



The Hemispherectomy Foundation Brain Matters Newsletter

**Happy New Year
from
The Hemispherectomy Foundation
Volunteer Team!**

Time to make Neurologist Appointments

Another year has passed and a new year is beginning. With this new beginning comes new HOPE and a sense of optimism that only a new year can bring. I am very optimistic about 2012. Personally, our daughter Jessie has been seizure free for nine months and out of the hospital for equally as long. We were finally able to take a family vacation up to Wyoming to see [The Hemi Lighted Forest of Hope](#) and the [Hemi Railroad](#). Our life actually resembled some faint glimmer of normalcy in 2011. So, I hope and dream of a 2012 that equals or exceeds 2011. I hope and dream this, not just for the Hall Family, but for each and every one of you reading this edition of Brain Matters; especially for YOU...because I know that 2011 was not such a great year for everyone.

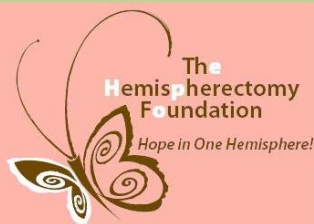
Through your blogs, Yahoo, and Facebook postings, I know that many of you had an extremely hard 2011, riddled with seizures, hospital visits, ambulance rides, medications, surgeries, and hardships beyond the comprehension of most parents. Tragically, we even lost one of our miracle children this year. So my dream for 2012 is that seizures are reduced and eliminated, that surgeries are successful, that children are healed, that therapy is successful, and that moms and dads get some peace.

As things get better in 2012, as I know that they will, I have a favor to ask of each of our families. Whether your child's surgery was a year ago, or 20 years ago, please get regular brain scans. A regular MRI, or CATscan can prevent many conditions, such as hydrocephalus and other complications, from getting out of hand, and even save your child's life. Please read the [latest study on The Hemi Foundation Website](#) about hydrocephalus among hemispherectomy patients. This groundbreaking multi-center, international collaboration clearly shows that hydrocephalus is not limited as an immediate post-operative complication. It can occur many years post-hemispherectomy.

So, this year, and every year moving forward, take some time to make an appointment with your child's neurologist. Ask for an MRI. If needed, ask them to review the study on The Hemi Foundation Website, and explain that our Hemi Kids need a yearly scan. A few hours of time early in the year may give you the peace that you deserve for 2012.

Happy New Year and Kind Regards,

Cris and Kristi Hall
Co-Founders, The Hemispherectomy Foundation
"Hope in One Hemisphere!"
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817-307-9880
Cris@HemiFoundation.org
Kristi@HemiFoundation.org



Visit Our Website
www.HemiFoundation.org

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Matters eNewsletter

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**The Hemi Foundation
Presents**

**"Hope in One
Hemisphere"**

Watch it Here!

*



Announcing The 2012 Hemispherectomy Foundation Conference and Family Reunion

**July 5th, 6th, and 7th, 2011
at the
DoubleTree Hilton, BWI in Baltimore,
Maryland**



Mark your calendars NOW for the 2012 Hemispherectomy Foundation Conference and Family Reunion. You don't want to miss this year's conference and family reunion in Baltimore, Maryland.

See [Preliminary Agenda](#) on The Hemi Foundation Website.

The 2012 Conference will have informative speakers from the [Johns Hopkins Children's Center Neurosurgery](#) and [Neurology](#), [The John M. Freeman Pediatric Epilepsy Center](#), the [Kennedy Krieger Institute](#), the [Taub Therapy Clinic](#), and more. There will be 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 see old friends and meet new 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 Johns Hopkins where your child may have had surgery. Before or after the conference is an ideal time to schedule those yearly follow-up appointments. Chances are, you will 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

[What can You Do with
Half a Brain](#)

Dr. Gary Mathern

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Gifts, Apparel, and
Merchandise Available
at :



[The Hemi
Foundation Store](#)

100s of Items to
Chose From!!!

Shirts
Mugs
Buttons
Magnets
Hats
Baby Clothes
Jewelry
Ornaments
Hoodies
Pajamas
Clocks
Calendars
Note Cards
Stickers

Sport the Latest Hemi
Gear and Support a
GREAT Cause.

On Our Website

the world, we want you in Maryland in 2012. 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 5th, 6th, and 7th for The 2012 Hemispherectomy Foundation Conference and Family Reunion !

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



**Post-hemispherectomy hydrocephalus
in children:
results of a comprehensive, multi-
institutional review.**

Anne E. Matthews, Adam Hartman, Yong D. Park, Anup D. Patel,
Sean M. Lew (on behalf of the Post-Hemispherectomy
Hydrocephalus Work-group)

Introduction: Hemispherectomy surgery for medically intractable epilepsy is known to cause hydrocephalus in a subset of patients. Identification of risk factors for hydrocephalus after hemispherectomy has been limited by the relatively small number of hemispherectomy cases performed by any single center. To identify these risk factors and better understand this phenomenon, a multi-institutional retrospective chart review was performed.

Methods: Fifteen pediatric epilepsy centers participated in this study. A retrospective chart review was performed on all available patients who had hemispherectomy surgery. Data collected included surgical techniques, etiology of seizures, prior resective brain surgery, symptoms and signs of hydrocephalus, timing of shunt placement, and basic demographics.

Results: Pertinent data were collected on 736 patients who had hemispherectomy surgery between 1986 and 2011. Forty-seven patients had pre-existing hydrocephalus. Of the remaining 689 patients, 171 (24.8%) developed hydrocephalus during the postoperative period. Factors associated with postoperative hydrocephalus included anatomic hemispherectomy, resection of basal ganglia/thalamic tissue, and prior resective brain surgery. Factors that did not have significant impact on the development of hydrocephalus included the use of hemostatic agents, post-operative CSF drainage, and etiology of epilepsy. While the majority of patients established a need for shunting in the acute postoperative period, fifty-one patients (29.8%) were shunted more than 90 days after surgery.

*Use Password : Butterfly



- [Ask The OT](#)
- [Ask The PT](#)
- [Ask The Vision Expert](#)
- [Ask The Teacher](#)
- [Ask The Specialty Directors](#)
- [Ask The Teen / Young Adult Panel](#)



- [Stories of Hope](#)
- [Family Blogs](#)
- [Prayer Requests](#)



- [Yahoo Support Group](#)
- [Facebook Support Groups](#)
- [Condition / Disease Pages](#)

* Use Password : butterfly



We Need Your Financial Support

Conclusions: Hydrocephalus is a common sequela of hemispherectomy surgery. Surgical technique and prior brain surgery influence the occurrence of post-hemispherectomy hydrocephalus. A significant portion of patients develop hydrocephalus on a delayed basis, indicating the need for long-term surveillance.

To see the entire results, [read the article](#) on The Hemispherectomy Foundation web site.



2012 Rasmussen's Encephalitis Survey We need your input!



Dear Families impacted by Rasmussen's Encephalitis,
As we prepare for the 2012 Hemi Conference and Reunion, we are conducting a new RE Survey. We have not issued a Rasmussen's Survey since 2009, and it is now 2012.

So, if you can, please take a few minutes to complete this survey. It will take about 15 minutes. The information (not names) will be shared with the medical community in the hope of bringing insight to this terrible disease.

Once completed, the information (not names) will be available for you all to view on The Hemi Foundation website. The 2009 Survey is currently on the website. We hope to get 100 or more participants in this year's survey, so please help.

Click the link below and when you have answered all of the question, please click "Finished". If you don't how to answer a question, or you don't feel comfortable answering it, please feel free to skip it.

[Click here to take the Rasumussen's Encephalitis Survey now.](#)

Thanks,

Cris Hall
Executive Director
The Hemispherectomy Foundation

[Donate](#)

[Support Hope in One Hemisphere.](#)

[Meet Our Medical Advisory Board](#)



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

Financial Resources

Cris@HemiFoundation.org



The Hemi Jam
Music and More, Dec. 17th
Lawrence, Kansas



Over 350 people joined us on December 17, 2011 for the inaugural Hemi Jam at the Granada Theatre in vibrant and unique downtown Lawrence, Kansas. The holiday decorations in the trees outside the theatre added to the festive mood as the crowd entered to enjoy an evening of music and fun.



Three distinct bands took the stage and entertained the crowd with rock, blue grass, and reggae music. Even Elvis (aka Gibson Huston) made an appearance dressed in his white jumpsuit and signed autographs. There was a whole lot-a shaking going on!



The Hemispherectomy Foundation's Resource Page for Medical Expenses. This document lists various grant-making organizations that offer grants to individuals for medical expenses, adaptive aids, therapies, and much more. While there are several organizations with National or International focus, most are limited to specific geographical regions. Contact information is provided along with preferred method of initial contact, if available.

The document is organized by geographic focus starting with International, followed by National. States are then provided in alphabetical order. The information is best searched using the "find and replace" option. Some ideas for search terms: your state name, therapy, hospital bills, equipment, wheelchair, etc.

This is by no means a comprehensive list of potential funding sources and the current giving status of each organization has not been verified. If you are aware of funding sources in your area, please let us know and we will add them to our list.

[Click Here to go to The Hemi Foundation Resource Page!](#)

If you have ideas, feedback or questions, contact Tammy Apitzsch, tammy@hemifoundation.org. Share your success stories with us!

Like Us! Follow Us!
Be Our Friend!

The Hemispherectomy
Foundation

Find us on Facebook 



Hemi kids -- Jessie Hall, Megan Howell, Rachel Cogil, Josie Wathan and Gibson Huston -- hit the dance floor and had a great time together.



The Hemispherectomy
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Rasmussen's Encephalitis

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Between ticket sales, the live and silent auctions, and donations for a chance to win a New Belgium Fat Tire bike, the evening raised over \$10,000 for The Hemispherectomy Foundation! Come join us for the second annual Hemi Jam in 2012!



Website Update Initiative by David Stauff

We hope that you all have found [The Hemispherectomy Foundation's website](#) to be full of everything that you need!

We are always looking for more help and ideas. In an effort to continue providing updated, professional, and intuitive information through the Foundation's website, a team is working together to maintain each and every page. This is a very long process and we need your help! As you are looking throughout each section of the website, please let us know if you happen to find any misspelled words, broken links, or something that just doesn't look right.

Please email us right away at website@hemifoundation.org to report your findings, and include a link and small description of what you have noticed. Thank you for your help!



Inaugural Denver event

by Alicia Grenold

We had our inaugural Denver Hemi event on 11/06/2011 and it went super well with 13 families -- over 60+ attendees! Very informal - introductions, sharing ideas, good food, and lots of playtime. We had a lovely Colorado day and an incredible playground that the kids loved, including an enormous wood chip pile that was climbed by all!



We had great feedback from families and there is much desire to keep the momentum going and get more gatherings scheduled. We will be planning a virtual 5K Walk in May to coordinate with the Texas run. A number of families didn't want to wait that long, so we might possibly plan something sooner. Jane Hittle and I both commented that the kids did beautifully, really seemed engaged with each other, even the siblings. It was a great day!





Who's New at The Hemispherectomy Foundation?

We are so proud to have several new team members working with us to serve the Hemispherectomy Community. The following individuals have graciously volunteered their time to serve in various aspects of the operation of The Hemi Foundation.

- David Stauff - Webmaster, and SalesForce.com
- Tammy Apitzsch - Family Assistance Grants
- Saasha Huston - Website
- Alexia Madigan - Newsletter and Website
- Kori Kielty - Hemi Family DB
- Alicia Grenolds - Denver & Rocky Mountain Area Support Group
- Jane Hittle - Denver & Rocky Mountain Area Support Group
- Sunshine Glen - Annual Hemi National Garage Sale

*If you are interested in creating a Hemispherectomy Foundation Support group in your area, contact Cris@HemiFoundation.org. Most support groups will try to do at least one local gathering and one fundraiser per year.



**Join Us in Texas for the
Dreams on Wings 5K
and
Family BBQ
May 12, 2012
Weatherford, TX
or
Run Virtually Any Where in the World!**
(see below for details and registration)



The Hemispherectomy Foundation and Parker County Physical Therapy will host a 5K and 1-mile fun run/walk on Saturday, May 12. "Dreams on Wings" will honor Aledo's Jessie Hall, a second grader who underwent radical surgery in which one half of her brain was removed. All proceeds from the event will benefit The Hemispherectomy Foundation, a non-profit organization dedicated to providing emotional, financial and educational support for individuals and their families who have undergone or will undergo a hemispherectomy, or similar brain surgery.

[Click Here to Register!](#)

The 2011 Dreams on Wings 5K was a great success! The foundation was able to raise just over \$30,000 for the children that we support. Best of all, 10 families with children that have undergone hemispherectomy surgery attended the race!



The 1-mile fun run will start at 8:00 a.m. followed by the 5K at 8:30 a.m. Both races will start at Parker County

Physical Therapy located at 879 E. Eureka in Weatherford, Texas.

Individual awards and Luke's Locker gift cards will be given for overall and masters male and female winners, plus the top three male and female finishers in the following age groups: 5 and under, 6-8, 9-11, 12-14, 15-19, 20-24, 25-29, 30-34, 35-39, 40-44, 45-49, 50-54, 55-59, 60-64 and 65+.

**Awards Will be Given to the
Largest Family Team!**



REGISTER NOW!!!
[Click Here to Register!](#)

Immediate Hemi Families are free, but count toward a family team.

Hemi Family Registration - Contact Kristi Hall
kristi@hemifoundation.org

Encourage friends, sisters, cousins, aunts and uncles to register for you team!

NO FEES!

Participants can register online at www.hemifoundation.org (no fees!) or download registration forms. Early registration ends April 29. The pre-registration cost for adults is \$25 and \$30 on the day of the race. For children under 6-12, the pre-registration cost is \$20 and free for children ages 5 and under. Teams of 3 or more can register for \$20 per individual.

**Can't make it to Texas?
Sleep in and get the t-shirt!
Virtual Runner \$30**



If you can't make it to Texas, we understand.
But we have an answer for you. We have a growing number of people that will be running or walking the race at home, and in other states as well. These are our "Virtual Angels" Some people will even be picking their own time to commit to 3.1 miles.

A 2012 Camp Scholarship will be named in honor of the largest Virtual Team
We encourage each family who is willing to have a goal to sign up 10 (or more) Virtual Runners. It could be 5 family members and 5 close friends. Signing up just 10 Virtual Runners would be raising \$300 for the Hemi Foundation. This is a great way to help be a part of the Hemi Foundation's largest fundraiser!

[Click Here to Register](#) - select the Virtual Runner tab.



So, there are NO excuses not to participate. Register NOW and come to Weatherford on May 12th or be a "Virtual Angel". More information will be coming your way in a separate news letter.

Registration forms and checks, made out to The Hemispherectomy Angels, Inc., can be mailed to The Hemispherectomy Foundation, P.O. Box 1239, Aledo, TX 76008.

Kristi Hall
President and Jessie's mom (RE, June 2008)
The Hemispherectomy Foundation
Kristi@HemiFoundation.org

For More Info, Click Here or Contact :
Kristi Hall
Kristi@Hemifoundation.org



**We Need YOU
at
The Hemi Foundation!**

If you are interested in sharing your talents with the hemispherectomy community and joining The Hemispherectomy Foundation Team, please send an email to Cris@HemiFoundation.org .

Current Volunteer Opportunities:

Baltimore Conference and Reunion Workers

Dreams on Wings Virtual Runner Team Captains

Regional Teams (West, East, Central, Northeast)
Specialty (Disease / Condition) Teams

Special Talents? What is yours?

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



Contact The Hemispherectomy Foundation

The Hemispherectomy Foundation
PO Box 1239
Aledo, Texas 76008
817-307-9880

