



# The Hemispherectomy Foundation **Brain Matters Newsletter**

## **On-Line Video Presentations Now Available from the Hemispherectomy Foundation Conference and Family Reunion in Anaheim, California**



As part of the strategic partnership between the ***Hemispherectomy Foundation*** and ***The Brain Recovery Project***, select portions of the physicians' and therapists' panel from the 2011 International Hemispherectomy Foundation Conference and Family Reunion are now available online at

**<http://www.youtube.com/brainrecoveryproject>**

Please take a moment to subscribe to this YouTube channel for immediate updates when a new video is posted.



Be sure to mark your calendars for the 2013 Hemispherectomy Foundation Family Retreat in Lawrence, Kansas on June 21st, 22nd, and 23rd. Watch the Hemi Foundation website for more details at [HemiFoundation.org](http://HemiFoundation.org)



**This annual Hemi Foundation event is one that you don't want to miss. It is a one of a kind event to have fun, strengthen bonds, and learn as a community. See You in Lawrence, Kansas in June!**



**Dreams on Wings 5K and Virtual Run**



Read Archived Copies of ***Brain Matters***

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The Hemi Foundation  
Presents

["Hope in One Hemisphere"](#)

[Watch it Here!](#)

\*



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

Dr. Gary Mathern

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# DREAMS ON WINGS 5K

2013

[WWW.HEMIFOUNDATION.ORG](http://WWW.HEMIFOUNDATION.ORG)

**Coming Your Way This Spring!  
May 18th, 2013**



You can Run it! You can Walk it! Heck, You can even sleep-in and get the T-Shirt, but you've got to be a part of the 2013 Dreams on Wings 5K. This year we have at least 2 fully sanctioned races in Texas and New Hampshire! And of course we will have our popular Virtual Running Teams! As in the past, the largest Virtual Team will have a 2013 scholarship named after their team!

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

\*Use Password : butterfly



This is your chance to help bring awareness to OUR kids and families and what they've endured. So start recruiting your teams now! Family, Co-workers, Friends, the mailman, strangers off the street...Recruit them all!



If you are interested in having a sanctioned race in your area, contact Kristi Hall via email at [Kristi@HemiFoundation.org](mailto:Kristi@HemiFoundation.org).





- [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**

[Donate](#)

## 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/>

[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](http://hemifoundation.org)

**Financial Resources**



**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](mailto: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!"**



**Contact The Hemispherectomy  
Foundation**

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



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](mailto:tammy@hemifoundation.org). Share your success stories with us!

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