



# BRAIN MATTERS

May 25, 2009

## In This Issue

[Camp Tuition Assistance Program](#)

[Scholarship](#)

[Upcoming News](#)

[Dreams on Wings 5K](#)

[Texas BBQ](#)

[California BBQ](#)

[Spotlight Abby Dawson](#)

[Hemi Conference](#)

## Camp Tuition Assistance Program

The Hemispherectomy Foundation is proud to offer the CTAP (Camp Tuition Assistance Program) to children who have endured hemispherectomy surgery.

This program is designed to help families with the tuition expense associated with sending their child to a quality camp.

Greetings!

This month [The Hemispherectomy Foundation](#) has been all about bringing people together. With large groups of people come courage, power, and influence. Hemi Families, Doctors, Communities and Volunteers have come together this month to make some incredible things happen, all for the benefit of our families and those families who are yet to come. Many of these things are highlighted in this month's eNewsletter.

This month, we had a meeting with the chairmen of [The Hemi Foundation Medical Advisory Board](#), Dr. Mathern and Dr. Cohen. We had our big Texas fundraiser : [The Texas Dreams on Wings 5K](#) and we hosted the [Texas Hemi Family BBQ](#).

On the 30th of this month will be the first annual [Hemi West Coast Family Picnic](#) in Los Angeles, California. Finally, on July 9th - 12th, the idea of "the power of people coming together" will be on grand display with the [Hemispherectomy Conference and Family Reunion](#) in Baltimore, Maryland.

Each time we are with other families we feel the incredible bond that we share and the power that resonates from that bond. Although we have not met all of you, the staff at The Hemi Foundation hopes that you can feel some of that energy from this newsletter and that you can share with us the HOPE that it brings.

Hope in One Hemisphere!

Kind and Warm Regards,

Cris Hall

There are no restrictions as to the type of camp the child attends, the goals of the camp, nor the financial state of the family. Applications can be found [here](#).

### The Jessie Hall Hemi Scholarship

Last year the Hemi Foundation awarded three college scholarships to deserving young people to further their post-high-school education.

The application deadline for 2009 is rapidly approaching.

Please submit your application soon. Information may be found [here](#).

### Spotlight Inspirations & Stories

Meet some of the kids and families that inspire us EVERY DAY!

Read their stories and get to know them. You'll learn some amazing things about these kids and a little about yourself.

VP and CFO  
The Hemispherectomy Foundation  
[Cris@HemiFoundation.org](mailto:Cris@HemiFoundation.org)



## Dreams on Wings 5K

INAUGRAL DREAMS ON WINGS 5K TAKES FLIGHT



Jessie Hall (center) sounds the bull horn for the 5K race at The Hemispherectomy Foundation's Dreams on Wings event on Saturday, May 16.

The inaugural Dreams on Wings 5K in Weatherford, Texas held on May 16, 2009 dawned gray and WET. Despite a steady rain, runners and walkers laced up their running shoes and lined up to support The Hemispherectomy Foundation. Many thanks go to our major sponsor, Parker County Physical Therapy, for opening their doors to allow a dry place for pre-and post-race activities!



## Medical Advisory Board



The Hemispherectomy Foundation Medical Advisory Board is hard at work for the The Hemispherectomy Foundation. Meet them at : [The Hemi Foundation Website](#) or the [Medical Advisory Board webpage](#) .

## Related Links

[The Hemispherectomy Foundation](#)



***The Hemispherectomy Foundation is Dedicated to Children and Families who are Impacted by Hemispherectomy Brain Surgery.***

***The Hemispherectomy Foundation is a 501c3 Non-Profit organization that provide college scholarships, trade school scholarships, camp fees, life-aid equipment, travel expenses, and other aid as approved by the officers.***

**The foundation is also dedicated to hemispherectomy education, awareness, fundraising and**

Pictures honoring the children were to line the race course but due to the rain, were placed throughout the therapy center.



Following the race, many runners and walkers gathered inside Parker County Physical Therapy to enjoy some great post-race food and attend the awards ceremony. The Dreams on Wings 5K was a HUGE success! Proceeds raised will sponsor seven families for the July Hemispherectomy Reunion/Conference in Baltimore, a scholarship and camp tuitions! The BEST part is that ten special families from all over Texas and Oklahoma were honored at the event. Feedback from the parents has been incredible!



The rainy weather did not slow down these kids! Several "Hemi Kids" walked the Dreams on Wings 5K with family and friends.

The Dreams on Wings 5K started as a fundraiser. Instead, this event soared high and became much more than anyone could have imagined. Everything that happened on May 16, 2009 was a compilation of what the Hemispherectomy Foundation is all about: Supporting families by providing a setting where they can meet and talk to others that are walking in their shoes; providing a fun event that parents feel

research of the medical conditions that lead to surgery and the surgery itself.



Help a Child Now.

Just \$10 will make a difference.

This Donation, Plus 2 minutes of your time will change lives.



OR

If you're looking for other opportunities to help The Hemispherectomy Foundation, [Click Here](#)

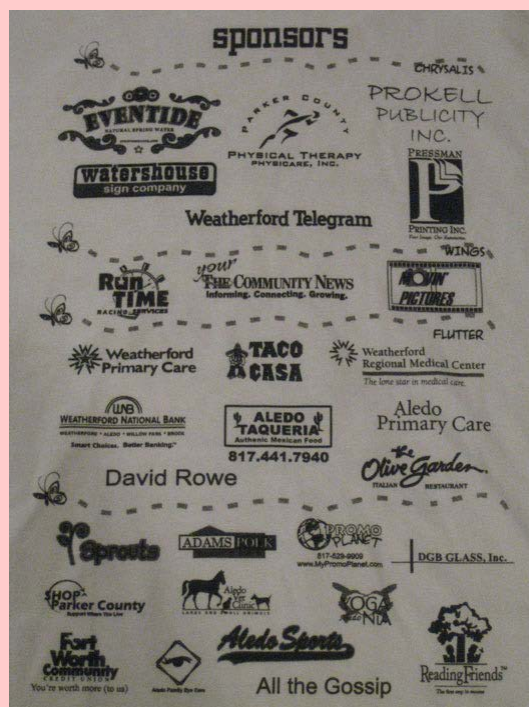


Check out :

comfortable bringing their child to - where everyone understands issues and limitations; a vehicle for raising awareness of these miracle children in our communities; and finally, a fundraiser of monies to be used to support these children, to provide scholarships, camp tuitions, life aids, and research.



Special certificates were presented to our honorees. A big TEXAS THANK YOU to all our sponsors that supported the inaugural Dreams on Wings 5K event. This race had, without a doubt, the BEST post-race food and goodie bags seen in North Texas!



Plans are already underway for the 2010 Texas Dreams on Wings 5K. If you are interested in learning more about hosting a Dreams on Wings 5K event in your area or would like to sponsor or volunteer for the 2010 Texas event, contact Kristi Hall at [kristi@hemifoundation.org](mailto:kristi@hemifoundation.org).

The  
Hemi  
Emporium

Get gear to proudly display  
your support of  
The Hemi Foundation.

Sign Up NOW to get your  
FREE subscription to :

Brain Matters

Information packets will be available soon.



## Texas Hemi Family BBQ

By: Caren Jennings

**You've heard it said that Texans do everything BIG, and so that is exactly how it went down on May 16th in Aledo, Texas.**

After a rain soaked, but highly successful race, our VIPs met at Cris and Kristi Hall's house for a BBQ and old fashioned reunion. It didn't take long for everyone to get to know one another. We had such a great time sitting around the pool talking, eating and watching the kids swim. There were water guns, bubbles and candy galore- and the children all seemed to have a fun and eventful afternoon. A poster sized picture of each child being honored was placed around the pool, and that was a warm sight for all to see. A special birthday cake with our logo on it marked the 1st Birthday of The Hemispherectomy Foundation. We had Ty Lawson blow out the candle and all sang Happy Birthday. After the cake and ice cream, we held a drawing for all families in attendance and everyone won something nice. That was really fun- and all of the prizes had been donated.

This was the first time most families had ever met another hemi child other than their own. Scott Apitzsch commented how miraculous it was to see his daughter Abby playing with other children, who had the same struggles as she. Abby was not 'the only one' and she was making new friends also dealing with the after effects of hemispherectomy surgery.



For the Aledo Hemi Foundation team, it was a privilege to finally meet some of the families we serve and the children we've grown to care for. Each team member commented on how amazing it was to feel such strong family ties to those previously known only through emails and pictures. Truly, it was a remarkable day!

One of our VIPs was Ty Lawson, the Oklahoma cowboy with his cute smile and sense of humor. He won everyone over with his personality and sweet disposition. We'll never forget that fabulous picture of him in his cowboy hat! Ty's Mom Karla had purchased a new digital camera just for the trip, then won a photo color printer in our drawing and couldn't believe her good fortune!

After running the race AND swimming for hours, Alyssa Gomez was exhausted! She snuck in a little nap, only to be awakened that she'd won an American Girl doll! Alyssa's family came up from Houston. Alyssa LOVED that hot tub and was turning into a beautiful raisin.



Reagan Tumlinson came the furthest- from Rockport on the South Texas coast. What a precious little baby girl! Rumor has it that a certain foundation worker got to feed her lunch and was the envy of the rest of the team. Jim Tumlinson had a smile on his face the entire time- we've never seen a Marine smile so much!

Gabby Yambo, with her thick, long, beautifully curly hair, came with her own private entourage - Chris and Jaime Buccambuso traveled from Plano to honor Gabby for the day. Gabby loved swimming and playing with the other children. Krista Yambo sat pool side and held court with Ricky and most of the foundation team.

It got kind of exciting when Noah Apitzsch fell into the pool, only to have 2 men dive in to save him. YIKES! Thanks Rick and Chris for saving that cutie patootie!

Abby Apitzsch, the oldest VIP in attendance and true socialite, made a number of friends and promised to come back soon for sleepovers. Scott Apitzsch taught us all about Woody's in Centerville- the best place in the

world to get your jerky fix. He kept us in stitches with his fun stories and great laughter. Tammy was so much fun to talk to and glean advice from.

Jessie Hall was the perfect little hostess to all her new friends. Graciously, she shared her pool and brothers with everyone. (Emphasis on the brothers!) Cris was at the grill making cheeseburgers and hot dogs and made sure everyone was having a good time. Kristi saw to it that everyone had plenty to eat, while mingling with all her new friends and exchanging valuable insight.



Gabby Perrin hung out in the pool with her sisters and brother. Gabby has the blondest hair and the most adorable smile ever! Her Mommy Dwan is amazing and the whole family came out to run the race in honor of her.

Abby Dawson from South Carolina wasn't present, but her Aunts from Austin were there in her honor. Lori Davis and Leigh Ann Sedum were having a great time meeting all the families and getting to know the kids.



A miraculous story we need to share is how one family in Allen, just hours before, heard on the radio that we would be having a race for the foundation. This family contacted Kristi Hall and made arrangements to come to the BBQ. There they were able to meet with Dwan Perrin whose daughter Gabby had a hemi for the same reason as their daughter was in need of. This family was

terrified for their daughter to have a hemi, and yet after speaking with Dwan, they left feeling comforted and having HOPE that their daughter could do as well as Gabby. It was utterly amazing to see this interaction take place as we were gathered having our BBQ.

We were so blessed to enjoy our first Texas Reunion with incredible families, beautiful children and the best foundation team around! Fortunately, we were able to have everyone's hotel room donated and a special Hemi Angel personally made amazing gift baskets that were waiting in each guests room. Many parents were talking about and making plans for the next reunion. It was hard to see everyone leave, after such an emotionally charged day, but we look forward to 2010 and the promise of a longer get together with more time to chat, laugh and brag on some pretty incredible children- we call our Hemi Heroes.



## California Hemi Family BBQ

**WHAT:** Picnic in the Park honoring hemispherectomy children in California.

**WHEN:** Saturday, May 30 at 1:00 p.m.

**WHERE:** Shane's Inspiration at Griffith Park located at 4800 Crystal Springs Road in Los Angeles

The Hemispherectomy Foundation is holding its first annual event in Los Angeles for families on the West Coast. Eleven families with children, teens and young adults who have undergone a hemispherectomy (removal of half the brain) will come together in a



fantastic opportunity to meet new friends in the hemispherectomy community. Families will visit and share experiences with one another and also have the opportunity to speak with neurosurgeons Dr. Gary Mathern of Mattel Children's Hospital at UCLA and Dr. Moise Danielpour of Cedars-Sinai Medical Center.

There will be food, entertainment provided by Send in the Clowns of Los Angeles and the L.A. Fire Department. Hemispherectomy patients will be honored with a certificate and a photo poster. Prizes and gifts will be given to all the children. Most importantly, these families will meet other families who can relate to having a loved one go through this life changing brain surgery.



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## Spotlight: Abby Dawson



Abby Dawson was a typical two and a half year old girl when her mother received a phone call that changed the life of their family. The call came from their daycare provider informing them that Abby was acting very oddly. Her mother, Kelly, arrived to find a perfectly normal little girl, but agreed

to take her to the pediatrician. The pediatrician found nothing to be alarmed about, but urged Kelly to watch Abby carefully and call back if there were any more episodes. About an hour later Abby sat in a stroller, and turned to look at her mom with absolute fear in her eyes. Her arm contracted, and began to shake, and Abby began to drool. This was the first obvious sign to Abby's parents that something was very wrong.

At first the diagnosis was epilepsy and medication was prescribed. Within a couple of weeks, however, the seizures would not be controlled, and Abby spent 3 weeks in the hospital with seizures every 3 to 5 minutes. Doctors began many tests and discounted many possible theories. The Dawsons were sent home with

the possibility of a terminal enzyme deficiency, or Rasmussen's syndrome. Brian and Kelly were told to call if Abby started to limp, or if she stopped using her left arm - this was a few days before Christmas. Two days after Christmas, while at dinner, Abby scooted her heavy drink glass into the crook of her elbow and tried to pick it up without using her left arm. The next day she began to limp. Their local hospital was unable to perform the necessary tests and surgery for Rasmussen's and they were referred to the Medical College of Georgia where they met Dr. Yong Park.

Dr. Park guided the family through this very difficult time. No medication was holding off the seizures, and Abby was experiencing many different types of seizures. A subsequent MRI compared with her previous ones showed areas missing from the right side of her brain. The decision was made by New Year's to perform a right functional hemispherectomy.

Towards the end of January, 2004 Abby underwent surgery, and awoke with different possibilities. Her body was no longer controlled by the seizures, but it also couldn't move on the left side. Beginning with swallowing, and then turning her head, and gradually moving on to other movements, Abby began her therapies. By the end of the week she could stand with assistance and sit up for about an hour at a time. She was able to return home after two weeks in the hospital, and inpatient rehabilitation in Atlanta.



Now seven, Abby is an energetic student in a regular first grade class. She still hasn't had a seizure since waking up from surgery. She is an active member of her Brownie troop, and

plays tennis on weekends. In the summers she participates in swim lessons and meets. Most people who meet her are impressed with her abilities, and captivated by her humor. She continues occupational and physical therapies. Her parents put few restrictions on any activity she may want to try and feel that Rasmussen's no longer rules their lives.

Family blog: <http://www.dawsondiaries.blogspot.com>  
Click on the Rasmussen's button at the top of the page to read current updates about Abby.



## Hemi Conference and Reunion Baltimore Maryland

Time is running out to register for the 2009 Hemispherectomy Conference and Family Reunion.

Check out this year's agenda, activities, and more, click on the following link : [2009 Hemispherectomy Conference and Reunion Website](#)

At this year's conference :

- \* Meet other families who have children like yours and make life-long connections and friendships.
- \* Listen to expert doctors and speakers on topics that are applicable to you, your family, and your children.
- \* Learn from the older kids and families.
- \* See your children's art work on display.
- \* Swimming Party.
- \* Talent Show.
- \* Sibling Workshops.
- \* Children's Activities.
- \* Enjoy Baltimore's [Many Attractions](#)
- \* Check out our [Nation's Capital](#)

Only \$99 for Adults and \$69 for Children

[Register Now](#) !! for an experience that you will never forget.

Warm Wishes and Hope in One Hemisphere!  
Cris Hall

Vice President and CFO

The Hemispherectomy Foundation

[Cris@HemiFoundation.org](mailto:Cris@HemiFoundation.org)

Thank You so much for taking the time to read this eCommunication. We are always striving to exceed YOUR expectations, so if you have any comments, suggestions, or other feedback for us, please email us at : [Newsletter@HemiFoundation.org](mailto:Newsletter@HemiFoundation.org) .

**Sincerely,**

The Hemispherectomy Foundation Newsletter Team  
The Hemispherectomy Foundation

