarships for trade schools and higher education as well as provide financial relief for struggling families
Read stories of hope about our families on hemifoundation.org hemifoundation.org

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Greetings!

Hello Friends of The Hemispherectomy Foundation!!! I am so excited to be writing the introduction for this edition of Brain Matters. There is so much happening in and around The Hemi Foundation, that I can't begin to talk about it all. Instead, I would like to do something that you rarely hear me do. I want to talk briefly about our desperately needed support.

As most of you know, The Hemi Foundation is run exclusively by volunteers. Not a single person, who works for The Hemi Foundation, is paid. We do it because we love doing it, and because we are passionate about the children and the families that we support. Because we are not paid, more of the funds that we raise can go directly to the children and families that we support. Also, if we need office supplies, we seek business donations.



The same applies to all the things that we need to run a top-notch non-profit. This again is to ensure that the funds we raise go DIRECTLY to the children.

Today, I was told by our Hemi Foundation accountant that we are using less than 1% of our funds for administration. That means that 99% of all donations go toward serving our families and not administration. This is unheard of in the non-profit world. So every Donation that you make, every Christmas Card that you buy, and every Fund-raiser that you host will contribute 99 cents on the dollar to impact the lives of Hemi Families.

Where does the money go? Good question. In 2009, The Hemispherectomy Foundation :

- Awarded 9 families with Financial Aid packages to allow them to travel to the 2009 Hemispherectomy Conference in Baltimore .
- Hosted 2 meals at the Hemi Conference (Negotiated that the hotel donate one)
- Hosted Kids Camp at the 2009 Hemi Conference, so that the parents could attend the conference activities
- Sent 44 Hospital Hemi Hugs across the USA and a few international
- Awarded 4 College Scholarships
- Awarded 2 Camp Scholarships
- Provided 4 Financial Assistance Grants

With all the great things that we did, sadly, we had to turn people away who needed help. That is why, I am asking you to consider supporting us this year. The amount is not important, but let us know, through your financial contribution, that you support what we are doing and that you want us to keep doing it. You can [donate online here](#), or send us a check at Hemi Foundation, PO BOX 1239, Aledo, TX 76008. If you can't afford a donation, then support us through our Holiday Card fund raiser on our website, or volunteer to share your talents. Anything, no matter how small would be appreciated so much by our wonderful Hemi families.

God Bless You and Hope in One Hemisphere!



[Support the Hemi Foundation by visiting our store.](#)



Meet Our Medical Advisory Board

[Read about Doctors from the U.S. and Canada who make up our Medical Advisory Board.](#)

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Cris Hall
VP and CFO, The Hemispherectomy Foundation
and Jessie's Dad (Right Hemi, 2008)



Clown School

By Beth Usher



I hate to admit this but for my thirtieth birthday my wonderful mom and dad gave me the best present ever; they sent me to New York Goofs Clown School for a week. I was so excited! I was going to spend a whole week with goof-balls just like me. Could my life get any better?

Growing up my mom and dad always told me, "Beth, you are such a clown" ! I thought that this school would help me in my job as an assistant kindergarten teacher. I love to make the kids laugh and I love to laugh as well. So, with baggy pants, suspenders, and a floppy hat in my backpack, off to clowning school I went.

At this school, I would learn how to throw a pie in someone's face as well as receive a pie in my own. We would all work together on techniques such as juggling and balancing. I was extremely proud when I finally taught myself how to balance a chair on one finger. Of course, we know that this feat is best performed under the watchful eye of professionals.

At first I thought clowning was going to be child's play...a walk in the park...a piece of cake. Boy, was I wrong! The class consisted of twenty unique individuals from various backgrounds and clowning abilities. Each and every one of us confessed profound exhaustion after the first day. We began each day at ten o'clock with aerobic exercises designed to get our clown brains working and our hearts pumping. We were all nervous and self conscience and no one desired to make a fool out of themselves - least of all me! We introduced ourselves and our lessons began with serious instruction. We quickly realized that we needed a strict hand as clowns could really waste a lot of time just laughing at each other.

We were taught by seasoned professionals the art of applying the clown face makeup. This lesson was a lot harder than one

would imagine. Every clown has a unique character and your makeup only compliments it. Finding your inner clown character is difficult and sometimes is years in the making. My sides often hurt from laughing so much during this activity. After washing our faces off we would break up into groups and perform mini skits. My favorite skit was called "The Interruption". It is where an announcer was on stage announcing me and I would run onto the stage and pose before the announcer was finished announcing me. Another skit was the illusion of falling into a big ditch and figuring out how to work together to get out of the ditch. We were miming with ropes and belts. It was hilarious! All of our teachers were phenomenal! They had loads of patience and understanding. They answered each and every question we had no matter how ridiculous they were.

By day two, we were crazy about each other. Crazy being the operative word! We were all different but had crazy in common. By crazy, I mean "good" crazy - nutty, spirited, kind, and over all just plain fun! Some of our skits and exercises involved a lot of physical activity. I was able to adjust my involvement in these skits to accommodate my comfort level. I must say that I never felt out of place during my entire week. My classmates embraced me as I embraced them. We shared little details about ourselves and no one asked me about my weak right side. I was accepted and quickly realized that nearly everyone in our group had something that was different about them.

I myself love to make people laugh whether they want me to or not. I know I'll never be a doctor but laughter is the best medicine I can administer without an M.D. It is the only contagious disease that is actually good for you and your body. I really wish everyone in the world realized that they had a little clown inside just waiting to be released. Most people are just so uptight and worried about each and every little thing. I'm not saying this in a bad way but there's just gotta be more Laughter and acceptance in the world today. We would have "World Peace" if everyone tried to understand each other and accepted people for who they were. The twenty of us had our own "World Peace" for a week or so.

I actually had tears running down my face as I left our clown school theater. We all promised to keep in touch and I do believe we will. Clown school is an experience I will never forget. My life has been an incredible journey full of miracles and self discovery. On my way to becoming a clown, I realized that my hemispherectomy does not define me as a human being. I am a varied, talented, and creative individual. What I am most proud of to be sure is the fact that I can make people laugh and feel good about themselves. No, I will never have a medical degree but I am someone who will make you feel better!



Second Annual Holiday Card Sale

The Holiday cards feature artwork by our precious children that have undergone hemispherectomy surgery. Funds raised will be used to support college and trade school scholarships, camp fees, and travel assistance for children and their families that are affected by hemispherectomy surgery.



The variety pack is now available for a cost of \$12 per pack plus shipping.



To purchase cards, [click here](#). Cards will be shipped beginning the second week of November.



A very special thank you goes to the Jay Stringer family and Pressman Printing for their partnership with The Hemispherectomy Foundation. Visit their web site at www.pressmanprintinginc.com.



Running with a Message

By Kristi Hall

Greg Bastian of Aledo, Texas is an avid runner. He runs 3 days a week, 20-30 miles per week. In 2009 Mr. Bastian will have run 3 marathons, 7 Half Marathons and 3 5K races. Greg also lives in the same neighborhood as the Hall family. Jessie Hall, age 7, had a right hemispherectomy to treat Rasmussen's Encephalitis in June 2008. "I know about Jessie primarily through the elementary school and Janet's involvement with Jessie." Greg's wife Janet is one of Jessie's PE teachers. "Then after that I know about Jessie through all the publicity she has received."



In August 2009, Greg approached the Hall family about promoting The Hemispherectomy Foundation at the USAF Marathon by wearing a billboard of sorts on his back during the race. Kristi Hall came up with a promotional sign and Greg literally ran with it. "Race morning was about 55 degrees F. I had a long sleeve shirt on over my race singlet up until about 20 minutes before the race. After I took the long sleeve shirt off to get ready for the start, your Hemispherectomy banner was finally visible to others. Ten minutes later, a woman came up to me and asked me about it." Mr. Bastian said that he came up with the idea because he has seen people at many races wearing slogans stating they are running for someone or a cause. "Not many people know what hemispherectomy surgery is and I figured this was a good way to get awareness for the foundation. I thought I would just put it on my back and do what I train to do."

"When I talk to people about hemispherectomy surgery they get the deer in the headlights look in their eyes - they are so amazed that this type of surgery is done successfully."

The Hemispherectomy Foundation wishes to thank Mr. Bastian for his support and enthusiasm for promoting awareness of hemispherectomy surgery.



We are happy to announce our first "The Dreams on Wings Music Benefit" for The Hemispherectomy Foundation! The first show will be 12/2 at the Tin Angel in Philadelphia, PA. Musicians who are donating their time and talent are Paul Kurrey, Dave Alexander, Teressa Wilcox and Valentina Virgilio.



An Ambulance with Wings

By Marsha Edens



Since Isaac's birth almost seven years ago, I have learned more about the brain than I ever thought imaginable. Isaac, my first born, came into the world having seizures and had already suffered a stroke in-utero, so we had very little time to digest what having a special needs child meant. Isaac spent two weeks in the intensive care unit as a newborn and that would be just the first of many intensive care stays that Isaac would endure. Over the next years of Isaac young life, he would begin to have status seizures, leading to him being in intensive care five more times, being emergency air lifted three times, put on life support two times and then heading into the operating room

for grid placements and hemispherectomy surgery. The scary part was, it all happened so fast and there was nothing I could do to stop it, make it better or make it go away. Our family had to search for answers through despair, search for hope through courage and find peace through faith. As the months after Isaac's surgery passed and the healing began, I wanted to write a book about our experience that could be a resource and encouragement for others going down that same unexplainable journey. A story of faith and hope from one family to another in the same valley of the unknown.

My book, *An Ambulance With Wings*, can be found online through Authorhouse.com, Amazon.com or Barnesandnoble.com.



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