

The Hemi Lighted Forest of Hope

A Brighter Place for Children who have been impacted by Radical Brain Surgery

The holidays bring magic and joy to children all over the world each year. Smiles and laughter, visions of presents, candy, and brightly lighted trees fill the stores and their minds. Some children, however, find their holidays spent in the hospital battling unstoppable seizures and/or brain surgery to try to stop these terrible seizures. Other children may have endured brain surgery many years ago for their seizures. The <u>Hemispherectomy Foundation</u> finds ways to make their holidays and lives better each

Now, imagine over 82,000 multi-colored lights, radiantly illuminating 542 live evergreen trees, with a backdrop of the great Rocky Mountains in Wyoming. Now imagine that each one of these trees represents a child who has endured an unimaginably radical brain surgery to combat unstoppable epilepsy. This is the vision of "The Hemi Lighted Forest of Hope" and just as each tree shines brightly, so does the hope of the child that it represents.

year.



All of these children have had a hemispherectomy, a brain surgery that provides relief from intractable epilepsy. In this radical surgery, half of the brain is removed or disconnected to stop damaging and life-threatening forms of epilepsy. Of the 50 million people in the world who struggle with epilepsy, these children are, by far, the worst of the worst cases.



This year, the Hemi Lighted Forest of Hope includes the Hemi Railroad. The Hemi Railroad features over 300 feet of track, 2 eight-foot long tressels over water-feature creeks, and five waterfalls. The train travels through the Hemi Lighted Forest and beautiful landscapes that are representative of the vast beauty of the state of Wyoming. There are eight locomotives pulling tons of cars by a train station, watch tower, freight docks, and much more!



Come out and walk through the forest or take a hay ride. It is a Christmas Tradition that you don't want to miss. It is all free, however donations are accepted to benefit these children supported by The Hemi Foundation.

"We think of these kids and the struggles that they have to meet every day. This is just one way that we can show support to each and every one of them," said Gary Kelley. Gary and Nancy Kelley are the creators of The Hemi Lighted Forest of Hope, and grandparents to Jessie Hall, who had a hemispherectomy in 2008 at the age of six.

Any funds raised from this project will go to The Hemispherectomy Foundation to help children impacted by hemispherectomy brain surgery. For All of the Details, <u>Click Here</u>.



"It makes you realize that you can make a difference in your community, and you can make a difference in communities across the United States and around the world", Kelley said of the project. "You think out of the hat a little bit and you make it happen. Nothing

is impossible. Nothing."



How to Help

People can participate in the Adopt a Child and Hemi-Lighted Forest of Hope project, by learning about Hemispherectomy at www.HemiFoundation.org or by contributing.
People can symbolically adopt a child with a large, lighted tree for \$100, adopt a child with a small, lighted tree for \$50 or donate whatever they can. Checks can be sent to The Hemispherectomy Foundation, Forest of Hope, P.O. Box 1239, Aledo, Texas, 76008.

Secure donations can be made on-line at <u>www.HemiFoundation.org</u>.

If you have any questions about the display, please email : garyk@ihswy.com

Or Write to : Gary & Nancy Kelley 6565 Ashley Drive Cheyenne, WY 82009 A special thanks go to High West Energy and their employees for putting up the lights this year in just 2 days!

The Hemi Lighted Forest of Hope in the News !

Wyoming Tribune Eagle CBS Channel 5



Visit Our Website www.HemiFoundation.org

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Brotherly Love for Baseball *Excerpts from The Woodbury Bulletin* Article written by Patrick Johnson, Staff Writer



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<u>The Hemi Foundation</u> <u>Presents</u>

<u>"Hope in One</u> <u>Hemisphere"</u>

Watch it Here!



<u>What can You Do with</u> <u>Half a Brain</u>



No Small Miracles: New East Metro Miracle League Begins

Greg Livermore loves baseball. He watches his older brother Scott play year-round for Stillwater High School and is a fan of the Minnesota Twins. However, he hasn't had a chance to play the game - until now.

"Greg just loves baseball, but he's always the fan and not the participant," Greg's mom, Shelley Livermore said. "It's fun to get him out here to give it a try. It's just great, because he loves being outside and being active. This is such a good opportunity for him."

Presented by Woodbury Parks and Recreation and The Miracle League of Minnesota, The East Metro Miracle League is designed specifically for children age 3 through 18 with cognitive and/or physical challenges. It was created to provide participants an opportunity to play baseball as a member of an integrated team.

Players in the league either can bring, or are provided with, a volunteer buddy, as needed, to help them bat, run the bases, and field. Greg Livermore, 16, plays for the Mets. His brother Scott showed him the ropes in his first game last week. In the East Metro Miracle League everyone hits, everyone gets on

base, everyone crosses home plate, and most importantly, everyone has fun.

Click here to read the full article



The Hemi Jam *Music and More, Dec. 17th at 7:00 PM* Lawerence, Kansas 2011 Brain Matters Newsletter : Fall Edition





The inaugural Hemi Jam will be held on December 17 at 7 PM to benefit The Hemispherectomy Foundation. A diverse music line up featuring Rock and Blues, Bluegrass, and Reggae is planned for the night. Auction items will be available to bid on and tickets will be sold to win some great prizes. Come join us for a fun-filled evening!

> Hemi Jam Info December 17, 2011

> > 7:00 PM

The Granada Theatre

Lawrence, Kansas

Live music, prizes, and auction items ** For more info on the Hemi Jam, contact Saasha@HemiFoundation.org



Krista's Courage by Krista McFall from Texas



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I am the Mother of Gabrielle "Gabby" Yambo. Gabby had her right hemispherectomy on Jan 8, 2008. My name is Krista and my husband's name is Rick. Many of you are facing or will soon be facing the unknown, stressful, and emotionally trying time of your child having seizures and the complete emotional and physical devastation of your child having the hemispherectomy surgery. The toll affects not just the child, but the entire family.





I am here to discuss how it almost destroyed my family and how we are learning to become strong and overcome the grief and stress we all face daily. Gabby had a major seizure in Feb 2006 which absolutely devastated our entire lives immediately. We had no clue of her brain abnormalities at all, which is HME, Neuronal Migrational disorder (with several others that fall into this category), and mental retardation. We woke up and found her seizing and found out later that she suffered a stroke from the several hour seizure which landed her in the ICU in septic shock on a ventilator, fighting for her life. Honestly I was instantly a nervous wreck, I have had several traumatic incidents go on through my life and this was another and my coping mechanism was to eat. Stress takes its toll on people in many ways. Some people do not eat, some people run away from their feelings only to have them come up later in life and others eat. That was me and my husband. It is what I had always turned to in times of stress. I was overweight when Gabby became ill, but not like what I was going to experience over the next few years as I ate and ate and ate all of my emotions. I was a wreck watching my only child start to have seizures to the point she was having over 100 a day. Also while trying to keep our finances and all my relationships intact including the one to my husband. As you know, a child getting sick can really make or break a marriage on top of everything else. I lost the ability to work due to her health and that was enough to cause a financial mess, not including all the while trying to get services for her and navigate the health care system in order to find out what was really going on with Gabby.



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The Hemispherectomy Foundation

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What I want to teach others is when going through such an emotional time it is very important to still take care of yourself, something I never really knew how to do since my weight was spiraling out of control and I did not care about myself because I was just trying to care for my child. It is a fine line to find balance in a situation like this and it is a daily struggle I still deal with because I am addicted to food and any time you have any addictions, a traumatic event will compound those issues and bring those demons to the forefront. The key is to learn how to manage your emotional stress while caring for your family and hemi child (or any child with any illness).



I reached a whopping 470 pounds a year and a half ago and I was

finally at the point I could no longer stand the way I felt. I was peripatetic, hypothyroid, high blood pressure, and I was 34 yrs old. Way too young to have any of these issues much less weigh close to 500 pounds. I was killing myself with food, a slow suicide, but I was so sad and helpless. I started to try and find a solution to get myself, my husband, and my entire family to regain our health. We needed to be here for Gabby and live for her because she will always need us and we want to provide her with the best life possible and we could not do that if we were sick or much less not here.





I started reaching out for help and looking into better ways to deal with our stress and emotions and I was pretty desperate that we contacted a TV show for help. I knew we needed a big change and well after trying out and interviewing and going through a long process to get chosen. We were chosen by Extreme Makeover: Weight Loss edition and that's how I met Chris Powell - the angel I



needed to get my life back. I worked with him for a year and lost 180 pounds and now I am down 203. Yes, I still have a ways to go to reach my goal weight but its all about the fight. The fight to stay healthy is what keeps us in check mentally and physically.



I want all the families who are facing a tough road to really start from the beginning or right were you are and just change the way you deal with your stress during this time. I wish I did not wait, but its my lesson learned that I hope inspires others to change today. I would suggest to carve out time for some exercise even if it is a 20 minute walk a day, it will clear your head of the emotions you are facing and help give you some of that time or take a family stroll, however it fits into your schedule it will help. Checking your nutrition is a must. I know it's hard when we are tired and exhausted to just choose what is easy, but you can eat easy that is still healthy.

Gabby recently in the last 7 months started having seizures again after almost 3 years seizure free. She is currently back on medication. This was unfortunately very frustrating and scary for us. At first, it totally derailed my goals of weight loss and I gained 25 pounds back initially because I fell back into old habits. Yes, I was still working out, but I was eating horribly. After the first few months of her seizures starting, I felt so defeated and the thought of her neurologist telling us that she will have to undergo a redo hemisurgery once she fails this medicine is extremely disheartening. I was told not if, but when!!! Those words you do not want to hear. I realized I had to change my thinking and quit trying to control everything because I cannot control what is going on with her and I had to put myself in a place of thinking, "I know Gabby is being taken care of to the best of our abilities, we have always done anything for her and always will fight for her and until we have to be back at the hospital doing her surgery". I will deal with it then instead of letting my anxiety control my emotions by what is not happened yet. This is something I literally have to tell myself daily, but it has helped me a lot. I cannot change the future or change the outcome, but I can change the way I think about it and how I let it affect me. That is the new me and I am now in a much better place.



I give praise to those families who have been able to change and those who were already doing this during all of this. It was a huge wakeup call for us and this goes for not just eating, but drinking and emotional issues too. Please reach out for help if you need it during this time or for that matter any time because you are not alone and we all need help to navigate our lives when our lives are rocked by hard times. Reach for counseling, ask for help, whatever it is just try not to keep your emotions bottled up because we are all here in the same boat dealing with a lot of the same issues. Yes, some harder than others, but the emotions are the same when it comes to your child's health and having to be strong. We are all stronger than we

think, so take that strength and make it a point to keep yourself happy and healthy even when there is not a lot to smile about all the time. This is something that I have really learned to do, because as you all know it could be worse and that keeps me going and fighting for a healthy me!!!

<u>Click here to view Krista's episode on Extreme Makeover: Weight</u> <u>Loss Edition.</u>

Click here to view Krista's FaceBook Fan Page.

I am here to help. I have free nutritional programming, meal plans, and healthy eating recipes for my hemifamilies if they are wanting some advice. I am certified in sports nutrition and certified in personal training too!!! For more details or questions, you can contact me at: <u>kristamcfall75@gmail.com</u>.



Infantile Spasms Resource Page by David Stauff

The Hemispherectomy Foundation is pleased to introduce the newly added Infantile Spasms resource page! This is a great addition to The Hemi Foundation's website, and its purpose is to share more information about this condition that so many hemi kids and their families have experienced. Visit <u>http://hemifoundation.intuitwebsites.com/infantilespasms.html</u> now to see the page! So what exactly are infantile spasms? It is a catastrophic form of epilepsy that affects young children typically before one year of age, but sometimes older. Infantile spasms are very distinct with certain characteristics that help identify and diagnose them. Infantile spasms can be very difficult to control and their effect on young children is very serious. Finding the underlying condition of why these spasms happen is very important to stop them, and in some cases, results in hemispherectomy.

Our goal with the addition of the Infantile Spasms resource page is to help others wanting to learn more or who may be faced with surgery

decisions after experiencing infantile spasms. It is here where others can come to learn more about infantile spasms, what they look like,what underlying conditions are known to cause them, and what treatment options might be available. Connect with other infantile spasms families through the Hemi Yahoo! Support Group through a link on the page or contact a Parent Representative directly at <u>David@hemifoundation.org</u>.

Also, please visit the Hemi Foundation's Medical Advisory Board to find a specialist with experience in infantile spasms and hemispherectomy. Have questions? Want to learn more about about infantile spasms? Let us help you find more answers! Visit the infantile spasms research database at the bottom of the page for great links and citations to articles and studies.



Zumba Your Brains Out! by Mary Lou Meier from Missouri



My family and I attended the central region gathering in April. While sitting in a conference room full of families like ours, whose lives had been impacted by hemispherectomy surgery, and hearing about the upcoming 5K Dreams on Wings, I couldn't help think how could our family give back to The Hemispherectomy Foundation? We are not a running family, that was for sure. The most "athletic" activity we (my daughter, Lexi and I) did was Zumba. Why not Zumba for The Hemispherectomy Foundation? That night I texted my Zumba instructors and asked if they'd be interested in helping. They both were very interested and had openings in their schedule to host a fundraiser in September. In the meantime, our family signed up as virtual runners in the 5K. On September 22nd, we had 25 participants show up ready to Zumba for The Hemispherectomy Foundation. The name of the fundraiser was actually "Zumba Your Brains Out" and it was a 90 minute class that was good for our brains and bodies. Information was shared on how we became involved with the foundation and

how the foundation helps kids and families affected by brain surgery. It was a lot of fun to Zumba for this cause. We burned a ton of calories, raised awareness for the surgery and foundation in our community, as well as raised \$300 for the foundation. And we plan to do it again next year!



Hemi Golf Tournament By Kori Kielty from Minnesota



After we attending the Central Region's Hemi Conference in April 2011, we decided we were going to put on a golf fundraiser to raise funds for The Hemi Foundation. We started by printing off donation letters, sponsorship letters, and registration forms for the players.

Between May and September, we collected about 35 prizes for a raffle. We met with the pro golfer at the course and he also gave us some tips on what to do! We ended up getting 4 people to sponsor signs at holes, and the company we got to print the signs ended up donating the signs as long as they could put one with their name on it.



We had a total of 17 golfers and about an additional 15 adults for the dinner only part. The golfers fee included golf, cart, dinner, 2 raffle tickets, a thank you card with Abby's picture, and one of Abby's "Hope in One Hemisphere" bracelets. It was nice because if you weren't a golfer, you could still come and enjoy a nice sirloin steak dinner! The golfers registered at 12:30pm with a tee time of 1:30pm. They came back around 6pm and we ate dinner and held the raffle. We sold the raffle tickets for \$1.00 each. Two other local hemi families joined us and plan on joining and helping out next year as well!



Josie Bemis brought along Zoey's cookbooks that they made, and we sold those, too. I made ornaments out of Abby's bracelets and sold them as well. We raised \$1,300 for The Hemi Foundation. It wasn't a huge event, but as we have been told many times over, these types of fundraisers ALWAYS start off small and then if you get 5-10 more

people each year by the 5th year, we should have alot of golfers! Everyone seemed to enjoy themselves and said for sure they would do it again next year! A huge thank you to each and every one of our friends and family who came out to support such a great foundation!



Yard Sale Fundraiser Brings in More Money by Sunshine Glynn



Two years ago, I wrote The Hemispherectomy Foundation in hopes of a scholarship to help us fund our first trip to the Baltimore conference. When the call came, followed by a check, I could not believe that the foundation had sent us \$1000. I was so overwhelmed with appreciation for such a generous gift, that I swore I'd repay the scholarship we were given.

In years past, we had yard sale fundraisers for my daughter's special needs trust to help cover the cost of her therapy. I sent the word out through her blog, and through Facebook, asking people to drop their goodwill load at our house instead of the thrift store. We had a really great showing and many people contributed. It was so obvious that we could do this same thing for The Hemispherectomy Foundation.

For two years, I have hosted a yard sale and lemonade stand to benefit The Hemi Foundation. The kids staffed the lemonade stand, many neighbors came out to help take money, to run kid interference, and to help customers. My Unitarian church community came out in droves to not only donate, but also to shop.



Although a bit labor intensive, what I got back from my experience clearly outweighed the time and energy commitment put into it. The many different circles in my life came together in one weekend. My kids' teachers, piano instructors, neighbors, long-time friends, church goers, friends I hadn't seen in years, family, they all came out to support not just The Hemispherectomy Foundation, but they came out to support me, my family, and my child. They did this out of love and compassion, and I think, out of appreciation for the sometimes difficult life we lead. Not only did we make money for our beloved Hemi Foundation, but it made our village of support stronger and more visible.



I can't help but think of the many hemi families out there who have circles like mine. People who have a village that are all working in their independent circles, but that come together when asked. And that's all I did. I just asked. I asked for donations, I asked for people to come visit the yard sale and ... they DID.

The yard sale cost me almost nothing; some time, some elbow grease, and some lemonade cups (although my husband would point out that being the first to "shop" the donations, we end up being the

biggest purchasers at our own yard sale). Both years have been wildly successful and we have repaid our scholarship twice over. If every hemi family sponsored a yard sale, a very simple effort would strengthen more than just the Foundation, it would strengthen the villages that support our children and bolster our own energy as we witness the show of love for our families.



1st Annual Rocky Mountain Area Hemispherectomy Fall Family Day

Please come join fellow Hemi families

to meet, greet, eat and play!

When: Sunday November 6, 2011 12-3:00 p.m. Where: Arbor House at Maple Grove Park 14600 West 32nd Ave, Golden, CO (Exit 264 off I-70, 1 mile west)

Pizza and drinks will be supplied. Please bring a side dish or dessert to share (store-bought is more than OK!).

Hotel info upon request for those outside Denver.

RSVP by Oct 31st to:

Jane Hittle - 720.261.6690 or jane@hemifoundation.org Alicia Grenolds - 617.216.1749 or alicia@hemifoundation.org



Need Financial Assistance? by Tammy Apitzsch

 Welcome to The Hemispherectomy Foundation's resource page for medical expenses. This document lists various grant-making organizations that offer grants to individuals for **medical expenses**, **adaptive aids**, **therapies**, and **much more**. While there are several organizations with National or International focus, most are limited to specific geographical regions. Contact information is provided along with preferred method of initial contact. if available.

The document is organized by geographic focus starting with International, followed by National. States are then provided in alphabetical order. The information is best searched using the "find and replace" option. Some ideas for search terms: your state name, therapy, hospital bills, equipment, wheelchair, etc.

This is by no means a comprehensive list of potential funding sources and the current giving status of each organization has not been verified. If you are aware of funding sources in your area, please let us know and we will add them to our list.

Click Here to go to The Hemi Foundation Resource Page!

If you have ideas, feedback or questions, contact Tammy Apitzsch, <u>tammy@hemifoundation.org</u>. Share your success stories with us!



Children's Hospital Tree Festival "Hope in One Hemisphere!" Tree

Dear Hemispherectomy Foundation,

I wanted to let you know that my family, the Osborne Family, is donating a tree to the Children's Hospital Tree Festival in the name of The Hemispherectomy Foundation. The name of the tree will be "HOPE in One Hemisphere!" The event will take place November 19th-27th at the John S. Knight Center in Akron, Ohio. Admission is free!

We'd love to have a bunch of Hemi Families come out and attend the event and celebrate with us. If you are interested in helping decorate the tree, I would love it! Decoration days are November 14th and 15th. Let me know!

For more information, please contact me. Dana Osborne

danaosborne@gmail.com.



Who's New at The Hemispherectomy Foundation?

We are so proud to have several new team members working with us to serve the Hemispherectomy Community. The following individuals have graciously volunteerd their time to serve in various aspects of the operation of The Hemi Foundation. David Stauff - Webmaster Tammy Apitzsch - Family Assistance Grants Saasha Huston - Website **Chris Jones - Website** Alexia Madigan - Newsletter and Website Kori Kielty - Hemi Family DB Alicia Grenolds - Denver & Rocky Mountain Area Support Group Jane Hittle - Denver & Rocky Mountain Area Support Group *If you are interested in creating a Hemispherectomy Foundation Support group in your area, contact Cris@HemiFoundation.org. Most support groups will try to do at least one local gathering and one fundraiser per year.



We Need YOU at The Hemi Foundation!

If you are interested in sharing your talents with the hemispherectomy community and joining The Hemispherectomy Foundation Team, please send an email to <u>Cris@HemiFoundation.org</u>. **<u>Current Volunteer Opportunities:</u>** Baltimore Conference and Reunion Workers

Dreams on Wings Virtual Runner Team Captains

Regional Teams (West, East, Central, Northeast) Specialty (Disease / Condition) Teams

Special Talents? What is yours?

Your Hemispherectomy Foundation Team, "Hope in One Hemisphere!"



Hemispherectomy Foundation Camp Assistance Thank You Hemi Foundation !

Dear Hemispherectomy Foundation:

This summer our five-year old son Ben had the opportunity to attend Adam's Camp, a week-long therapeutic camp for children with disabilities and their families, with the help of a camp scholarship from The Hemispherectomy Foundation. The camp is located at the YMCA of the



Rockies in Winter Park, Colorado. Each child at Adams Camp receives individual, multidisciplinary therapy from professional therapists for five full days, all in the beauty of the Colorado mountains. With Ben beginning Kindergarten this fall, we were hoping that he would have the opportunity to gain some important skills and most importantly gain confidence before this milestone. The experience was exactly what we hoped it would be for Ben and our whole family. Ben canoed, went horseback riding, climbed a rock-climbing wall, did archery, went swimming, all while working on specific therapeutic goals including using his affected hand, speech, and gross motor goals. He was encouraged to take risks and try new things. He learned some important skills like taking off his shirt and putting on his socks by himself in addition to riding a twowheeled scooter (using two hands) and speech goals. Ben was changed by this experience and returned home a more confident child. Our other children attended the sibling camps which included fun, friendships, and support groups led by a LCSW while my husband and I listened to speakers on various topics. Thank you to The Hemispherectomy Foundation for this life-changing experience!!

Sincerely,

Jane Hittle and Family



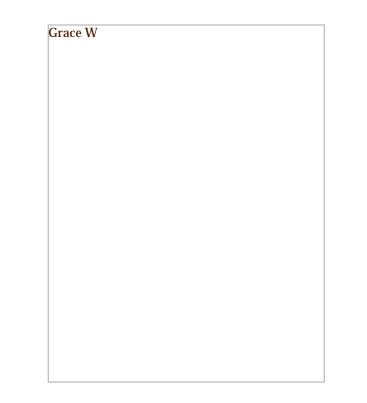




Hemispherectomy Foundation Holiday Cards by Hemi Artists on Sale Now!

Cameron M		
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'Tis the season to purchase your Christmas cards. Raise awareness and proudly show your support of The Hemi Foundation by sending out Christmas Cards created by a hemispherectomy child. All proceeds from sales will be used exclusively to help and support those who need, or have had, a hemispherectomy.



This year, we will be offering exclusively Variety Packs. The Variety packs will consist of a beautiful collection of 12 cards made exclusively by our Hemi Children . Make a difference in a child's life. All orders will be shipped after November 15, 2011.

Irene P			
	?		

To Order your Cards Today, <u>Click < Here ></u> or go to <u>The Hemispherectomy Foundation</u> Website.



New Book Available on Understanding Differences, particularly Craniofacial Abnormalities

The inspiration for this children's picture book is my daughter, Ella P. Rozin, now 10 years old, (R hemispherectomy in 2002 at age 10

months due to hemimeganencephaly). She has hemi-facial hypertrophy, commonly secondary to hemimegalencephaly. The book's message is: all of us ARE different, especially in regards to our reactions when we see someone who looks very different. This is perhaps the only children's book on craniofacial issues aimed at teaching young children what these are and that one need not be afraid of people with facial differences. Also, the book teaches that

it is okay to acknowledge differences and not be ashamed of reactions. I believe the book will be particularly helpful in settings where children with disabilities, particularly craniofacial anomalies, are entering new situations/school. When my daughter's teacher read a draft of the book to her integrated kindergarten class, it was a chance for the kids to talk about Ella's facial differences. Of course, these children already knew her well, but in a new setting it is hard to initiate a conversation to make others (and Ella) feel more at

ease.

The book may be helpful to other members of The Hemi Foudation. It is available as an e-book (at this point, the least-expensive way to self-publish) from:

<u>Amazon</u> .

It can be bought (\$5.99), downloaded on a regular computer and viewed using the freely-downloadable Kindle Previewer. Please send feedback!

Dr. Michelle Portman Author of: LOPOPA! The Lopsided Girl michelle@rozin.com



2012 Hemispherectomy Foundation Conference and Family Reunion



Baltimore, Maryland

July 5th - 8th, 2012

Mark Your Calendars Now!!



Contact The Hemispherectomy Foundation

The Hemispherectomy Foundation PO Box 1239 Aledo, Texas 76008 817-307-9880



Try it FREE today.