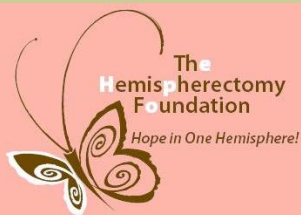




# The Hemispherectomy Foundation Brain Matters Newsletter



Visit Our Website

[www.HemiFoundation.org](http://www.HemiFoundation.org)

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Read Archived Copies of **Brain Matters**



## 2013 Dreams on Wings

Dreams on Wings 5K series is entering its 5th year as the number one Awareness & Fundraising Event for The Hemispherectomy Foundation.

Join us on May 18, 2013!



### The Dreams on Wings 5K

is entering its 5th year as the number one fundraising event for The Hemispherectomy Foundation.

The Dreams on Wings 5K Events include the marquee race in Texas, Virtual Running, and a new, official timed race in Brookline, New Hampshire.

Where ever you may be, the **Dreams on Wings 5K Events** has a race for you!

[Click Here To Register!](#)



Our most popular event is **Virtual Running Teams** because you can participate any where on the globe and still get a t-shirt! We are encouraging as many Hemi families as possible to sign up their own team of Virtual Runners (Angels) to help make this event an even greater success of raising funds to support and serve children who have been impacted by Hemispherectomy Brain Surgery ! Wouldn't it be wonderful to have Hemi Virtual Runners (Angels) in all 50 states, as well as several countries? We were so close last year with 48 states represented! This is also an opportunity to educate others and spread awareness of what the Hemi Foundation does for families.

**A 2013 Camp Scholarship will be named in honor of the largest Virtual Team!**

[Click Here To Register!](#)

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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

\*

Gifts, Apparel, and  
Merchandise Available  
at :



The Hemi  
Foundation Store

100s of Items to  
Chose From!!!



### 2012 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)
- Fighting for Amina of CA** - Amina Cirkic (Dzermine & Asmir Cirkic)



## Hemi Foundation Family Retreat

### Lawerence, Kansas : Raintree Montessori School

**June 21,22 & 23, 2013**

It's that time of year again! It is time for the Annual Hemi Foundation Family Retreat! It is time to get with old friends, and meet new ones. It is time to learn about how to take better care of our children, and how to take better care of ourselves. Most of all, it is a time to get together with other who understand US, and who understand our children. We hope to see you there in June!

The information below will tell you how to register, and get your hotel booked, as well, as a little about the Retreat. Please book your hotel early, as the block is limited at the discounted price. Also, please register early, so we can better plan food and activities.

Friday Evening: Meet and greet at the hotel. Informal gatherings.

Saturday/Sunday: breakfast at hotel, then meet at Raintree, the Huston family's school, for days of fun ([www.raintreemontessori.org](http://www.raintreemontessori.org))

Day's events include:

**OUTSIDE:** Swimming in one of 5 pools, fishing, paddle boating, basketball, 3 playgrounds, giant sandboxes,  
**INSIDE:** ping pong, air hockey, board games, art activities, cooking projects, practice for talent show, video games, movies, nap time, legos, blocks, etc.

Staff will be there to assist and supervise certain rooms and spaces. It is important that parents know where their children are and who is watching them.

A schedule of planned activities will be given to parents so that children can choose to participate in certain activities like a certain art activity or cooking project.

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



- [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](#)

For parents: We will have a few local people who will be available to discuss topics like: doctor/patient relations, orthotics and speech. These will not be formal presentations but instead a time to ask questions or visit with one another about a common topic. Schedule to be announced later.

Lunch and Dinner on Saturday and Lunch on Sunday will be served on site. Dinner on Sunday will be on your own, hopefully at a common local place.

Families should plan on arriving Friday afternoon and leaving Monday morning.

For those that are flying: Fly into Kansas City International Airport. It will probably be best to rent a car for the weekend. Families can communicate to do this together if possible. Lawrence is about 45 minutes from Kansas City.

Once in Lawrence almost any location can be reached within 10 to 15 minutes.

### The Hemispherectomy Foundation Family Retreat Registration and Hotel Info is READY!

Go to <http://www.HemiFoundation.org>

Or Click Here :

[http://hemifoundation.intuitwebsites.com/2013\\_Hemi\\_Foundation\\_Marriott\\_Hotel.pdf](http://hemifoundation.intuitwebsites.com/2013_Hemi_Foundation_Marriott_Hotel.pdf) for the Hotel Info sheet. It has the reservation phone number, website, and don't forget to use the Group Codes for our Hemi Discount Rate!

Click Here to register for the Conference :

[http://hemifoundation.intuitwebsites.com/2013\\_Family\\_Retreat\\_Registration\\_Packet.pdf](http://hemifoundation.intuitwebsites.com/2013_Family_Retreat_Registration_Packet.pdf)

Just print it off, fill it in, and mail to the address on the form and register NOW! Also, you need to get your hotel reservations ASAP, as the block is limited.



## Best iPad Apps for Kids with Special Needs

There are a number of apps for electronic devices which can help kids practice their skill or acquire new ones with ease. Joan L. Green provides a list of such apps in her book "The Ultimate Guide to Assistive Technology in Special Education". The list below includes the software developer and cost.

**Another great source for finding these apps is [www.momswithapps.com](http://www.momswithapps.com)**

### Speech

#### **Dragon Dictation**

Converts speech to text or e-mails. Nuance Communications, free.

#### **ArtikPix-**

Combines flashcards and other activities to help children with speech delays practice making sounds correctly. Expressive Solutions, \$29.99.

#### **Articulation Station Pro**

Allows kids with speech delays to practice making sounds in words, sentences and stories. Little Bee Speech, \$49.99.

### Language

#### **VAST Autism 1-Core**

- [Prayer Requests](#)



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

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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

helps students with autism or other disorders, such as apraxia, learn to speak. SpeakinMotion, \$4.99.

### **First Phrases HD**

Helps toddlers or children with speech delays learn to put words together into phrases. Hamaguchi Apps for Speech, Language and Auditory Development, \$9.99.

## **Reading**

### **Bob Books #1-Reading Magic HD**

A phonics-based game to help young children learn how to read. Learning Touch, \$3.99.

### **Rainbow Sentences**

Helps students learn good grammar by color-coding the parts of sentences. Mobile Education Tools, \$7.99.

### **Rhyming Words**

Rhyming activities to help build early reading skills. GrasshopperApps.com, free.

## **Writing and spelling**

### **Cimo Spelling**

A game that uses a list of 255 high-frequency and sight words to help children in kindergarten through third grade develop basic spelling and reading skills. PlaySmart-Kids, \$2.99.

### **FirstWords Deluxe**

Helps teach toddlers letter and word recognition. Learning Touch, \$4.99.

### **iWrite Words**

Reinforces correct letter formation and spelling. Gdiplus, \$2.99.

## **Organization and note-taking**

### **Abilipad**

A notepad app that allows users to customize the keyboard. It also has a text-to-speech function. Cheryl Bregman, \$19.99.

### **Audionote Notepad and Voice Recorder**

Synchronizes typed notes with recorded audio for students who struggle with fine motor skills or organization. Luminant Software, \$4.99.

### **Notability**

Take Notes and Annotate PDFs with Dropbox combines handwriting, typing and voice recording for note-taking. Ginger Labs, 99 cents.  
Communication

### **Custom Boards**

Allows users of all ages to create custom communication boards, schedules and activities from a library of more than 11,000 symbols. Smarty Ears, \$39.99.

### **My First AAC**

A communication app for toddlers and preschoolers with delayed speech and language. Injini, \$24.99.

### **Proloquo2go**

Includes symbols and a text-to-speech function for students of all ages with speech and language difficulties. AssistiveWare, \$189.

### **TouchChat**

Helps students of all ages who have trouble speaking with their own voices. Silver Kite, \$149.99.



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



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](#)

## Listening skills

### **See. Touch. Learn Pro**

A picture-learning system designed for children with autism and other special needs. Brain Parade, \$24.99.

### **LanguageBuilderDeluxe**

Helps children practice coming up with ideas and forming sentences. It uses lots of audio clips to help kids work on listening skills, and can play back the child's own voice to help them develop their language. Mobile Education Tools, \$14.99.



## **Posthemispherectomy hydrocephalus: Results of a comprehensive, multiinstitutional review**

*Epilepsia, 54(2): 383-389, 2013*

In a study of 736 patients who underwent hemispherectomy surgery between 1986 and 2011, 162 (23%) required treatment for hydrocephalus.

### *hy-dro-ceph-a-lus (noun)*

*an accumulation of serous fluid within the cranium, especially in infancy, due to obstruction of the movement of cerebrospinal fluid, often causing great enlargement of the head; water on the brain.*

Hemispherectomy surgery has been used to control intractable seizures since 1950 (Krynauw, 1950), and hydrocephalus is a potential complication of such surgery (Oppenheimer & Griffith, 1966). This particular study was done at 15 pediatric epilepsy centers including

- *Nationwide Children's Hospital, Columbus, OH*
- *NYU Langone Medical Center, New York, NY*
- *Phoenix Children's Hospital, AZ*
- *Sanbo Brain Sciences Institute, Beijing, China*
- *Seattle Children's Hospital, Washington*
- *UCLA Medical Center, Los Angeles, CA*
- *Children's Hospital of Alabama, Birmingham*
- *Wayne State University, Detroit*
- *Children's Hospital of Wisconsin,*
- *Children's Hospital of Denver, Colorado,*
- *Cook Children's in Fort Worth, Texas*
- *Duke University Medical Center, North Carolina*
- *Johns Hopkins Hospital, Maryland*
- *Medical College of Georgia*
- *National Center for Neurology and Psychiatry, Tokyo, Japan*

[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!

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

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Hemispherectomy Foundation "Our Hemi Kids" Channel

[View our videos on YouTube](#)

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Twitter

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**Table 2. Univariate analysis of potential risk factors with the development of hydrocephalus**

Variable	Hydrocephalus (%)	OR (95% CI)	p-Value
<b>Hemispherectomy technique</b>			
Anatomic	74/244 (30)	4.2 (2.3–7.6)	<0.0001
Functional	87/435 (20)		
<b>Basal ganglia/thalamus resected</b>			
Yes	75/219 (34)	2.8 (1.2–6.6)	0.02
No	87/471 (18)		
<b>Prior surgery</b>			
Yes	32/122 (26)	1.7 (1.1–2.9)	0.03
No	130/568 (23)		
<b>Use of any hemostatic agent</b>			
Yes	157/649 (24)	3.6 (1.0–12.2)	0.04
No	5/41 (12)		
<b>Postoperative CSF drainage</b>			
Yes	485/690 (70)	0.8 (0.3–2.5)	0.75
No	196/690 (28)		
Unknown	6/690 (1)		
<b>Postoperative infection</b>			
Yes	50/690 (7)	1.5 (0.7–3.2)	0.25
No	640/690 (93)		
<b>Etiology of epilepsy</b>			
			0.50

**Table 4. Presenting symptoms and signs of hydrocephalus**

Presenting symptom/sign	Frequency (%)
Failure to wean CSF drain	77/126 (61)
Imaging changes	67/84 (80)
Headache	37/84 (44)
Emesis	37/80 (46)
Diminished level of consciousness	35/81 (43)
Cognitive decline	13/83 (16)
Behavioral changes	13/81 (16)
Wound issues	13/75 (17)
Other	20/68 (29)

Variable denominators reflect unavailability of data on some patients (162 patients developed HCP).

This study looked at presenting signs and symptoms in two groups: 0-90 days after surgery and post 90 days. The only significant difference detected in the symptoms of these two groups was headache. It was more frequent (55%) in the first 90 days after surgery as compared with the second group (38%). Promising is the fact that hydrocephalus is progressive, and all of the patients in this study were eventually treated.

Several theories exist, which are discussed in detail, regarding the cause of hydrocephalus. It is clear that several conditions are associated to hydrocephalus including hemorrhage, inflammation, infection, trauma and tumors. This study did, however, reveal that "the strongest predictor for the development of hydrocephalus after hemispherectomy was surgical technique" (p. 386). It is believed that an anatomical hemispherectomy simply leads to a larger area being exposed, and a larger area where change can occur. In 2002, Murphy et al. resolved that the risk for patients who had subarachnoid or intraventricular hemorrhage correlated with the amount of blood. An independent risk factor was prior brain surgery due to the increase in tissue exposure, inflammation and scarring.

This study also looked at what can occur when the basal ganglia and/or thalamus were resected during surgery. According to Norden and Blumenfeld, these structures play a significant role in the "propagation of seizures". It is necessary in some hemispherectomies to remove these structures to ensure complete disconnection. However, exposing these deeper structures can increase risk of hydrocephalus.

Interestingly, postoperative infection was not associated with the development of hydrocephalus.

Lastly, the study points out the importance of remembering that the brain will continue to change over time after hemispherectomy surgery. Remaining tissue in the brain and fluids will be redistributed. This could be a reason why hydrocephalus can be delayed rather than occur shortly following surgery.



## **Reaching our Kids...physically and spiritually KARATE FOR ALL**

As parents of hemi children, there is so much to do to "maintain" our children's needs. But what about getting them ahead? Physically, we do not know the boundaries of each hemi-child, and the question is, how will you help them to reach their greatest potential? Traditional physical and occupational therapy is often a start, but for many kids, they become bored or undriven to push themselves. We found a secret. Children's Hospital of Orange County (CHOC) referred us to one of their top therapists, who used karate as therapy. The program is called Karate For All in Tustin and Mission Viejo, CA. While it's a drive every Saturday, it has helped our daughter, Amber, use her left arm.

The occupational therap-based martial arts program works with individuals on motor, cognitive, sensory and motor skills through the practice of karate. Students are from a wide variety of age groups and ability levels. Sensei Wayne does not differentiate kids- he treats them all with respect and helps them to work hard with whatever modifications need to be made. He spoke to the parents and explained the he was inspired by his blind grandmother who raised him and taught him that everything he achieved he would have to work for. He shares that philosophy with our students.

When I asked Sensei Wayne why he has been so successful, he stated "Being occupational therapists, we are able to decipher their limitations and assist them while doing karate". For example, some students lack verbal skills and require extra prompting. Sensei explained how this is handled in a typical dojo, "A lot of these kids go to other karate places and end up standing in the corner and get yelled at. " Classes are typical karate lessons and students must follow the rules including bowing when you enter or exit the Dojo, and not speaking out of turn. Students are assisted by one-on-one volunteers who are aspiring Occupational Therapists. While he insists on offering a rigorous program, students are inspired by this safe, interactive setting.



**Sensei Jeff, Amber,  
Sensei Wayne**

Learn More at  
[www.karateforall.org](http://www.karateforall.org)



**Sharing Our Children's Stories...**

## "A Fool's Hope: Joscelyn's Journey"

On February 27th, her mother writes "You ever had one of those wars where everything goes wrong?"-  
Hawkeye, M\*A\*S\*H

When I began this blog, we hoped that our war with epilepsy, which began when Joscelyn had her first seizure at two months of age, would come to an abrupt and happy end when she underwent a hemispherectomy procedure in July of 2012. Instead, we find ourselves seven months out from that first surgery and still very much in the trenches."

To read about Joscelyn's courageous journey, go to

<http://joscelynsjourney.wordpress.com>

## "Reading Without the Left Hemisphere"

S. de Bode, Ph.D.

Chief Scientific Officer

Director of Research and Rehabilitation Programs

December 2012

A concern for any hemi parent is getting our children to read. Our world is largely accessed in print, and our ability to be even slightly independent requires that we read. The "typical" brain learns to read as an "almost exclusively left hemisphere function in the early school ages" (de Bode, Dec. 2012). However, children who have had a portion or entire left hemisphere resected also learn to read.

Dr. Stella de Bode published her research on the topic for The Brain Recovery Project. In the article, she states that preliminary data shows that the phonological learning (sounds and corresponding letters or groups of letters) is "severely impaired". It is important for parents of children who have undergone a left-sided hemispherectomy to understand that this is the method primarily taught in public schools (rather than a whole language approach). The whole language method of teaching reading involves gaining word meaning through the whole (printed) word. As Dr. DeBode notes, the "Open Court/ Imagine It! reading method should not be used as the sole method of teaching children following left-hemispherectomy surgery". Open Court is widely used in U.S. elementary schools as the curriculum for reading and writing.

To gain more information on your school district's reading/ writing curriculum (if one is used across the particular district or school), visit your local school district website.

To learn more about teaching through whole language versus phonics, visit

[http://jan.ucc.nau.edu/~jar/Reading Wars.html](http://jan.ucc.nau.edu/~jar/Reading_Wars.html)

"The Reading Wars"



## 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.

Lisa Branham - Brain Matters eNewsletter Publisher

Be sure to send all of your great ideas for newsletter stories to Lisa at [LisaB@HemiFoundation.org](mailto:LisaB@HemiFoundation.org) . Or if you want to be on the Newsletter Team, also contact Lisa.

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





## 2012 End-of-Year Giving!

Dear Hemi Foundation Supporter,

Thank You for your support of the Hemispherectomy Foundation in 2012 and Thank You for your support of children and families who have endured the most radical brain surgery in existence, to cure unstoppable cases of epilepsy. We look forward to your continued support in 2013.

Below is a list of some of the programs that YOU help fund through your generous donations.

### [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 Hemi Conference & Family Retreat and multiple regional events.

We need YOUR help again this year to continue these valuable programs. 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](http://www.HemiFoundation.org).

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



**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 [CrisHall@HemiFoundation.org](mailto:CrisHall@HemiFoundation.org).

Brain Matters eNewsletter Team  
Specialty Director, Sturge-Weber

Regional Teams (West, East, Central, Northeast, South)  
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**



*Try it FREE today.*