



The Hemispherectomy Foundation Brain Matters Newsletter

Families Unite in Baltimore for the 2012 Hemi Foundation Conference



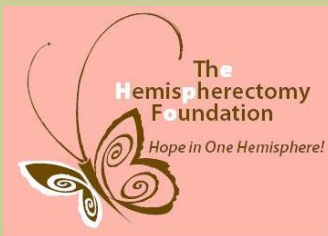
The 2012 Hemispherectomy Foundation Conference and Family Reunion, in Baltimore, Maryland was held this summer with record breaking temperatures and record breaking attendance. The Grand Ballroom was at capacity as we enjoyed expert speakers and doctors present useful material to our Hemi Community! The speakers were from Johns Hopkins, Kennedy Krieger, University of Alabama at Birmingham, and UCLA .

During the Lunch Sessions we were all treated to presentations from our Young Adults who were such an inspiration to the parents and children alike. What hope for parents to listen to the amazing things that past hemispherectomy patients were doing in their life. From getting married, to raising their own children, these adults were enjoying life and doing amazing things. We were taught that it is OK to laugh again and learned that driving is a possibility. One young lady talked to us about helpful gadgets, while another showed us all post-high school options, while another young-man showed us his use of technology...one-handed style.

Kids Camp was a HUGE hit again this year, as Hemi Kids and their siblings enjoyed games, crafts, movies and other entertainment by a GREAT group of volunteers.



This year's annual conference was the largest Hemispherectomy gathering ever! Unfortunately, it had to come to an end for those in attendance, but don't worry! Summer will be here soon and we will all be together again June 21, 22, 23 in Lawrence, Kansas at the Raintree Montessori School. If you came this year, we are looking forward to seeing you and your children again in 2013. If you couldn't make the 2012 event, we look forward to seeing you in 2013 in Lawrence.



Visit Our Website

www.HemiFoundation.org

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The 2012 Hemispherectomy Foundation Awards

Congratulations to this year's Hemispherectomy Foundation Award Winners. From Doctors to Families, Volunteers to Donors, the Hemi Foundation is proud to recognize the following people for their contribution to the Hemispherectomy Foundation and the Hemispherectomy Community as a whole.



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Read Archived Copies of **Brain Matters**

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The Hemi Foundation
Presents

"Hope in One



Lifetime Achievement Award

Dr. John Freeman, Retired - Johns Hopkins

Lifetime Achievement Award

Dr. Ben Carson, Johns Hopkins

Lifetime Achievement Award

Dr. Eileen Vining, Johns Hopkins

Medical Advisory Board Member of the Year

Dr. Adam Hartman



Lifetime Achievement Award

Lynn and Al Miller

Director of the Year

Jane Stefanik, CFO and NE Regional Dir. - The Hemi Foundation

Hemi Angel of the Year

Lindy Shelton, Accounting Dir. - The Hemi Foundation

Hemi Foundation Volunteers of the Year

Sherame Anderson - Dir. Hemi Hugs - The Hemi Foundation

David Stauff - Western Regional Dir and Webmaster

Laura Rasnick - Fundraising and Special Projects

[Hemisphere"](#)

[Watch it Here!](#)

*



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

Dr. Gary Mathern

*

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



2012 Reunion Committee

- Jane Stefanik - Chair
- Mary Beth Norwood - Registration
- Samie Stefanik - Dir. Kids Kamp
- Diana Waguespack - Photographer
- Nickie Stefanik - Kids Kamp



Dreams on Wings Largest Family Teams

- Dashing for Dante of NH** - Dante Bergskaug Gina & Rich Bergskaug)
- The Trevadores of CA** - Trevor Conrad (Kelly & Barin de la Torre)
- Rachel's Rainbows of Hope of IA** - Rachel Cogil (Roxanne & Craig Cogil)
- Benjamin's Buddies of WY** - Benjamin Swanson (Becky & Isaac Swanson)
- Elysia's Angels of WI** - Elysia VanDerPerreon (Gretchen & Tim VanDerPerron)
- Team Jaxon of OH** - Jaxon Fuller (Nicole & Jerry Fuller)
- Team Bean of WA** - Jayna Bean Doll (Sunshine Glynn Doll & Jamie Doll)
- Team Hannah Rose of MO** - Hannah Webb (Gib & Sandy Webb)
- Jogging for Georgia of CO** - Georgia Grenolds (Alicia & Rick Grenolds)
- Team Ashlyn of CA** - Ashlyn Barkley (Don & Renee Barkley)

Clocks
Calendars
Note Cards
Stickers

Sport the Latest Hemi
Gear and Support a
GREAT Cause.

On Our Website

*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 /](#)

Fighting for Amina of CA - Amina Cirbic (Dzermina & Asmir Cirbic)



A Thank You Letter to The Hemi Foundation



Dear Cris, Kristi, and all our HemiFoundation family,

I can't tell you how touched Al and I were to receive the Lifetime Achievement Award at the recent Conference in Baltimore, all the more so since the Foundation has only given out 5 and all the others were medical-related. We really do not feel that we did anything special; Al even says that "anyone would have done the same." I'm a bit more realistic - if anyone would have done the same, they would have already done it when we came along on this journey. However, the fact remains that for us, to turn around and offer support to others going through the same difficulties we had just experienced was natural. We really did not have any other options, in our minds. We had been given hope for a reason - to turn around and offer it to those who came after us, for truly only those who have experienced something can offer what is needed to those suffering that same thing. We were just glad that Jody could be such an inspiration to other families! And we have received so much back from seeing the families we've met with - talked with - sat with - bounce back to live their lives again, generally without the "s" word.

The reunions were not really our idea and we can't take the credit for starting them. I suspect that's one more thing we can thank Diana Pillas for. We just took a good idea and continued with it. As I said at the Conference, it was so gratifying to us to see all the families who came and to realize that the small seed we nurtured has grown into something so relatively big! It always chokes me up to realize how God has used the little bit that I am able to do (or in this case, that *we* were able to do) to accomplish something big. We poured ourselves out to grow the first few gatherings, Ellen Synakowski followed on from us, and the Hemi Foundation has now taken it to the next level. Thank you, Cris and Kristi and all the other volunteers who run this

[Disease Pages](#)

* Use Password : butterfly



We Need Your Financial Support



[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

wonderful organization! All of our families are just as grateful to you, maybe more, so major props to you as well! We love you all!

Al and Lynn Miller



**Hemi Jam 2012
Coming December, 8th, 2012
Lawrence, Kansas**



The 2nd Annual Hemi Jam will be held on December 8 at 7 PM to benefit The Hemispherectomy Foundation.

A diverse music line up featuring :
The Band that Saved the World
Danny McGaw Band
The Recessionists

is planned to rock the night away with GREAT music for a GREAT cause.

Auction items will be available to bid on and tickets will be sold to win some great prizes. Come join us for a fun-filled evening!

higher education as well as provide financial relief for struggling families
Read stories of hope about our families on

hemifoundation.org

Financial Resources



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!

Hemi Jam Info December 8th, 2012

7:00 PM

The Granada Theatre

Lawrence, Kansas

Live music, prizes, and auction items
** For more info on the Hemi Jam, contact Saasha@HemiFoundation.org



Hemi Lighted Forest of Hope 2012 Providing Lights of Hope for Children Impacted by Hemispherectomy Brain Surgery



The Hemi Lighted Forest of Hope in Cheyenne, Wyoming, is a celebration of LIFE and HOPE for children all over the world, who have had their lives turned upside down, in a battle against intractable epilepsy. These children all underwent radical brain surgery in HOPE of living a life seizure free. A tree will be lighted for each child who has undergone Hemispherectomy Brain Surgery and who has registered with The Hemispherectomy Foundation. These trees and lights represent a celebration of each child's HOPE for a life without seizures.

This year, 600 trees will be lit and each year more trees and lights will be added to the Hemi Lighted Forest of Hope.

The Hemi Lighted Forest Facts:

- 108,000 lights and parade float

**Like Us! Follow Us!
Be Our Friend!**

The Hemispherectomy
Foundation

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Foundation
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Find us on Facebook 

The Hemispherectomy
Foundation
Pediatric Stroke

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Hemispherectomy
Foundation Videos

View our videos on YouTube 

Hemispherectomy
Foundation "Our Hemi Kids"
Channel

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Hemispherectomy
Foundation
Twitter

Follow us on 

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[Yahoo Group HME](#)

- Display open from November to end of December
- 4.5 Acres of Trees
- 2,000 Feet of underground wiring
- Over 700 Extension Cords
- Over 800 Strings of Multicolored LED Christmas Lights
- Indoor garden scale railroad and Christmas display
- Lighted water feature iwth 5 water falls, 140 ft of creeks, and garden scale railroad
- Hay rides through the trees from 6:30 to 8:30 weather permitting through New Year's Day
- Hot chocolate and hot apple cider served after hay rides

This year the Hemi Lighted Forest of Hope will be adding a picture of the kids on special 4"x4" ornate garden markers. Watch for these in early November. More information will be coming soon.



How You Can Help

If you get a chance - go to the <http://www.HemiFoundation.org> website. Much information about the causes of seizures that result in the option of having a hemispherectomy, the procedure and the challenges that await the child and family is available.

Donations are accepted by the Kelley's at "The Hemi Lighted Forest of Hope"

A donation box is conveniently located by the indoor display.

For more information call (307) 634-7806

Make check out to "Hemifoundation".

For: "donation to Forest of Hope"

Checks may be mailed to:

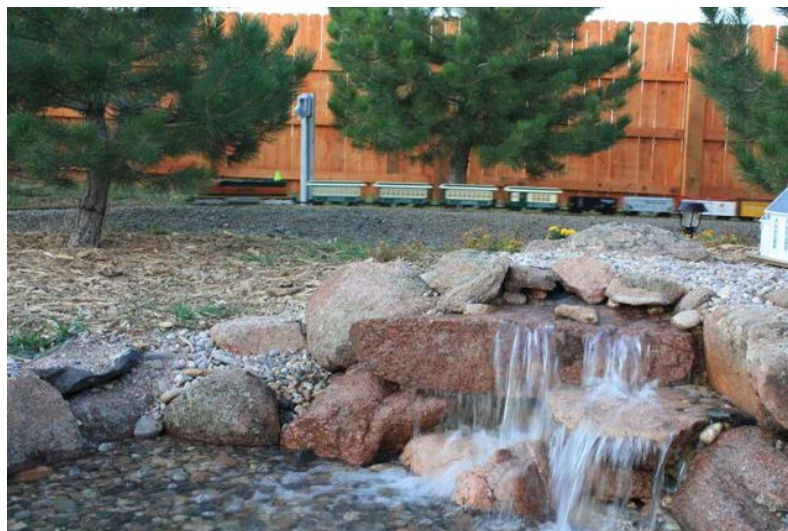
Gary Kelley

6565 Ashley Drive

Cheyenne, Wyoming 82009

Or
Mail direct to
The Hemispherectomy Foundation
Forest of Hope
PO Box 1239
Aledo, TX 76008

Or
Secure on-line donations can be made at
<http://www.HemiFoundation.org>



Directions

- * Go East on old Highway 30
- * From College Drive - 4.2 miles to Reese Road
- * North on Reese Road 1 mile to Beckle Road
- * One block west to Ashley Drive
- * Go North on Ashley Drive
- * 5th House on Right to 6565 Ashley Drive

Any questions please call Gary at 307-630-6641 or e-mail us at papa@hemiforest.com.



**Hemi Hugs Donations Fill the Cabinets for
Children in the Hospital undergoing
Hemispherectomy**



A Letter to Sherame Anderson, Director - Hemi Hugs Program, The Hemispherectomy Foundation:

Hi Sherame,

My name is Jeanie Branstutter, I have a 5 yr old daughter, Kendall, who had a hemi in June 2009. While we were in the hospital, or shortly after we received a package from you that was so thoughtful. Since things are starting to slow down on our end, well to a controlled chaos level, we were looking at someway to try and help out other families. Last month I had a Scentsy party and we sold candy bars at work to cover the costs of any Scentsy Buddies, so with the candy bar funds and the hostess credit/half off items we have purchased 10 Scentsy Buddies to donate to Hemi Hugs. In addition to that I sell Thirty One products and the special this month is spend \$31 and receive an all in one organizer for \$5, so we used that special to purchase bags that embrodered with Hemi Hugs. This is something we would like to do for the remainder of the year.

Jeanie Branstutter



Thanks Jeanie and Sherame for helping keep the Hemi Hugs Program going strong for the 5th year!



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.

Karan Crowe - Southern Regional Director
Karen White - Australian Representative
Kendra Campbell - Canada Representative

*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.

Also, we are in desperate need of a eNewsletter coordinator and team. If you are interested, send an email to Cris@HemiFoundation.org.



Tissue Collection Protocols

by Seth Wohlberg, RE Children's Project

For the past few months we have been transferring brain tissue following hemispherectomy surgery to research teams at UCLA, Yale, and Johns Hopkins. As previously discussed in prior blogs, this is not an easy task and has been an enormous step forward in our efforts to advance research in rasmussen's. The availability of this tissue will create and drive research interest into RE.

The RE Children's Project has now completed a [manual \(click on this link to view\)](#) that addresses the transfer of this tissue. It is a step-by-step guide on how neurosurgeons can extract the rasmussen's tissue, properly store, and then ship it for research purposes. The manual was assembled by Joe Voros, our Research Coordinator with input from several research organizations. This is a first of its kind manual and we are hopeful it is a major step forward in our efforts to increase awareness and drive research dollars into RE research.

Please print out this manual and provide it to your neurologists and neurosurgeons. This is an absolute imperative and a moral responsibility for the families impacted by this disease. We have already missed a few surgeries and opportunities to transfer the tissue. RE is very rare and although there is great tragedy and despair associated with the surgery, having access to the tissue after surgery will help us prevent other families from experiencing their own devastation. A heartfelt thanks to Joe Voros for his hard work. Please let us know if you are aware of an individual that is scheduled to have hemispherectomy surgery due to RE.

As the year winds down and Fall begins (in the northern hemisphere) please consider the RE Children's Project for your year-end philanthropic giving. Any amount is fine. The RE Children's Project is a labor of love and we have made enormous strides in 2 years, but the cold hard reality is that we need funds to keep this going. I frequently receive e-mails of admiration and expressions of support with questions of how can I help. It's simple donate, please click on this [link](#), donate what you can afford no matter the amount and let us know you stand shoulder to shoulder with our efforts to fight a rare disease and demonstrate to other rare diseases that despite the odds that they can make a difference with hard work and determination.

Solving rasmussen's will shed light on the epilepsies. There are no celebrity spokespeople for epilepsy admitting that they suffer from seizures. Epilepsy affects over 3 million Americans of all ages - more than multiple sclerosis, cerebral palsy, muscular dystrophy, and Parkinson's disease combined and 50,000,000 worldwide. There are approximately 50,000 deaths a year attributed to epilepsy, that is more than breast cancer. In over one-third of epilepsy cases, the seizures are uncontrollable. With rasmussen's the only course of action is to remove half the brain. There are no drugs to stop the seizures. It's time for the epilepsies to come out of the shadows.

For more information on The RE Children's Project, visit <http://www.rechildrens.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.

Brain Matters eNewsletter Team

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

Special Talents? What is yours?

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



2012 End-of-Year Giving!

Dear Hemi Foundation Supporter,

Thanks to you and your support, the Hemispherectomy Foundation is fully established and supports children and families who have endured the most radical brain surgery in existence, to cure unstoppable cases of epilepsy.

[How does the Hemi Foundation use your donations?](#)

Sends Hospital Hemi Hug Care Packages worldwide to kids facing Hemispherectomy brain surgery.

Provides Financial Aid Hardship Grants and Financial Travel Aid Grants to families.

Awards College Scholarships and Camp Scholarships.
Research Fund to support research into targeting hemi-related epilepsy and rehab.

Hosts International Hemi Conference & Family Retreat and multiple regional events.

We need YOUR help again this year to continue these valuable programs. Please consider these children in your end-of-year Holiday Giving. Just a small donation will make a difference in a child's life.
[How can my gift can make a difference to a child today and beyond?](#)

\$10 - \$25 will pay the postage to send one child a Hospital Hemi Hug care package.

\$50 will pay for 100 Brochures to send to new families and doctors.

\$100 to \$500 will send a child to the Summer Camp of their choice.

\$1,000 will fund one College or Trade School Scholarship or help fund Research.

Please donate today by check or a secure online donation at

<http://www.hemifoundation.org>

Thank You !

Kristi Hall

President and Co-Founder,

The Hemispherectomy Foundation

Donations can be sent to :

[The Hemi Foundation](#)

[PO BOX 1239](#)

[Aledo, TX 76008](#)

or Online at www.HemiFoundation.org.

All donations are 100% tax deductible. Hemispherectomy Angels is a 501c3 Public Charity EIN:26-2864993



Contact The Hemispherectomy Foundation

The Hemispherectomy Foundation

PO Box 1239

Aledo, Texas 76008

817-307-9880



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