



# The Hemispherectomy Foundation Brain Matters Newsletter

Monthly E-News

July 2009

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## On Our Website



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)

## Greetings!

School and football are starting and fall is in the air. The Hemispherectomy Foundation has had a productive summer and we are excited to share the news!

To kick off the summer, we celebrate the graduation of Miss Alaina Clements. Alaina is a story contributor to the web site and is a past scholarship recipient. In July, The Hemispherectomy Foundation attended the 2009 Hemispherectomy Conference and Family Reunion in Baltimore. Special thanks go out to Jane Stefanik, Caren Jennings, John Jennings, Traci Cottrell, Heather McLean and Rob McLean for their help in supporting the reunion and for providing outstanding childcare during the conferences. During the conference, Cris Hall, Caren Jennings and I gave a presentation about The Hemispherectomy Foundation and we concluded by awarding scholarships to four outstanding students! You can read more in Cris Hall's article below.



2009 has been an economically challenging year to say the least. Fundraising efforts and donations are an important aspect of running a foundation and we are incredibly grateful to all that have provided support this year. In this edition of Brain Matters, we give special thanks to a family that have been thrown into the most chaotic year of their lives but have chosen to support The Hemispherectomy Foundation in a manner that will allow us to provide greater support for families and to initiate much needed research.

We hope you enjoy reading about some of our summer activities and encourage you to celebrate the end of summer by doing what you can to provide HOPE in One Hemisphere. Reach out to others, submit articles, have a car wash!

HOPE in One Hemisphere!

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## National Hemispherectomy Reunion, Baltimore, Md.

by **Cris Hall**

As we prepared to leave Baltimore, and the 2009 Hemispherectomy Conference and Family Reunion, the "Good-Byes" were bittersweet; happy and sad at the same time; Happy that we had the opportunity to meet so many amazing families and their children, but sad that the time was almost over. As I said "good-bye" to everyone on Saturday night and Sunday morning, I wondered why I would miss everyone so terribly, and why tears filled my eyes. I mean honestly, I had just met these people for the first time a few short days ago. How could I have possibly built up a bond with anyone in 3 days?



As I thought more about it on the flight home, remembering the sweet faces of all the children and the friendliness of all the families, I realized that it hadn't been ONLY 3 days. It had been almost 2 years for our family and a lifetime for others. The bond, in fact, wasn't built just over the weekend of the reunion, but over many, many years. From the first seizure, through surgery, rehabilitation, and a lifetime of adversity, an enduring bond was formed. This was a bond that was founded on such a unique, common experience that most people will never have the privilege to experience it. God forbid that they would have to.



Nevertheless, as time goes by, I forget the good-byes, and I remember mostly the good times. There are fond memories of a group of doctors who cared enough to give-up part of their weekend and spend it with us, because of their dedication to our children. There are stories of random meetings of Hemi Families in airports across the United States. I remember listening to extremely proud parents as they talked about "Firsts" for their

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[View the One Handed Gadget presentation](#)

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children. I had the privilege of meeting some AMAZING siblings who don't know the word "self", yet have an incredible outlook on life.



There were useful presentations by people who cared enough to share what they knew. I saw a group of children playing together in Kids Kamp that didn't see disabilities, but only saw fun, play, and being a kid. And what about that amazing Hemispherectomy Chorus? Angels!!



The most incredible thing that I remember, however, is a group of parents who were strong and compassionate about doing the best that they could for their children. This group of parents were strong, by themselves, but together, they were invincible. You could feel the strength that they gained from each other. It was electric. It was magical. It was necessary.



This year's Reunion was the largest yet, with 67 families, 218 participants, from 27 states and 4 countries. In addition to this national event, there were two regional reunion events this year;

one in Los Angeles, and one in Texas. Because of the increased interest and benefit of these events, The Hemispherectomy Foundation has committed to host the next three national events: Indianapolis in 2010, Los Angeles in 2011, and Baltimore in 2012. In addition, there will be many regional events throughout the years to come. With unity comes strength, and with strength comes the power and influence to help our children, and those yet to come.



I encourage you to keep those wonderful memories alive from the 2009 Hemi Conference and Family reunion. Stay in touch with those that you've met. Share your struggles and victories. Share your successes with new devices, medications, and other helpful life-aids that you find. Get active with The Hemispherectomy Foundation where you can. Every little bit helps to keep our Hemi Community strong and influential.

To see more pictures of the reunion, visit the [photo albums](#) on our website!



## 2009 Jessie Hall Hemispherectomy Scholarship Winners Announced

Each recipient was awarded \$1,000.00 towards tuition, books or other needs to make their college experience more rewarding. This scholarship is given annually to young people who have undergone a hemispherectomy and been accepted into an institution of higher learning.

**Karla Accordino**



Karla will be attending the College of Western Idaho as a freshman in the fall.

#### Jody Miller



Jody will be returning to Eastern University where she hopes to major in Early Childhood Education. She will be a student chaplain this year at school and help lead a bible study every week.

#### Christina Santhouse



Christina attends Misericordia University in Dallas, PA. where she is pursuing a Master's degree in Speech Pathology.

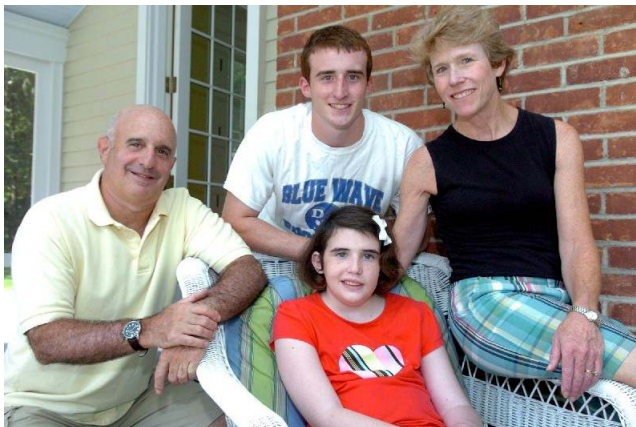
#### Nick Bunker



Nicholas Bunker will be attending Schoolcraft College in Livonia, Michigan this Fall. He will be a Freshman.

Read the winning essays found at <http://hemifoundation.intuitwebsites.com/winnerscircle.html>





On behalf of the Friends For Grace Foundation the Wohlberg family of Darien, CT made a donation of \$50,000.

## Thank You Wohlberg Family

The Hemispherectomy Foundation wishes to acknowledge and thank the Wohlberg family, of Darien, Connecticut, for their generous donation of \$50,000. Because of their continuous generosity and support, The Hemispherectomy Foundation will be able to increase its level of assistance to the families that it supports. In addition, this donation will allow the foundation to begin supporting Medical Research surrounding hemispherectomy and the various conditions that may lead to hemispherectomy surgery.

The Hemispherectomy Foundation, a 501(c)(3) non-profit organization, was founded to provide emotional, financial, and educational support to individuals and their families who have undergone, or will undergo, a hemispherectomy or similar brain surgery. It provides assistance which includes, but is not limited to: college scholarships, trade school scholarships, camp fees, life-aid equipment, travel expenses, and other aid as approved by the officers.

The Hemispherectomy Foundation is also dedicated to hemispherectomy education, awareness, fundraising, and research of the medical conditions causing intractable epilepsy that lead to surgery and the surgery itself.



**Alaina Graduates**

by Alaina Clements and Kelly Dawson

As the parent of a young child with a hemi, I always read with interest the emails, and celebrations, of families with the older "kids." Now, by all rights, these are not actually kids, but young adults showing the rest of us the possibilities for our own children. I was very excited to hear about Alaina Clements' recent graduation from college, and was thrilled when she agreed to answer my questions about growing up and succeeding.

Question: What was school like for you growing up?

My parents have always played a huge role in my education when I was growing up, mostly my mom because her work schedule was more flexible than my dad's. My mom was at all of my IEP meetings when I was in school and she was very good at helping my teachers understand the things that I found hard. I remember that at the first meeting of the year she used to buy cheap party masks and cover

up half of the eye pieces to show what I was missing in my vision. All of my teachers had to put them on and try to do a test she'd written because she wanted to make sure they were aware of this problem so that if I missed test questions they didn't get marked wrong. I think that her doing this for me made a huge difference in how my teachers understood this part of my disability.

**Question:** Could you describe your transitions into both high school and college?

Both the transitions through high school and college were made easier by my older sister because, being a year older than myself, she was able to tell me what to expect. The hardest transition for me was into high school because it was the first time that a lot of people of different ages would be together and I also didn't have an aid to help me navigate the hallways, thus I got pushed all over the place a lot. To be honest, the scariest part about high school for me was that by then my friends didn't really consider me handicapped at all and so I didn't get as much help



from them as I used to. Also, I got put in all the really low classes because everyone assumed that it was the right place for me. All of my teachers and even my parents did a lot of assuming about me. I know they were just trying to help but it seemed like they were speaking for me instead of to me and I remember feeling pretty bogged down by that. High school was a pretty lonely time for me because of both of these things.

When I went to college I went to a school that was literally a mile away from my house but I lived on campus because I can't drive and also I wanted to experience dorm life. I remember being more curious than scared when I moved into my first dorm room. I was in a good situation because I didn't have to live at home but if ever I needed, or wanted to, I could go home. I did my laundry at home because I wasn't comfortable getting down the stairs carrying stuff and my mom was still able to bring me to all of my regular appointments. I ended up transferring out of that school, but it was a good place for me to start out. It made transitioning from

high school to college a bit more comfortable for me, and besides, if I ever missed dinner in the dining hall I could always see what my parents were having!

If I could offer any advice to people who are in one of these two places, I would say that letting things happen as normal as possible is the best way to transfer from one situation to the next. I never wanted to be treated differently from others but when I got into high school or into college it seemed like people wanted to make my transition as smooth as possible, but I just wanted to be considered like everyone else. I felt like people were treating me like some sort of fragile sea shell placed as gently as possible into a new environment when all I really wanted was to be thrown to the sharks like everyone else. Perhaps this analogy doesn't explain what I mean but it seems like the best way to describe what I was feeling.

**Question:** How did you participate in college activities?

At my first school I had a non work study job on campus that required

me to work four days a week minimum. I worked in the admissions office calling perspective students for three or so hours every night Monday through Thursday. Because of this I didn't get to join the club that I really wanted to be a part of, the Christian Fellowship. I had met a few of the members and it seemed like a fun club so when my Sophomore year rolled around I opted out of having a job and instead joined this club. The Christian Fellowship was one of the only clubs offered to civilian students at a military school, so that is what I joined. When I transferred to the school I graduated from, Johnson State College, I didn't get involved in too much outside of classes. Most of the time I was at Johnson I had at least four upper level English classes that required me to read one full length novel (per class) every week. I found myself too bogged down to join in any of the clubs. I never lived in an apartment when I was in college because of the fact that I can't drive. Since for the majority of the school year it is winter time I could barely walk too! My campus was

nestled on top of a hill where, while the view of the mountains was amazing, I was barely able to leave campus because it was too dangerous. Because at Johnson most people only have class until Thursday, I was able to go home and relax for three days. I was thankful for my boyfriend who graciously picked me up every Thursday and brought me back every Sunday!

Question: What are your plans for the future?

My plans for the future are highly uncertain because while I would really like to have a job, there are plenty of other people who've been laid off who want one too and I am competing with them. Because of my disability I have to make sure that the place I live has public transportation and is not too snowy in the winter along with other aspects too. I have a lot of things that I have to consider when I am looking for a job that others don;t, and at this point who knows where I'll end up. My plans for a day job are open ended but I certainly would like to have at least one book published in my

lifetime!

Since this interview, Alaina has accepted a position at the Vermont Center for Independent Living helping others with accommodations in their homes.



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