



# The Hemispherectomy Foundation Brain Matters Newsletter

March 4th, 2010



## [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 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

## Hemi Foundation Dreams on Wings Music Benefit a Smashing Success!!

OK, I have to admit to you that It's been a long time since I've been to a bar to listen to Rock-and-Roll. But I must admit that I felt 20 years younger and had the time of my life at the Hemi Foundation Dreams on Wings Music Benefit in Baltimore last weekend. Broadcast and Starcrush rocked Bourbon Street in downtown Baltimore as Hemi Foundation supporters came out to have a FUN and Exciting time raising money for The Hemi Foundation.



Jane Stefanik, Hemi Foundation Northeast Regional Director, did a marvelous job organizing the event. Even her girls, Samie and Nickie joined in to make sure the day was one to remember.



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.

Participants can register online at [www.hemifoundation.org](http://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

Jane was an outstanding host and made sure EVERYONE had a Good Time!



Dr. Adam Hartman, Neurologist from Hopkins, joined us for the event and accepted a plaque in memory of Diana Pillas. During the dedication, Kristi and Cris read memories, about Diana, from Hemi Families all over the world.



Al, Jody, and Lynn Miller joined us for the event. Al showed us his best moves, but couldn't compare to Jody's years of dancing. (Jody, Right Hemi 1993, Rasmussen's Encephalitis and currently a sophomore at Eastern University in Pennsylvania) - pictured above.



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](mailto:Kristi@Hemifoundation.org)



[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

Also, the Norwood family joined us for the event. Mary Beth, Katie, Stephen, and Dylan (right to left) stand with Jane Stefanik. Dylan had a Right Hemi in 1994 due to seizures from a stroke. He is currently in High School and working on his Eagle Scout, which may just involve The Hemi Foundation.



Starcrush Rocks Out with 90's and 21st century Rock Tunes!



We had lots of Awareness material for everyone, including a live demo of the website, and lots of materials for people to take home.

By the time everyone left, we had many people who wanted to help and participate in next year's Hemi Foundation Dreams on Wings Music Benefit. We saw old friends, and met some new ones.

Most importantly, however, we raised the awareness of Hemispherectomy Brain Surgery and got some people excited about a group of children that often get overlooked.

We received some GREAT Hemi Awareness coverage from WJZ-TV Baltimore. You can read and watch the News video that showed several times over the weekend on the WJZ Website, or [Click Here](#).

You Rock Jane! We can't wait until next year!!!

*All Money raised for this event will go to benefit children and*

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, 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

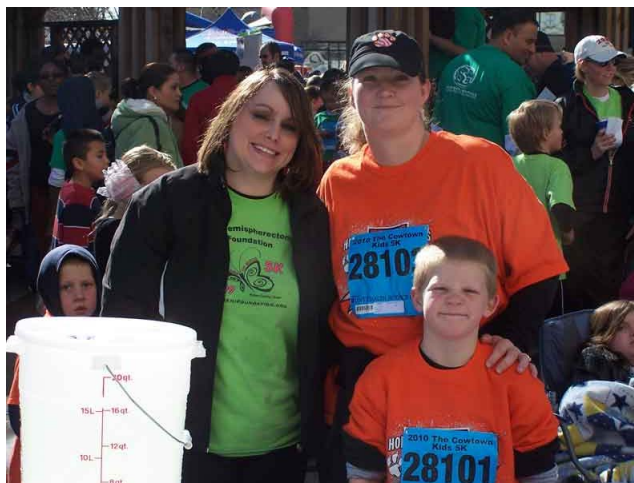
families who have faced or will face hemispherectomy surgery. Programs include this summer's Family Retreat in Indianapolis, Hospital Hemi Hug Care Packages, Scholarships, Financial Assistance, and Medical Research.



## Hemi Foundation Volunteers Work Cowtown Marathon for Hemi Awareness



While the Baltimore Volunteers were rocking out at the Hemi Foundation Dreams on Wings Music Benefit, some of the Texas Hemi Foundation Volunteers were raising awareness in the Dallas - Fort Worth Area.



Sherame Anderson, Shane Anderson, Ryan Anderson, Caden Anderson, Sue Larue, Laura Rasnick, Travis Rasnick, Katelyn Rasnick, and Lindy Shelton braved the early morning cold, and 30,000 runners as they worked a fluid station at the 2010 Cowtown Marathon Races. They were lucky enough to get to work the largest of the races, the 5K, where thousands of runners were hydrated by The Hemi Foundation.

Foundation Family Video  
to be used for Public  
Relations, Education, and  
New Family Support.

We hope to see ALL of YOU  
there in July!

[For More Info, Click Here](#)



### **International Hemispherectomy Workshop**

**Sept. 29th - Oct. 2nd,  
2010**

**Utrecht, Holland**

*(continue from Previous Edition of Brain  
Matters, Article by Stella de Bode, PhD)*

Another topic I wanted to share with you is the fact that we are organizing the **First International Hemispherectomy Workshop, "Why Would You Remove Half a Brain?"** in 2010 (9-29 to 10-2). I already have UCLA, Cleveland and John Hopkins confirming their participation in addition to a number of European centers. We will discuss all aspects of hemispherectomy: from indications, techniques and how not to miss a child who can clearly benefit from such surgery to outcomes and therapy. We will also hold a satellite session for parents. I have high hopes for this workshop. I hope it



In addition to proudly displaying a Hemi Foundation sign, The Hemi Foundation is listed on [The Cowtown Marathon Website](#) as a Fluid Station Participant.



Also, [Lukes Locker](#) (Hemi Foundation Dreams on Wings Sponsor) was there promoting the Hemi Foundation Dreams on Wings 5K coming up on May 15th. We look forward to seeing many of you there.



Thanks Texas Hemi Foundation Volunteers for getting the word out about Hemispherectomy Brain Surgery and all of our wonderful families. We couldn't do this without YOU!

will unite all of us around the globe to look together for even better information and methods. I believe, this will translate into new approaches and, ultimately, more saved lives, better quality of life for more children. I would like to invite you to spread a word to your neurologists and therapists about our Workshop in the University Medical Center Utrecht.

Utrecht is one of the largest Dutch cities and is only 40 minutes from the Amsterdam airport. If you decide to come and need a place to stay you are always welcome in my house! I am considering opening a forum to collect your questions and concerns so that a panel of specialists during the workshop would answer the most frequent questions. If you think this is a good idea, please, write to me, and I will collect and process all questions.

Thank you all of you, my warmest wishes in 2010 and much love,  
Yours, Stella

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

On Our Website



## Our Hemi Family Today Show Appearance Tomorrow !

Our very own Cameron Mott will be making an appearance on The Today Show with Matt Lauer and Meredith Vieira tomorrow (Friday, March 5th). No Really!!!

As long as there aren't any breaking news stories, it should air. I know that many of you have been waiting on this.

For those of you who do not know Cameron, she is one of our GREAT Hemi Kids who underwent hemispherectomy back in 2007 due to intractable seizures caused by Rasmussen's Encephalitis.

I'm sure that Cam will steal the show, but watch for Dad Casey, Mom Shelly, and little sister Caroline as well. So set your DVRs.

Cameron (2nd from left, with her buddies Hanna, Abby, and Jessie) .



## The Hemi Foundation Needs YOU !

The Hemi Foundation has made amazing progress in the past 2 years, but, since it is a volunteer organization, we need YOUR help.

If you've always wanted to share your talents for a GREAT cause, please joining us. No matter how little you can volunteer, any amount of effort is appreciated.

But what can I do?

Below is a list of current areas where your volunteer efforts can make a difference. We would love to have you on one or more



Read [stories of hope](#) about our families on [hemifoundation.org](http://hemifoundation.org)

### 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) [hemifoundation.org](http://hemifoundation.org)



[Support Hope in One Hemisphere.](#)

### Visit Our Store



[Support the Hemi Foundation by visiting our store.](#)

of the teams, no matter how small or large your time contribution. If you would like to help, please email me at [Cris@Hemifoundation.org](mailto:Cris@Hemifoundation.org).

Reunion Committee  
(2010 - Indianapolis, 2011 - LA, 2012 - Baltimore, 2013 - Texas)  
2010 : Chair - Holly Paauwe  
2011 : Chair - Rachel Waters  
2012 : Chair Needed  
2013 : Co-Chairs - Cris and Kristi Hall

Brain Matters E-Newsletter Team and Other Communications / Constant Contact  
Lead : Cris Hall  
Team : Kelly Dawson, Kristi Hall

Website Team  
Lead : Rachel Waters  
Team : Cris Hall, Kristi Hall

Grant Team  
Lead : Lindy Shelton  
Team :

Northeast Region Team  
Lead : Jane Stefanik  
Team : Holly LeFevers, Randi Scanlon

Easter Region Team  
Lead : Nancy Geschke  
Team :

Central Region Team  
Leads : Needed  
Team : Cris Hall, Kristi Hall

Western Region Team  
Lead : Rachel Waters  
Team :

HME / CD Specialty Team  
Lead : Holly Paauwe  
Team :

Pediatric Stroke Specialty Team  
Lead : Barbara Frazier  
Team :

Rasmussen's Encephalitis Specialty Team  
Lead : Lynn Miller  
Team :

Sturge-Weber Syndrome Specialty Team  
Lead : Rachel Waters  
Team :

Any Other Areas where you have Talents and would like to Share Your Talents?  
Hope in One Hemisphere!



## Meet Our Medical Advisory Board

[Read about Doctors from the U.S. and Canada who make up our Medical Advisory Board.](#)

[Join Our Mailing List](#)



## Upcoming Events



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  
PO Box 1239  
Aledo, Texas 76008  
817-307-9880



Try it FREE today.