



The Hemispherectomy Foundation Brain Matters Newsletter

October 26, 2010

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www.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



On Our Website

International Hemispherectomy Workshop

University Medical Center, Utrecht, The Netherlands

In early October, several of us from The Hemispherectomy Foundation were privileged to attend the first International Workshop on hemispherectomy. This workshop, organized by Stella DeBode, was held at The University Medical Center in Utrecht, Holland and brought together some of the most brilliant scientific minds in neurosciences. A big THANK YOU to Stella, who is a member of The Hemispherectomy Foundation [Medical Advisory Board](#), for organizing this event. This conference was a first-of-its-kind event to merge neurologists and neurosurgeons with neuropsychologists, neuroscientists and rehabilitation specialists. The goal was to bridge clinical knowledge with insights into cortical plasticity and reorganization. From The Hemispherectomy Foundation, Lynn Miller, Specialty Director, Rasmussen's Encephalitis, her husband Al, and daughter Jody (Right Hemispherectomy in 1993, and current college student) were in attendance. Co-Founders Kristi and Cris Hall were there as well. Hemi Foundation Medical Advisory Board Members in attendance included Gary Mathern, Neurosurgeon from UCLA Medical Center, Adam Hartman, Neurologist from Johns Hopkins, Harry Chugani, Neurologist from Children's Hospital of Michigan, Yong Park, Neurologist from Medical College of Georgia, and of course Stella DeBode, Neuroscientist from the Rudolf Manguis Institute of Neuroscience.



The Program and Abstracts from the event, can be found at <http://www.umcutrecht.nl/subsite/Hemispherectomy-workshop/Program/>



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Other Neurologists, Neurosurgeons, and Neuroscientists from all over the world were in attendance, including from the UK, Japan, Russia, Germany, South America, USA, Holland (host) and others.



At the end, I was allowed to talk on behalf of the hemispherectomy families. I was honored to be able to speak to this most amazing group. Reflecting on the weekend and what was presented, I realized that the doctors really do understand a lot of the hardships that our families face on a day-to-day basis. Many of them have devoted their lives to solving the problems that our kids and families endure. It is not an easy job for them, and many of them work long hours to try to find solutions for us. So, the next time you get a chance, don't forget to thank them for their dedication. For all of the doctors and neuroscientists reading this now, *We Thank You!*

There are more scientists doing hemispherectomy research than you can imagine (pre-surgery, surgery, post-surgery, and rehab) This is happening all over the world. As I watched presentation after presentation, I began to appreciate the volume and diversity of current and past research.

From a surgical perspective, there are many hemispherectomy techniques being used. It's not as simple as anatomical and functional. There exists a virtual continuum of techniques and procedures, starting from vertical and horizontal hemispherectomy, where very little tissue is removed, to a complete anatomical hemispherectomy where the complete hemisphere is removed, including some of the deeper brain structures. The variations, although similar, vary based on etiology, age of patient, seizure location and frequency, surgeon's preference, and more. The refreshing part of this workshop wasn't a realization of "the best" techniques, but rather a realization that the scientists and doctors were talking about it and listening to each other. They might not agree, but their openness is the key to making this surgery better for all families yet to come.

From a few of the sessions, here are a some items to keep in mind as you move forward post-hemi:

- 1) Keep your kids as active as possible. Just like for me and you,

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



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they will do better in the long run if they stay active.

2) Give them as much freedom as possible. It is scary at times, but they will do better and be happier if you give them the chance to explore. This, of course, has to be weighed with each child's functional level and safety.

3) If doctors or scientists ask for data or are doing a study, please take time to participate, even if you don't see the value. Participation and larger numbers will help the doctors and scientists move forward in their research to help our families and those to come. We have only a small pool to draw from; the more of us who participate, the better the results.

4) If your doctors didn't participate in this workshop, encourage them to get involved next time and in other events related to hemispherectomy.

5) Parents, get involved. If you don't know how, contact The Hemispherectomy Foundation and we can help you get started. Start small, and if you like it, the rest will fall into place.

As always, we at The Hemispherectomy Foundation continue to work for the betterment of our community. No Hemispherectomy Foundation funds are used for our travel to events like these. It is paid for out of our own pocket, because we love what we do, because we adore your children and because we seek to make the lives of our community better.

Warm and Kind Regards,

Cris Hall, Co-Founder, The Hemispherectomy Foundation

Additional note from Lynn Miller, Specialty Director for Rasmussen's Encephalitis

For myself, I want to encourage the doctors. Your field is not an easy one to work in. Not every case turns out as well as one would like, not every case is even successful. The neurologists, especially, can have some pretty bleak days. I myself was greatly encouraged to see how all of you were very serious about learning the most you can about this surgery and the different outcomes and would like to add a huge thank you to Cris's. Let me also add my encouragement to the parents to participate in any studies you can, and to have your child followed medically after surgery. This gives a lot more data for the doctors to work from and makes any studies just that much more reliable. When the pool you have to draw from is small, it is very difficult to get meaningful results.

Best Regards,

Lynn



RE Children's Project

By Seth Wohlberg



On October 6th-8th 55 doctors and research scientists travelled from around the world to attend the RE Children's Project's Building New Pathways Conference. Countries represented included Italy, Austria, Nigeria, Germany, Great Britain, US, and Canada. The purpose of the conference was to ignite and jumpstart the worldwide research efforts into Rasmussen's Encephalitis (RE). The conference was held in Deer Valley, Utah at the Stein Erickson Lodge, an isolated and beautiful spot that motivated the group to focus on RE.



Grace and Seth

I founded the RE Children's Project in 2010. My daughter Grace developed Rasmussen's in June 2008, and had a right hemispherectomy in March, 2009.



Dr. Mathern and Dr. Bien

The attendees included many prominent neurologists and neuro-

surgeons, but the conference was also well attended by immunologists, geneticists, and experts from other diseases such as multiple sclerosis. The agenda of the conference was designed to generate bold and fresh ideas by combining the expertise across the various disciplines and diseases.



Dr. Wylie, Dr. Andermann, and Seth Wohlberg

Cris Hall, co-founder of the Hemi Foundation attended the meeting and presented to the group. Other advocacy organizations in attendance also included Susan Axelrod of [CURE](#).



Deidre Wohlberg, Grace Wohlberg, Seth Wohlberg, Susan Axelrod, Cris Hall

The conference was deemed a success by many of the participants. A preliminary research agenda was crafted and a plan to move forward was drafted. There was a real sense at the meeting that a tipping point of sorts had occurred. With all of the attention on epilepsy and rare diseases, there seems to be a momentum building to address RE and move forward in our understanding of this devastating condition.

Please visit [RE Children's Project](#) for more information. To access Seth's summary of the conference [click here](#).



Hemi Kids on YouTube

by Kelly Dawson

Within our community of families, we often share our celebrations of our children's achievements, Whether its earning a Master's degree, learning to walk, or anniversaries of being seizure free, our families love to applaud our kids. This past June, however, it

wasn't just a girl graduating from middle school, it was also the support of an entire community for that girl that deserves our attention. Meet Emily Stoermer.



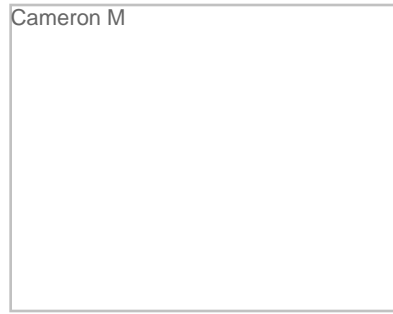
Emily began her journey with Rasmussen's at the age of seven. Not the typical case, Emily had emotional difficulties, and eventually fainting spells and occasional seizures. She was eventually diagnosed with Rasmussen's after a biopsy, and underwent her hemispherectomy.

This past June her mom wrote about graduation experience: "Emily had a great school year this year. It was really difficult at times, and she had to work really hard to catch up from her absence last year, but she did it!! Emily graduated from middle school!! She is gearing up for high school, which starts in a little over a month. EEK!! The graduation was a tremendous thing for us and very emotional (at least for me!). Emily WALKED across the stage with her classmates and accepted her diploma. We were a little worried, because she was the last to walk the stage, that the audience would be restless and that people might start getting up to leave (you know how crowds can be), but we were pleasantly surprised. Not only did they stay, her entire 8th grade class stood up and applauded her! Needless to say, I was in tears (I am tearing up right now just thinking about it)." To view the [video of the graduation, please click here](#). With the support of her family, and obviously her community, Emily has started her high school years. This young woman is an example of the quiet bravery all of our children demonstrate and we wish her every success.



Holiday Cards by Hemi Artists

Cameron M



Tis the season to purchase your Christmas cards. Raise awareness and proudly show your support of The Hemi Foundation by sending out Christmas Cards created by a hemispherectomy child. All proceeds from sales will be used exclusively to help and support those who need, or have had, a hemispherectomy.

Irene P



You may order one particular style, or a variety pack of one of each style. Make a difference in a child's life. Individual packs are on sale until October 31, 2010. All orders will be shipped after November 15, 2010.

Tyler P



[Click here to buy your cards and support The Hemi Foundation](#)



**2011 Hemispherectomy Foundation
Conference and Family Reunion
July 7th, 8th, and 9th, 2011 at Disney's
Paradise Pier Hotel in Anaheim, California**



Mark your calendars NOW for the **2011 Hemispherectomy Foundation Conference and Family Reunion**. You don't want to miss the 2011 conference and family reunion in sunny southern California at the Disneyland Paradise Pier Resort.

<http://disneyland.disney.go.com/hotels/paradise-pier-hotel/>



The 2011 Conference promises to be a well-balanced mix of informative speakers, educational topics, and information geared specifically for families who have been impacted by Hemispherectomy Brain Surgery. In a relaxed, family atmosphere, among other families just like yours, you will be able to learn from others who have walked in your shoes. You will hear from doctors, experts, and scientists who are leaders in the fields that impact your child. Most importantly, you will meet new friends and see old friends who will walk the journey with you.



Make this trip part of a family summer vacation, or come exclusively for the event, but don't miss it. This is also a great chance to schedule appointments at nearby hospitals where your child may have had surgery. Before or after the conference is an ideal time to schedule those yearly follow-up appointments. You may even see your favorite doctor at the conference.

Everyone is invited. It doesn't matter whether you are from the East Coast, West Coast, somewhere in-between, or on the other side of the world, we want you in California in 2011. The Hemispherectomy Foundation Team is putting together an affordable package so that everyone can make it. And as always, The Hemispherectomy Foundation will be offering some financial aid for those who want to come, but just can't fit it into their budget without a little help.

So Block-Out those calendars now! And watch [The Hemispherectomy Foundation website](#) for more details throughout the year. We can't wait to see you on **July 7th, 8th, and 9th** for **The 2011 Hemispherectomy Foundation Conference and Family Reunion !**

Your Hemispherectomy Foundation Team,
"Hope in One Hemisphere!"



Contact The Hemispherectomy Foundation

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Try it FREE today.