



# BRAIN MATTERS

June 21, 2009

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**Brain Matters**

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Greetings!

## Happy Anniversary Hemispherectomy Foundation!

On June 23, The Hemispherectomy Foundation celebrates its one year anniversary! In recognition of this important date, the board sat down and reviewed our goals for 2009 and I thought I would share them with you! It really is amazing to see how much we have accomplished since January .

In January we started to build our Medical Advisory Board - now its members include some of the most prestigious pediatric doctors and specialists in the United States. Our brochure was completed and distributed to our families and pediatric neurologists and surgeons all over the world. Our beautiful web site underwent a makeover that focuses on telling the important stories of our children.

Fundraising efforts from Connecticut to Texas to California have have been inspiring. And last but not least, the creation of this newsletter, "Brain Matters", an important communication tool to unite our families, doctors, therapists, friends, teachers, and supporters. Here we bring you information, stories and hope. The remainder of 2009 is full of promise, excitement, and purposeful work. July 9-12, is the Hemispherectomy Reunion and Conference in Baltimore, Maryland. The Hemi Foundation will be there to help out and we are looking forward to meeting everyone that is able to attend. At this conference, the foundation will announce our 2009 college and camp scholarship winners! We will continue to build our support to families by adding the

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.

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. To Apply, [Click 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 by June 30th. Winners will be announced in July. Information may be found by [Clicking Here](#).

### Spotlight Inspirations & Stories

capability to "Ask a Speech Therapist" and "Ask a Neuropsychologist". By the end of the year, a strategic plan will be in place. Committees to oversee specific annual goals for fundraising, grant writing, research, and many more areas will be created. We are excited to announce that we will again have our Holiday Card fundraiser! Soon you will see more details and a request to submit artwork in a future newsletter.

And speaking of the newsletter, this newsletter is for you! If you have read an interesting book about a topic related to living with hemispherectomy, send us a book review. If you learned a new tip or technique at therapy, share it! We would love to hear from you. After all, the purpose of this newsletter is to bring you information, stories and hope. Please send those to [info@hemifoundation.org](mailto:info@hemifoundation.org)

Hope in One Hemisphere!  
Happy Anniversary,

Kristi Hall  
President and CEO  
The Hemispherectomy Foundation  
[Kristi@HemiFoundation.org](mailto:Kristi@HemiFoundation.org)



## Anes' Story

By Holly Paauwe



*Imagine...  
... the joy of meeting your newborn child for the first time.*

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.

[Click Here to read more Inspirational Stories !](#)

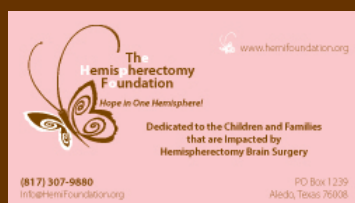
## Medical Advisory Board



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](#)



*... taking him home with such overwhelming love and joy in your heart.*

*... the heartache of learning something is gravely wrong with him and having few answers.*

*... learning that the medical treatment he needs is not available in your country.*

*... feeling scared, lost and alone without the knowledge of what to do next.*



**Can you...imagine it?  
Could you live it...if it happened to you?**



The Dzebic family in Bosnia and Herzegovina has lived it, for nearly 15 months. In March 2008, Adis and Aldina welcomed a son, Anes, into their world. They took him home and marveled at him. It was only a couple of days before their happiness turned to worry when Anes began to have what they would quickly find out were seizures. They took him to a local hospital, but were quickly sent to one of the few hospitals in Bosnia that can treat pediatric emergencies, "Kosevo". There they learned that Anes was born with right-sided hemimegalencephaly. There they learned that the Bosnian medical system knew little about his condition and that they did not have the technology, nor the medical staff with the skills

***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 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](#)**

necessary to treat a child like Anes. There they learned that a special surgery, called a hemispherectomy, might be able to help their son; only to find out that it was not available in their country.



Anes came home from Kosevo hospital after 110 days, on medication for the seizures, but which serve only to lessen them ever so little. The family wondered what would come of their son. What could they do to help him, with so few answers available? Luckily, they would soon find some answers...

[Read Anes' Incredible Story Here.](#) Find out how Anes is going to get to America and the HOPE that his family now has!

See pictures and a summary of the story [Here on the home page of the Hemispherectomy Foundation Website.](#)



## **Lose the Training Wheels**

By Nancy Geschke

Part of summertime fun is riding bicycles, something that is a challenge for a hemispherectomy child. My son, Brian, proved that it is absolutely possible to ride a regular bike with the help of an organization called Lose the Training Wheels.

Brian had a right hemispherectomy for Rasmussen's shortly before he turned four years old. As he grew, he had difficulty riding his training wheel bike as his strong right side was overpowering his weaker left side. He eventually became too big for his bike and would fall



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over every time he pushed against his training wheels. Like many older children, he just stopped riding. When Brian was eight I discovered a bicycle camp called Lose the Training Wheels.



Lose the Training Wheels is an adaptive bicycle camp that teaches children with mental and/or physical disabilities how to ride regular bicycles without training wheels. Children start off on stable, roller-wheeled bikes and progress to increasingly less stable bikes. By week's end, the majority of children are on regular bikes without any support. Each participant has an individual trainer to guide them through the five day camp. Participants attend camp for 75 minutes each day. Seven or eight children ride at one time. Children must be at least 7 years old and be able to ride a regular bike with training wheels. They must be able to follow directions and pay attention during the 75 minutes of continuous riding each day. Lose the Training Wheel has successfully helped children with numerous disabilities or challenges including mild autism, mild Down's Syndrome, amputations, brain injury, mild cerebral palsy, spina bifida and ADHD.

What is important to realize, though, is that unlike a typical child - "once you learn to ride a bike you never forget", our kids and others with disabilities will forget how to ride without a lot of practice. I have always told interested families that the whole family needs to commit to riding if they want their special child to be successful. It takes months of practice every day after camp to keep this new skill progressing to true independence.





After some research I decided to bring LTTW to Cleveland, Ohio as I knew there were multitudes of children who could benefit from the program. Brian was 9 years old when he and 34 other kids took part in this amazing camp during the summer of 2006. My prayers were answered when Brian rode a regular bike, unassisted on the third day of camp! The tears in our gym flowed for five days as child after child rode on their own for the first time. Thirty-five miracles occurred that week, and with that I decided to host the camp again in 2007 and 2008.

The success rate for any given camp is between 70 and 90 percent depending on the disabilities present. Any parent will tell you that going through the camp has changed both their child's life and the life of their family. I cannot begin to express how incredible it was to take our first family bike ride with Brian and our two daughters. Brian is now 12 and rides his bike daily. We take family bike rides several times a week and take our bikes on vacation as we will this summer on a trip to Hilton Head Island.

Our hemi kids are amazing and riding regular bicycles is certainly within their reach!

To see a video from the Cleveland LTTW camp, go to the YouTube site on the HemiFoundation website. For more information about participation in a camp go to [www.losethetrainingwheels.org](http://www.losethetrainingwheels.org) or contact me at [nancy@hemifoundation.org](mailto:nancy@hemifoundation.org).



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**California Hemispherectomy Family Picnic**  
**!**

LOS ANGELES - A light breeze whips through Griffith Park, as Dr. Gary Mathern cradles 19-month-old Addisyn Ross in his arms. The doctor smooths Addisyn's tawny curls as she cries, while he talks lightly with her mother, Krissta Ross of Stockton.



Mathern, a pediatric neurosurgeon at Mattel Children's Hospital UCLA, is visiting the park on happy business. He's reuniting with several of his former patients amid a rare gathering of individuals - mostly youth - who share something in common: They're each living with half a brain. Each, for different reasons, has undergone a hemispherectomy, a radical operation in which half the brain is removed or disconnected to treat severe seizure disorders.



At the first-ever Picnic for West Coast Hemispherectomy Families on Saturday, May 30, more than a dozen "hemi" patients and their families from all over California assembled at Griffith Park for an afternoon of celebration and support.

To read the rest of the story [Click Here](#) .



To see ALL of the pictures [Click Here](#) .



## Rasmussen's Encephalitis Survey

Dear Parents of children who had or have Rasmussen's Encephalitis,

From the Office of the Specialty Director - Rasmussen's, Lynn Miller and Kristi Hall have created this Rasmussen's Encephalitis survey to help address common concerns with Rasmussen's cause, treatment and follow-up.

We would very much appreciate it, if you would help us with our data gathering and analysis by taking some time to take this on-line survey.

If certain questions don't apply or you don't know, please skip them.

This survey will take about 20 minutes. We plan to analyze the results and pass information on to doctors across the US and World, as well as share the results with families who are interested.

There is no way to identify who you are as you take this survey, so it is completely private. No identification questions are asked, but there are some very detailed questions. No one, including us, will ever know who took this survey.

Please only take the survey **once per family**.



Thanks so much for taking the time to take this survey. To take it, please click on the link below, or cut and paste it into your browser.

[Click Here to take the Rasmussen's Survey](#)

<http://www.esurveyspro.com/Survey.aspx?id=d80b3e89-fa17-479e-9c82-774ec974b104>

Thanks,

Cris Hall  
VP and CFO, The Hemispherectomy Foundation  
"Hope in One Hemisphere!"  
Cris @ Hemifoundation . org  
817-307-9880



## 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

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

