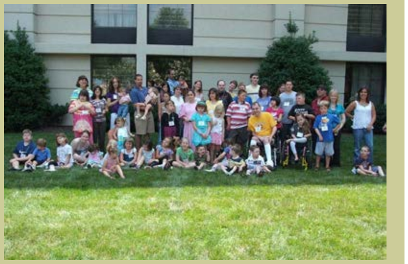
The Hemispherectomy Foundation

Brain Matters Newsletter

Good News Edition February 11, 2010



The Hemi Foundation Family Retreat Indianapolis, Indiana July 8th - 11th

Holly Paauwe, The Hemi Foundation Specialty Director of HME/CD is one busy person these days. Besides being a director at The Hemi Foundation, she also runs the HME Family Support Network, and finds time to be with her family, John, Caiden, and Avery (Left Hemi 2006, 2008 HME)

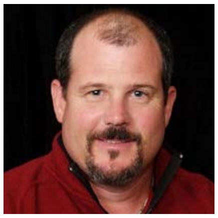
But right now Holly's focus is on putting together The Hemi Foundation Family Retreat this summer. This retreat is for everyone in the family and is going to be a GREAT chance for us Hemi families to hang-out,

Greetings!

In this issue of Brain Matters, which we are calling "The Good News Edition", I am excited to highlight some of the GREAT things that happened in 2009 and that are happening in 2010 and beyond. Much incredible work was done by The Hemispherectomy Foundation Volunteers, as well as by many other individuals and organizations that work for our kids and community, directly or indirectly.

Every time I review this list, I get more excited about the prospects of 2010 and I am honored to be able to communicate this information to you. From across the board, there is something in this edition for EVERYONE. Medical Research, Rehab, Events, Disease Specific information, and more.

This Brain Matters has a ton of valuable information, so take your time and enjoy. You don't want to miss a word, picture or link.
Hope in One Hemisphere!



Cris Hall
Co-Founder
The Hemispherectomy Foundation
and Jessie's Dad (Right Hemi, 2008

The RE Children's Project

We are pleased to report that Seth Wohlberg, one of our active parents and supporters from Connecticut, has created a non-profit organization dedicated to finding a cure for Rasmussen's Encephalitis. The RE Children's Project, as it is named, is currently working with an all-star cast of medical professionals, from top centers around the world, to lay the groundwork for this organization. I have personally been involved in preliminary meetings and phone conferences, and let me tell socialize, and enjoy the long weekend together.

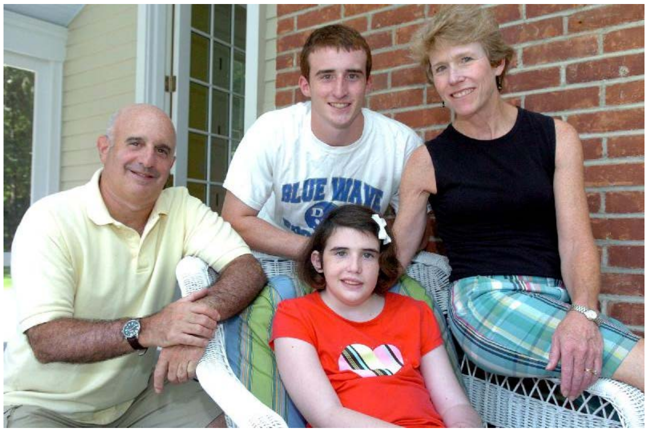
Although there will be a few speakers, this event is focused around the word "Retreat". It takes place at the beautiful [Jameson Camp in Indianapolis](), where you will feel like you are back in kid's summer camp with no cares in the world. Camp Fires and Cabins will take you back to summer camp and build treasured memories. Although you may feel like you are miles from nowhere, this camp is near all the modern conveniences that we need for our special families. And if Summer Camp isn't your thing, you can always stay at a nearby hotel and come out for the family activities. It's close and convenient.

There will be a special surprise this year, as the Epsteen Family will be filming The Hemispherectomy Foundation Family Video to be used for Public Relations, Education, and New Family Support.

you, it is an impressive undertaking. Expect big things from The RE Children's Project in 2010 and beyond.

Their kick-off and seminal organizational meeting is a conference planned for later in the year. As the project gains commitments from neurologists, neurosurgeons, geneticists, immunologists and other cross-functional specialists, ideas are beginning to flow in defining the problems that exist, and how to approach them. They are looking at new and innovative ways to approach the problem, as well as some other stategies that have been successful with many other diseases. There have been discussion about an international brain tissue bank, genome mapping, and shared resources across hospitals and research centers.

As Mr. Wohlberg said, "The purpose of the organization is to increase awareness concerning Rasmussen's Encephalitis (RE) with the express purpose to support and foster research directed toward finding a cure for the disease. The organization will also support research dedicated toward the recovery process following hemisphrectomy surgery with the goal of assisting individuals with RE and their families cope with the life altering consequences of this radical surgery. As part of it's mission, the Project will offer educational, emotional, and financial assistance to the families of individuals with Rasmussen's Encephalitis."



Mr. Wohlberg's daughter underwent a Hemispherectomy in 2009 for Rasmussen's Encephalitis.

For More Information Contact : Seth H. Wohlberg 212.840.1341

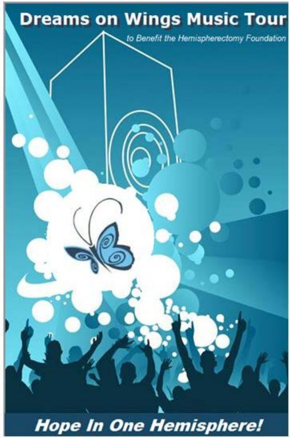
email: swohlberg@farhills.com

Sturge-Weber Research Announced

The Sturge-Weber Foundation Announces Major Leap Forward In Sturge-Weber Syndrome Research

We hope to see ALL of YOU there in July!

[For More Info, Click Here]



The Hemi Foundation Dreams on Wings Music Tour

Jane Stefanik, The Hemi Foundation Northeast Regional Director, has put together an exciting musical event, featuring some outstanding musical guests from her area. It will be a family-friendly event, so COME ON OUT!

The Event will take place on Sunday, February 28th at 3:00PM at Bourbon Street Near Downtown Baltimore.

The performing bands will be Starcrush, Broadcast, and Quikfire and will be emceed by Tyler Daniel from 103.7 FM.

Some special give-aways include AirTran Airline Tickets, Baltimore Orioles Autographed Ball and Glove, and Much More!!

The Sturge-Weber Foundation (SWF) announced it will actively participate in the Brain Vascular Malformation Consortium, which will focus on three related disorders - Sturge-Weber syndrome (SWS), Hispanic mutation familial cavernous malformations, and hereditary hemorrhagic telangiectasia. The inclusion of Sturge-Weber syndrome and the SWF in this prestigious research effort marks a significant leap forward for SWS research. The foundation has maintained a database of natural history since 1987 which provided documentation for further studies on DNA and angiogenesis in SWS.

"This grant has been made possible because of many dedicated families, volunteers, physicians and crucial financial support of the SWF's endeavors to improve the quality of life for our members," said Karen Ball, president and CEO of the SWF. "With their enduring commitment and financial support, the SWF will continue to lead the fight on behalf of our members to increase the pace of discovery in our rare disease."
The consortium is part of the newly-announced expansion of the Rare Diseases Clinical Research Network (RDCRN), which is under the umbrella of the Office of Rare Diseases Research (ORDR) at the National Institutes of Health (NIH). NIH recently announced that 19 new and returning consortia will be awarded $117 million for research. The RDCRN was created to address the difficulties inherent in rare disease research. The RDCRN fosters collaboration amongst researchers, actively involves patient advocacy groups in the research process and creates a specialized infrastructure to support rare disease research.
To Read the Rest of this Article Click Here

SOURCE: The Sturge-Weber Foundation
Contact for Sturge-Weber:
Rachel Waters
Aiden's Mom, Right Hemi in 2008 for Sturge-Weber
The Hemispherectomy Foundation
Specialty Director, Sturge-Weber Sydnrome
Rachel@hemifoundation.org

CHASA

CHASA - The Children's Hemiplegia and Stroke Association

So if you live in the Washington D.C. or Baltimore Area, or within driving distance come out and listen to some good music and support The Hemi Foundation.

Cris and Kristi Hall, Co-Founders of The Hemispherectomy Foundation, are flying in from Texas for the event and hope to see you there.

For More Info, Click Here
or Contact :
Jane Stefanik
Jane@Hemifoundation.org

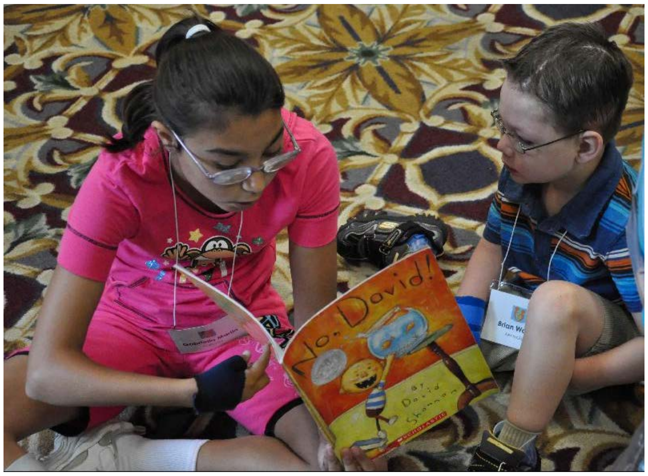
DREAMS ON WINGS 5K
2010
Parker County, Texas
WWW.HEMIFOUNDATION.ORG

The Hemi Foundation Dreams on Wings 5K and 1 Mile Fun Run

The Hemispherectomy Foundation and Parker County Physical Therapy will host a 5K and 1-mile fun run/walk on Saturday, May 15. "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

When my daughter, Allison, was 7 months old the internet was young. My brother, being the first in our family to jump on the "information superhighway", found a bulletin board with a couple of moms posting questions back and forth and discussing their children with Hemiplegic CP (Cerebral Palsy) resulting from perinatal stroke. I quickly had my husband hook me up via his work laptop and found the opportunity to share similar experience, and discuss issues related to my daughter's stroke and resulting health issues.

It was wonderful to be able to voice concerns to others who understood from personal experience what my child and my family were dealing with, especially at this very early stage. This was the most amazing thing that could have helped and happened to us. One of the Moms who reached out and starting making these connections was Nancy Atwood. Being able to communicate with Nancy and others from across the country and know that we were not alone in our experiences, concerns, fears, challenges and triumphs was the best kind of support I could have hoped for. One of the most informational and comforting aspects of the email list in the early days was the opportunity to ask questions to an adult who had grown up with hemiplegic CP and ease some of my concerns for Allison's future. We were not alone.



The group of families grew and, with Nancy at the reins, became The Children's Hemiplegia and Stroke Association, or CHASA. (www.chasa.org). Today, CHASA has an email family discussion group of over 1590 members from all over the world. CHASA holds a yearly family retreat in various areas of the country, posts updates on research and clinical trials, seizures, hemiplegia and speech/language challenges, to name a few. Mostly, CHASA is a place to turn for support and information when a family finds out that their child has suffered a stroke.

When we found out that Allison needed a Functional Hemispherectomy for seizure control, The Hemispherectomy Foundation was not yet established. I hooked up with Nancy Geshke, The Hemispherectomy Foundation's Eastern Regional Director, who was then heading up a new parent support group for families facing Hemispherectomy at the Cleveland Clinic. Nancy was a "been there, done that" parent devoted to helping other families through this very difficult time. I know how important it is to have a network of support through such a

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.

"The 2009 Dreams on Wings 5K was a great success! The foundation was able to raise just over $7000 for the children that we support. Best of all, 10 families with children that have undergone hemispherectomy surgery attended the race! Not one family had ever met another family that has walked in their shoes! Can you imagine that?," said Kristi Hall, race chairwoman and president/ CEO of The Hemispherectomy Foundation.

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 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 for the largest Corporate, School and Family Teams.

trying time and I am so pleased to be a part of the Hemispherectomy Foundation and to have the opportunity to help provide assistance to families facing Hemispherectomy through my personal experience and to be a member of this group that is helping so many families cope with this complex journey. Utilize this amazing resource and, if your child has suffered a Pediatric Stroke, check out www.chasa.org.

Barbara Frazier
The Hemispherectomy Foundation
Specialty Director, Pediatric Stroke
Barbara@hemifoundation.org

CURE Awards Innovator Research Grant to Study Rasmussen's Encephalitis

CURE (Citizens United for Research in Epilepsy) Announces its 2010 Research Innovator Award to study Rasmussen's Encephalitis. Mr. Lionel Carmant, from the University of Montreal, received an Innovator Award this year from CURE for his Innovative research approach into the perplexing world of Rasmussen's Encephalitis. CURE awarded this One-year grant to support his exploration and highly innovative new concept to an important problem relevant to Rasmussen's Encephalitis and epilepsy, in general. The abstract of his research project is listed below.

Congratulations and Thank You Mr. Carmant and Thank You CURE!

"Rasmussen encephalitis (RE) is a rare but severe brain disorder that starts in childhood with seizures that become more and more frequent and progressive weakness of the affected side. The mechanism of RE are still not well understood, even if some experimental data suggest an immune mediated disorder.
By injecting RE patients' blood cells to very immunocompromised mice, we induced seizures and pathological findings in brain similar to pathological lesions observed in RE patients. Moreover, we have demonstrated that our data are reproducible with frozen patients' cells, making our strategy more feasible. Preliminary data tend to show that RE is immune-mediated and that seizures are due to the release of inflammation products followed by an infiltration of white blood cells in the brain.
This model should allow us to identify the cells responsible for the disease and to precise the immunophysiopathology of this rare disorder. Moreover, this new model could provide a useful tool to test therapeutic strategies for this."

Contact for Rasmussen's Encephalitis:
Lynn Miller
Jody's Mom, Right Hemi in 1993 for Rasmussen's Encephalits

Participants can register online at www.hemifoundation.org (no fees!) or download registration forms. Early registration ends May 9. 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. **New this year!** Sleep in and get the t-shirt! Virtual Runner $30. 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.

For More Info, Click Here or Contact :

Kristi Hall

Kristi@Hemifoundation.org

On Our Website

Read stories of hope about our families on hemifoundation.org

Our Mission

To Encourage and Support impacted families by connecting them with other families who have had a hemispherectomy or similar surgery.

The Hemispherectomy Foundation
Specialty Director, Rasmussen's Encephalitis
Lynn@hemifoundation.org

Summary of Rehabilitation Program, Netherlands

Dear Families;

Many of you know me from UCLA and USC, this summary is for both those of you I have met and those I only hope to meet one day through our work in rehabilitation. It is with great love and gratitude that I am using this opportunity to address all of you. Working in this field is the most amazing experience as you and your kids teach me courage, strength and dignity. All of this I needed when I had to undergo brain surgery and debilitating seizures in 2001. I feel that experiencing this brought me even closer to what our kids have to go through. I feel blessed to be a part of this community!

Professionally, I have been focusing on brain reorganization, particularly after cerebral hemispherectomy, for the past 15 years. I am trained as a neuroscientist with major interests in language and motor systems. While trying to understand what happens to the brain when one hemisphere is gone, I am also attempting to understand how we can maximize the potential of the remaining hemisphere.

Following my graduation at UCLA I joined the Department of Neurology where together with Drs. Mathern and Dobkin we pioneered the first ever rehabilitation program for children after hemispherectomy. We aimed to provide intensive task-oriented therapy for a group of 20 hemispherectomy individuals related to gait functions and relate them to fMRI before and after intensive physical therapy. The question being asked was whether walking with a hemiparetic gait can be improved with neurologically-informed and intensive physical therapy, and does this show an fMRI (brain imaging) correlate. This unique study took place at the University of South Carolina (2005-07) where I was offered excellent rehabilitation facilities and a Faculty position.

We are expecting to publish the results of this study this year. It is clear that our therapy, Intensive Mobility Training including elements of Body Weight Supported Training was successful and, may be, a few families who participated would be willing to share their experience with us all.

I am also pursuing volumetric studies to explore whether there is atrophy and/or augmentation of gray and white matter in the remaining hemisphere. This is a challenging task because we have to account for brain deformation one often sees following illness, seizures and hemispherectomy. The next step will be to explore whether changes in the brain volume have functional meaning, i.e. atrophy of the remaining hemisphere is associated

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 hemifoundation.org

Donate

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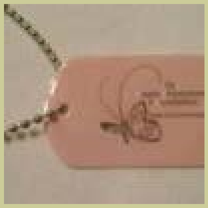

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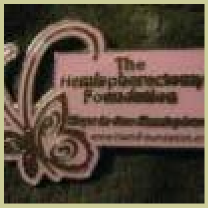

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with more profound deficits and, if so, how we can introduce interventions that would reduce atrophy process.

In 2007 I was offered the opportunity to start a rehabilitation post-hemispherectomy program in Europe, in the Netherlands.

In 2008 we started the intensive program aimed to improve the paretic side's function and bilateral coordination in Dutch and German children after hemispherectomy. My main concern is that therapy in our children will be affecting only one hemisphere. At this point it is not completely clear how cortical representations of the two sides of a body share cortical representations in the hemispherectomized brain. This is why we do therapy together, therapists in the St Marten's Clinic, Nijmegen, and my colleagues and I at the University Medical Center Utrecht. Our program is 3 week long, in-patient, and consists of 8 hours a day. Children loved it! This year we will start regular post-hemispherectomy therapy training for all children who come from the European Union. The idea is to repeat this pulse of therapy (perhaps, of a shorter duration) every year to prevent limb shortening and muscle atrophy.

One of the conditions when I accepted this job was to make it possible for the US families to participate in our programs (gait therapy is to follow). Right now I am going around finding out who may be willing to share costs for the US families.

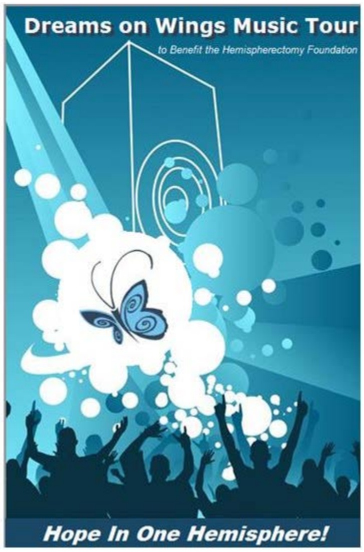
I realize this is anything but trivial to bring a child transatlantically for treatment. My hope is that with our future developments one day I will be able to find a similar setting back home (in the US) and bring back my experience to all of you.

Stella de Bode, PhD (UCLA)
Current Position: Ass Prof & Sen Researcher at the University Medical Center Utrecht, Netherlands
E-mail <sdebode@ucla.edu>
Specialization: brain reorganization following pediatric surgery

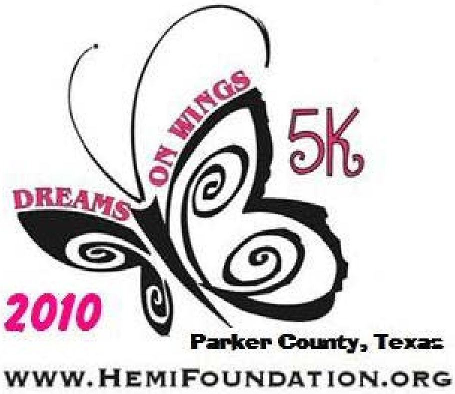
There will be a Medical Conference devoted entirely to Hemispherectomy that is currently slated for September 2010. More Details will be communicated as they unfold.

More from Dr. de Bode's letter in the next issue of Brain Matters.

Upcoming Events



More information about the [Dreams on Wings Music Tour]



More information about the [Dreams on Wings 5K Run]

More information about the [2010 Family Retreat in Indianapolis]

Contact The Hemispherectomy Foundation

The Hemispherectomy Foundation

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