



The Hemispherectomy Foundation Brain Matters Newsletter

August 20, 2010

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



International Hemispherectomy Workshop

Sept. 30th - Oct. 2nd, 2010
Utrecht, Holland

Christina's Journey

by Christina Santhouse

When I was in the third grade I underwent a hemispherectomy - a radical operation in which the right hemisphere of my brain was removed to alleviate me from over 100 seizures a day from a virus I encountered called Rasmussen Encephalitis. The cause of Rasmussen's is unknown and there are few clues to help find a way to discover its origin. There are probably somewhere between 200 and 500 cases worldwide. After surgery, I had to endure years of ongoing therapies and tutoring sessions to help me overcome my new physical and cognitive disabilities, many new challenges and obstacles that are often associated with a hemispherectomy. I was so grateful that after years of speech, physical, occupational, mobility therapy and special education accommodations, that each therapist and teacher believed their area of specialty was not just a profession rather it was a passion. It was because of each of their enthusiasm that I followed suit into a service vocation. My career choice was Speech Language Pathology.

This choice was easy to make but a hard and long road to pursue. The road began when I was told by a high school teacher that I would do no more than answer telephones in a medical office. At that point the whole "college thing" seemed to be against me. But I had my devoted parents, loving grandparents, great family members and supportive friends who stayed by my side and told me how remarkable I was. They encouraged, listened, guided, trusted and impressed in me that even through exhausting and overwhelming times would come, I would prevail.



My high school graduation day arrived, I was ecstatic knowing I would enter Misericordia University in September, 2005 to pursue my career. I did not enter Misericordia as a Speech Pathology student; I had to earn that declaration. My freshman year was difficult academically and satisfying socially. With my own drive and determination as well as with the assistance of the supportive staff from the Alternative Learner's Program, I ran the freshman year race with impressive grace. Many days I wanted to rest along the sideline but I knew I had to forge full force ahead just to stay in the competition.

Sophomore year came with me hearing from a professor that maybe I should consider a different major. I called my parents with a flood of tears and broken dreams. Once again, "Do not give up", they said adamantly. "You

"Why Would You Remove Half a Brain?"

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On Our Website



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



**BUILDING NEW PATHWAYS
CONFERENCE**
October 6, 7 and 8th

The RE Children's Project will be
sponsoring a research
conference dedicated to RE. The
conference will seek to leapfrog
our current understanding of RE

have so much resilience. You continue with vengeance and do your best. That is all the Good Lord asks of us." With their encouraging words and my stick-to-it-ness spirit, I made it through the required courses and became a well-rounded student.



By the beginning of my junior year, I earned a high enough cumulative average to finally declare my major, Speech Language Pathology. This is the year I realized my dream no longer would be denied. My junior year I worked very closely with my professors. Painstakingly, I met with each of them every week, some two times a week to ensure I was thoroughly grasping the knowledge necessary for my success. My professors had the power to humanize or de-humanize me. They made an untiring effort to humanize me. Each was an instrument of inspiration. They influenced and became a strong motivating force when they coached, praised and encouraged me all the way. Mind you, I had to possess the willpower, heart, and stamina to stay strong and keep up with my peers and that I did.



Inconspicuously, I spent my two grad years in the Library. My major criterion for these years was to study, study, and study more. I had to prepare for my boards, comprehensive exams and clinic work. My roommate watched me wake early; spend endless mornings, nights and weekends in the Library. My parents listened to my challenges concerning some of the materials, procedures and the amount of responsibility that seemed to endlessly be thrust into my life during these years. I was in diagnostic clinic and started to treat clients. I continued with my summer rotation, early intervention internship, field work in education and adult placement. After these experiences, I remembered saying to my parents, "I am starting to feel like a SLP." I suppose this is a true testament to my courage and humility. "Good," they stated exuberantly, "You are smart, articulate and a good leader. It won't take long for your personality, warmth, and strength to take center stage in the classroom. We are in awe of an extraordinary SLP who stands before us."

I had worked hard to prepare and begin my journey to heal and help others in need. I realize now that I have the tremendous power to make a difference in many people's life. Thinking back I was once a "high risk" student who has come full circle. Therapist helped me in earlier years, now I am finally giving back and prepared to be a positive impact and advocate in other people's lives.

and identify new pathways for research by incorporating research disciplines beyond neurology into the conference proceedings. The conference attendees will consist of global experts from neurology, immunology, genetics, oncology, multiple sclerosis, and pharmacology who will bring their collective expertise to RE.

If you are interested in finding out more about The RE Children's Project please visit their website at <http://rechildrens.com/> or email Seth Wohlberg at swohlberg@rechildrens.com .



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New Hats

several colors to choose from



New Window Decals



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



This past May Christina graduated from Misericordia University with a Master's degree in Speech Language Pathology. She will soon begin working for Bucks County Intermediate Unit # 22 and work to make a difference in the lives of children. She is a former recipient of the Jessie Hall Hemispherectomy Scholarship.



2010 Hemi Reunion

By Kelly Dawson

As a community of people raising children with hemispherectomies, we usually rely on the internet to keep us in touch, and help us discover answers to our questions from those who are also experiencing our journey. Once a year though, we are able to gather together, develop deeper friendships, and gain insight into new possibilities for our children. As the mom to an 8 year old who is five years post surgery I always look to the young adults in our group to inspire me and help me keep my daughter moving forward. Each year there are new families that join us searching for information and comfort, and there are others who have been online for awhile but are attending their first conference.



This past year the reunion was held in Indianapolis and many families came together. Seminars in education, and health topics were offered to parents while the children, and their siblings, attended a camp just for them.



Meet Our Medical Advisory Board

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



[Join Our Mailing List](#)



Two parents attending the reunion for the first time share their experiences:

The Apitzchs

By Tammy Apitzch

Upon our arrival at the Hemispherectomy Conference and Reunion in Indianapolis, Abby and I couldn't wait to check in and let the weekend begin. We unloaded the car, dropped our things in our cabin and headed to Jameson Lodge, eager to start meeting the other families in attendance. Keeping an eye out for the families we had previously met, we found a table and sat down to review our notebook with the weekend's agenda. At first, Abby and I stuck pretty close to each other but before I knew it she struck out on her own. Never a shy girl, Abby soon was introducing herself to parents and children of all ages and abilities. After dinner the first night we didn't eat a meal together, both of us preferring to use every opportunity to get to know as many families as possible. While there were a few families that I missed having the chance to speak to over the weekend, Abby made it her mission to seek out and chat with every single person in attendance. She happily doled out advice to parents and kids alike.



While connecting with the other families was wonderful, one of my favorite parts of the weekend was simply observing the children. Without exception, these kids are the most kind spirited, determined souls I have ever been blessed to know. Their beautiful smiles warmed my heart and made me glad to know them. I was reminded time and time again of things I had

forgotten as challenges have been overcome only to be replaced by new ones. I chuckled to myself as I saw numerous little girls running about with their shirts sliding off their affected shoulder and down their arm. Pulling back my toes to avoid being stepped on is no longer second nature as Abby's awareness and compensatory abilities have improved over the years. Suffice it to say, by the end of the weekend that defensive mechanism was firmly back in place! What an amazing thing, to be able to have those glimpses into the past and realize just how far Abby has come. I look forward to seeing each of these kids next year and know that each of them will have overcome today's obstacles and moved on to conquer new ones.

By the end of the weekend I had been approached by so many that just wanted to tell me how inspiring they found Abby to be and how grateful they were to have the chance to visit with her. When I asked Abby how she felt about the reunion she replied, "I felt like a celebrity". I've never been more proud that God chose me to be her mom - and I've never felt more blessed.



The complexity of emotions spanned during this weekend was unreal. The exchange of ideas, advice and support were amazing. The camaraderie and understanding shared by all of us is something I pray all of our families get to experience at some point. There is nothing that compares to being surrounded by those who "get it".



The Hardys

by Melissa Hardy

Surgical hemispherectomy or hemispherotomy for any reason leaves the patient and family feeling isolated and uneasy, to say the least. The journey through this process is just beginning with

hospital and therapy visits multiple days per week. Avery began this journey in September 2007 when she underwent a functional hemispherotomy. We felt so alone at times trying to be an encouragement to Avery when therapy was difficult, and when progress was slow. Then we learned about the Hemispherectomy Foundation and it has provided a tool to communicate with others who are travelling along the same path.



Once we heard about the Hemispherectomy Foundation family retreat in Indianapolis, we were sure that we would attend; this would be the first time my family was able to meet anyone else that had gone through a hemispherectomy surgery. We had a fun time meeting new friends of all ages and with so many different talents. These children have unlimited potential, and their positive attitude is contagious. The things that we thought were so unique with Avery, such as her shoulder straps always falling off of her left shoulder or her not able to pull up her pants or underwear on her left side, were characteristics of many of the other children at the retreat.

The kid's camp provided multiple safe activities, making picture frames and coloring bags for all their goodies that kept the children busy. Carnival day was extra special with a clown and face painting; this was a big hit with my kids. In addition, many families brought storyboards of their children's' achievements during the year. These storyboards demonstrated school successes, 4H projects, dancers, softball players, bike riders and many children having a great deal of fun. My family left the retreat relieved that we are no longer alone in this journey, and we are encouraged that our Avery can do anything and everything that she dreams.





Hemi Kids in the News

Sasha Sabet underwent her hemispherectomy and it was documented by 60 minutes. Christina Santhouse is also profiled. To view the video online follow [this link](#) . Please know that parts of the surgery are shown. This tremendous piece shows the emotion, and frustration felt by many parents as they go through this process. It does however, end with the hope we all have for a better life for our children.



CURE AWARDS

Citizens United for Research in Epilepsy (CURE) funds a wide range of innovative studies, spearheading new directions in epilepsy research.

The 2010 Falk Medical Research Trust Award was awarded to Steven Roper, MD of the University of Florida. His research involves "Treating Cortical Dysplasia with Adult Human Neural Progenitor Cells"

Cortical Dysplasia is another reason to have a hemispherectomy, and families with the hemi foundation will be following the results of this research closely.



Calling All Hemi Artists

It's that time again! Time to get serious about our Holiday Card Fundraiser!

To make this a successful fundraiser, we need your help! We need winter or holiday artwork created by our super special kids (of all ages!)to adorn our cards!



The 2009 fundraiser was a huge hit! All cards were sold individually during a pre-order period - after that, cards were sold in variety packs. We had a great response from families, therapists, and friends!



The sky's the limit! Let their imagination go wild and use lot's of color! Submitted artwork must be on white paper or card stock and preferably between 8.5x11 to 6x4 in size. Any media is acceptable as long as the picture can be scanned.



Please send your child's signature on a separate piece of white paper (preferably using a dark marker) along with the following information:

Age
Home town/state
Hemi Side/Surgery date

Send artwork to:

Kristi Hall
Holiday Cards
P.O. Box 1239
Aledo, TX 76008

Submission Deadline: September 30

Send artwork early! The first 12 submissions will be used (based on post-mark). We have already received 8 entries! Send your child's artwork now!

We sincerely appreciate your participation!



**GoodSearch**

Want to help the hemi foundation? Check out [Good Search](#) and [Good Shop](#) . Each time you use Good Search (powered by Yahoo) as your search engine, the hemi foundation will receive a donation. Likewise Good Shop is an online marketplace that donates a percentage of your purchase to the hemifoundation.

You can choose from hundreds of popular merchants and the experience of shopping through GoodShop is exactly the same as going to the retailer's websites directly.

As always, the hemi foundation is "staffed" only with volunteers so all donations benefit families and research directly.



Contact The Hemispherectomy Foundation

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