



The Hemispherectomy Foundation Brain Matters Newsletter

The 2011 International Hemispherectomy Foundation Conference and Family Reunion Disney's Paradise Pier Hotel and Conference Center July 7th - 9th, 2011

This year's Hemispherectomy Foundation Conference and Family Reunion was an informative and growing experience for the Hemi Families and the professional speakers alike. Each family took away valuable information that will enrich the lives of their child and their entire family.



However, one question remains unanswered...Is it really a conference if we're having this much FUN?!



Friday Night's Luau : Who says you can't Hula while wearing an AFO?!?!

It was a magical weekend, set in the magical setting of Disneyland, in Anaheim, California. The sun was ever present, and the temperatures were cool and pleasant; just what you would expect from Southern California. What you might not expect, however, was a hotel full of families, from around the world, who share an unimaginable and life-changing bond. This bond of intractable seizures and radical brain surgery was a bond that made total strangers seem like long-lost family, during an unforgettable three days.

This year's Hemispherectomy Foundation Conference and Family Reunion had a record 250 participants, over 70 families (three families from Australia and one family each from Canada and Italy), and over 50 volunteers, speakers, and ancillary support groups.

As families arrived, excitement filled the lobby of the Paradise Pier Disneyland hotel. There were sounds of reunited families, and introductions of new friends. It was a whirlwind of activity that culminated in Thursday afternoon's welcome from founders, Cris and Kristi Hall, and a special address given by 18 year-old Tanner Lanksbury. Tanner, who had a right hemispherectomy himself, was an inspiration to the parents and other children listening attentively to his story. It gave so much HOPE to the parents to watch this young man speak to the audience with confidence, clarity, and meaning.



Thursday night, for those who were interested, were treated to a free Anaheim Angel's baseball game and Angel's baseball cap, compliments of The Hemispherectomy Foundation and the Anaheim Angels. Some went to the game, while others stayed back at the hotel to rest from their trip or socialize with the other families.

The conference sessions started in earnest on Friday morning. Parents checked their children into Kids Camp for a fun-filled day of games and activities, and Mom and Dad got a rare chance to enjoy the conference, interruption-free...well, mostly. At Kid's Camp, the children could do arts and crafts, play games, watch movies, and even get a surfing lesson. A favorite among some of the girls were the dance lessons, given by a nationally recognized dance/drill team. They even choreographed and performed at dinner for some very proud parents.



Speakers included many of the doctors from UCLA Mattel Children's Hospital, and other specialists in various fields impacting our children. See the full list of speakers and topics [HERE](#).

The food was outstanding, especially the Hawaiian Luau themed dinner, with authentic Hawaiian dancers, who of course, let the kids join in. The highlight for many of the parents during dinner and lunch, however, was when a young-adult hemispherectomy patient would speak to the attendees and tell their story, inspiration, or some insight into their life.





In the evening, when conference activities were over, many families could be found at the hotel pool, strolling down Downtown Disney, or at Disneyland. All of this was within walking distance of Paradise Pier and many families took advantage of the close proximity to so much entertainment. Musicians played on the walkway throughout Downtown Disney, and at night you could see the magnificent firework display.



Leaving at the end of the conference was the only bad part, but knowing that this time next year will bring us all together again, somehow softened the goodbyes. As always, we make new friends, and see old friends, and our kids will get older each year. We, in the hemispherectomy community, know that the year will be full of challenges, and celebrations, hardships and successes. We also know that there will always be HOPE that comes with the choice that we made for our child. HOPE in knowing that we have a community that will always be there for our child.

"Hope in One Hemisphere!"

See You All in Baltimore on July 5th - 8th for the 2012 International Hemispherectomy Foundation Conference and Family Reunion. If you are interested in helping with this event, please send an email to Jane@HemiFoundation.org.

**Please send your comments and suggestions about this year's event to: Cris@HemiFoundation.org



Visit Our Website

www.HemiFoundation.org

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2011 Hemispherectomy Foundation Awards

At this year's International Conference and Family Reunion, The Hemispherectomy Foundation presented several outstanding individuals with an award for their contribution to the Hemispherectomy Community.

Hemispherectomy Foundation Director of the Year

Roxanne Cogil

Hemi Foundation Central Regional Director

Family Education and Support Award

Jack Epstein and Julie Dolson

Hemi Family Advocate of the Year Award

Seth and Deb Wohlberg

Medical Advisory Board Member of the Year Award

Gary Mathern, M.D.

Lifetime Achievement Award

Sue Yudovin





The Hemi Foundation
Presents

"Hope in One Hemisphere"

Watch it Here!

*



What can You Do with Half a Brain

Dr. Gary Mathern

*

Gifts, Apparel, and Merchandise Available at :



The Hemi Foundation Store

100s of Items to Chose From!!!

Shirts
Mugs



The 2011 Hemispherectomy Foundation Conference and Family Reunion would not have been possible without the dedication of this year's planning committee. These individuals worked tirelessly and many late nights to ensure that we all had a special event to remember for years to come.

Chair : Monika Jones

Chair : Rachel Waters

Don Barkley

Jeff Catania

Stella DeBode

Julie Dolson

Grace Hashimoto

Matthew MacDonald

Gary Mathern

Sandy Rabins

Sarah Swank

The Hemispherectomy Foundation would like to thank these individuals for their dedication to our children. Each of the winners received a plaque recognizing their outstanding achievement and dedication to the hemispherectomy community.



Hemi Foundation Supported Research



- Buttons
- Magnets
- Hats
- Baby Clothes
- Jewelry
- Ornaments
- Hoodies
- Pajamas
- Clocks
- Calendars
- Note Cards
- Stickers

Sport the Latest Hemi Gear and Support a GREAT Cause.

On Our Website

*Use Password : Butterfly



- [Ask The OT](#)
- [Ask The PT](#)
- [Ask The Vision Expert](#)
- [Ask The Teacher](#)
- [Ask The Specialty Directors](#)
- [Ask The Teen / Young Adult Panel](#)

Post Hemispherectomy Hydrocephalus

Dr. Sean Lew - Organizer

Because Hydrocephalus can present so differently in hemispherectomy patients, a cross-center collection of data is needed to help facilitate a quicker diagnosis. Many of our Hemi Family's hospitals are already participating in this consortium. So far over 20 hospitals are working together, sharing data, and building a better future for our kids.

Genetic Marker Exploration of Rasmussen's Encephalitis

The Hemispherectomy Foundation

Yale - Chris Cotsapas

RE Children's Project

The Hemispherectomy Foundation has partnered with Yale University, and The RE Children's Project to investigate the possibility of genetic markers associated with Rasmussen's Encephalitis. The Hemispherectomy Foundation confirmed the first related children with Rasmussen's Encephalitis. With funding from these three organizations, Yale is in the process of genetic mapping of the children and parents.

Executive Deficits and Autistic Features

Stella DeBode

UCLA/Neurorehab Rancho initiated a new research direction to investigate the prevalence and extent of executive deficits (planning, organization, completing tasks) and possible autistic features in our kids. For those of you who would like to participate, please fill out the two questionnaires on this [Yahoo Group Posting](#).

Functional Imaging Correlates of Functional Recovery in Children who have Undergone Complete Hemispherectomy

Dr. Harry Chugani

The proposed study aims to determine structural and functional imaging correlates of functional recovery in children who have undergone complete hemispherectomy. If you are interested in learning more about this research or participating, [Read Here](#).



North Central Regional Family Retreat



- [Stories of Hope](#)
- [Family Blogs](#)
- [Prayer Requests](#)



- [Yahoo Support Group](#)
- [Facebook Support Groups](#)
- [Condition/ Disease Pages](#)

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We Need Your Financial Support



[Support Hope in One Hemisphere.](#)

[Meet Our Medical Advisory Board](#)



Our Mission

On April 1st & 2nd, 28 Hemispherectomy Families gathered at the Sheraton Hotel in West Des Moines, Iowa for a low-cost, informal gathering to get acquainted with each other. This is 50% of the Hemi Kids Database for these Northern Central states in attendance! It was the first time for many to meet another Hemi family and the ages of the children with hemis ranged from 8 months to 16 years old. There were 2 Hemi Families from North Dakota, 2 from South Dakota, 3 from Nebraska, 3 from Kansas, 4 from Minnesota, 2 from Iowa, 3 from Missouri, 5 from Wisconsin and 3 families from Illinois who attended. Hemi Foundation's HME/CD Specialty Director Holly Paauwe from Indiana, along with her husband Jon and daughter Avery also attended.



All Hemi Kids!

Friday evening was an informal social. Each family took a turn at the microphone with family introductions, which was followed by family pictures. Hanger Orthotics was available throughout the evening for informal trials of the Walk-Aide. The children enjoyed watching the movie "Tangled" in one of the kids' camp rooms, while the parents visited with each other for the rest of the evening.



Movie Night for the kids - watching "Tangled".



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

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Hemispherectomy
Foundation Videos

[View our videos on YouTube](#) 

Saturday morning started out with breakfast, followed by the large group picture of all the Hemispherectomy kids in attendance. The morning session for parents included a presentation by Central Regional Director Roxanne Cogil who discussed the mission, purpose, services, resources and support available with the Hemi Foundation. Roxanne then did an overview of the International Hemispherectomy Conference Speakers and Topics. Following her was Jesse Wathan of Iowa who led the discussion on ideas for fundraisers for Central Region and Virtual Runner Team Sign-ups. The morning concluded with a presentation by Learning RX who went over cognitive rehabilitation, cognitive therapy, re-training the brain and neuroplasticity in order to gain/re-gain cognitive function in people with brain injury to strengthen weakened cognitive skills.



Having fun in Kids Camp.

Angie Wathan of Iowa coordinated the activities for Kids Camp, which had a total of 65+ children. The kids made crafts and were entertained by magician Keith West who performed a FREE hour long magic & illusion show, in which he had many kids participate to help him perform magic tricks. The morning ended with Tana Goertz doing a book reading to the children on her book, "I'm Bigger Than This", which is about Finny who hides himself in an orange fish outfit, since he is different than his friends, because he is a shark. During the lunch hour, Tana Goertz also did a book signing and had her picture taken with several kids.

Hemispherectomy
Foundation "Our Hemi
Kids"
Channel

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[Yahoo Group HME](#)



Keith West the Magician.

The first talk for the afternoon session for parents was led by Josie Bemis of Wisconsin. She brought an assortment of items to "show and share". Many other parents also shared ideas/items which they have found helpful for their child. The second talk was facilitated by Holly Paauwe of Indiana, along with Josie Bemis. The talk was on "Topics of Interest". Previously, during the lunch hour, parents went up to the flip chart and wrote down topics they were having challenges with and Holly went through each topic to discuss it. It was an interactive discussion of parents helping parents, which was very informational.



**Participants in the Kids Apprentice Program
with Tana & "Donald"!**

While the parents were in session, Tana Goertz (www.heyтана.com) and her assistant, who was dressed up as Donald Trump, did a Special Needs Kids Apprentice Program during afternoon Kids Camp. The program focused on building skill sets and is a mini version of the hit TV show Apprentice. Tana was a finalist on the Season 3 Apprentice TV show with Donald Trump and she lives in West Des Moines, Iowa. Dr. Fitzgerald, Hemi Foundation's "Ask the Vision Expert", sponsored Tana's program for kids camp. The Special Needs Kids Apprentice Program lasted the entire kids camp afternoon session for Hemispherectomy children and their siblings. They divided the kids into 5 teams

and each group came up with their own team name and worked on three tasks throughout the afternoon: designing a poster, making a 30 second commercial and doing Finny trivia. The kids all had a blast and each team presented their poster "in the boardroom", along with their 30 second commercial and trivia results! Tana Goertz said, "This group of kids was the most loving group I have EVER worked with. I got more kisses and hugs in one day than a normal person gets all year!!".



Nellie having fun at Incredible Pizza.

The group then headed out for an outing to Incredible Pizza for supper, games and fun! Incredible Pizza provided incredibly low rates to everyone in our group for their all you can eat Smorgasbord Buffet, which was funded by the Hemi Foundation's Central Region Budget. Incredible Pizza also offered FREE unlimited game play cards to each Hemispherectomy child in attendance. Families enjoyed the indoor go-kart track, mini-bowling balls in the bowling alley, arcades and many, many other games. We all returned back to the hotel for a couple hours of swimming, then finished out the remainder of the night in the meeting room with social and snacks.



New best friends!

Many thanks to Angie Wathan, Josie Bemis and Patty Kettelhut for helping Roxanne plan this event and to all our sponsors (Sheraton Hotel, Dr. Fitzgerald, Applebee's, Olive Garden, Hy-Vee, Fareway, Starbucks, Panera Bread, Baker's Square, West End Diner, Roberts Dairy, In The Bag, Incredible Pizza, Madonna Rehab Center, Keith West & Tana Goertz) and our volunteers for helping keep this a no-cost event, so many families could attend. It was great to see kids who had hemispherectomies make friends with each other; siblings make friends with other siblings, as well as parents connecting with other parents who "get it".



Dreams on Wings Awards



Team HEMI Miracles with little Alex Jones & family

Congratulations to HEMI Miracles in Virginia who finished in 1st place of raising the most dollars on a Virtual Runner Team and is the WINNER of getting a 2012 scholarship named after their team! Angie Jones spearheaded this team in honor of her grandson Alex (11 months old) who had a left hemispherectomy less than six months ago for Hemimegalencephaly.

At the International Hemispherectomy Conference, we recognized those Dreams on Wings Hemi Teams who went above and beyond and fund-raised **over \$1,000** for the Hemispherectomy Foundation! The recipients were presented with framed Dreams on Wings Gold Medals for achieving this honor.



Teams who raised over \$1,000

HEMI Miracles (VA)
Team Kinley (TX)
Josie Wathan (IA)
Jessie's Miracle of Hope (TX)
Jogging for Georgia (CO)
Rachel's Rainbows of Hope (IA)
Team Jaxon (OH)
Ben Hittle's Team (CO)

We also recognized, at the International Hemispherectomy Conference, those Dreams on Wings Virtual Runner teams who achieved the Hemispherectomy Foundation's initial challenge of recruiting 10 or more Virtual Runners (the equivalent of \$300 or more) for the Dreams on Wings Fundraiser. The recipients were presented with Hemi Angel Certificates for achieving this honor.



Teams who raised over \$300

Ryan's Runners (ND)

Hoosiers for Hemis (IN)
Team Ty (OK)
Team Amina (CA)
Friends of Grace (CT)
Team Nellie Jo (IL)
Mallory's Mighty Movers (SD)
Team Ashlyn (CA)
Avery's Angels (GA)
Jody's Team (MD)
Team Elysia (WI)
Team Payleigh (NE)
Team Jacob W. (ID)
Team Jake (IL)
On The Right Track (MI)
Aaron's Entourage (NE)

If your team is listed above and you weren't in attendance at the International Hemi Conference, then you will be receiving your awards in the mail very soon.
If we missed anyone, be sure to let us know.

*Congratulations and Thank You for providing
Hope In One Hemisphere!*

Pictures of Virtual Runner Teams



Team HEMI Miracles of Virginia!
Grandma Angie Jones organized a Virtual Walk at a
local
park in Virginia in honor of her grandson Alex and
WOW what a great turnout...in the rain!



Team Jogging for Georgia of Colorado!
Alicia Grenolds rounded up friends and ran in a 1/2
Marathon
in Colorado in honor of her daughter Georgia.



Team Jaxon of Ohio!
Nicole Fuller organized her first Fun Run/Walk
with friends and family in honor of her son Jaxon.



Team Hoosiers for Hemis in Indiana!

Holly Paauwe rounded up other Hemi Families, plus family members and friends to raise funds and walk in honor of their children on a local trail.



Team Ashlyn of California!

Don Barkley of California organized a walk/run on a local river trail including running bibs and goody bags for all the participants.



Aaron's Entourage of Nebraska!

Brianne McDonald of Nebraska rounded up some friends and family to walk at a park in honor of their son Aaron.



Team Jody of Maryland!
Lynn Miller & family of Maryland organized a 1 mile Fun Walk on a local trail.



Team Josie Wathan of Iowa!
Jesse Wathan & family rounded up family, neighbors and friends for a Fun Walk on a local trail.

Thank you for being HEMI ANGELS to help raise funds and create awareness to serve and support Hemispherectomy Families!



Hemispherectomy Foundation Scholarships

Congratulations to the winners of the 2011 Jessie Hall Hemispherectomy Scholarship. [Read their winning essays here.](#)



Sarah Shivock



Nicholas Bunker



Hailey Stroud



Dylan Norwood

The Jessie Hall Hemispherectomy Scholarship (JHHS). The JHHS is a scholarship awarded annually to young people who have undergone a hemispherectomy and who have been accepted into an institution of higher learning. This years recipients will receive \$1,000 toward books, tuition, or other needs as they see fit to make their college experience more rewarding.

The 2011 Dreams on Wings 5K Virtual Runner Team Scholarship Winner

Congratulations Jody Miller, the winner of the 2011 Alexander Ethan Jones Hemispherectomy Foundation Scholarship. [Read her winning essay here.](#)



Jody Miller

The Dreams on Wings 5K Virtual Runner Team Scholarship is named each year for a child who has undergone a hemispherectomy, and has the largest virtual runner team in the annual Dreams on Wings 5K. Miss Miller will receive \$1,000 toward books, tuition, or other needs as she sees fit to make her college experience more rewarding.



Alicia Grenolds and Jane Hittle

NEW! Denver & Rocky Mountain Area Hemi Support Group

Western Region is looking for Denver, CO and Rocky Mountain Area Hemi families! If you are interested in being part of a local Hemi support group, please email: Alicia Grenolds (alicia_staub@hotmail.com), Mom to Georgia, 4 years, or Jane Hittle (jkhittle@comcast.net), Mom to Ben 5 years. We are hoping to organize a gathering for our wonderful Hemi kids and families in the fall or winter to get the ball rolling. Details to follow. Hope to meet you all soon!



Nicole Fuller

NEW! Cleveland Area Hemi Support Group

In the Eastern Region, Hemi Parents Nicole Fuller and Dana Osborne are starting up a Hemi Support Group for the Cleveland, Ohio area to get families better acquainted with one another for support! If you are interested in attending, please contact Nicole at nicole@hemifoundation.org or Dana at danaosborne@gmail.com. Nicole is also the new Eastern Regional Director for The Hemi Foundation.

Details for the event:

Date: August 13th * Time: 1- 5 p.m.

Location:

Mt. Zwingli United Church of Christ

2172 S. Medina Line Rd.

Wadsworth, Ohio 44281



Hemispherectomy Foundation Camp Assistance

Thank You Hemi Foundation !

Thanks to The Hemi Foundation, Kayci was able to attend a speech aerobics camp in Atlanta that met every Tuesday for 6 weeks. the camp was to focus on speech, how to have conversations, how to take turns, remembering names so that you can approach people by name and then they did some light movement activity which was little relay races that kayci thought was so much fun, (she loves to run) Kayci had the pleasure of meeting jake who was her favorite cause he talked to her and played whatever she wanted to play. Jillie was nice but she didnt talk much so kayci pushed her for conversation (they had to teach personal space), Kelsey was very active and kayci loved that but she didnt know that she helped Kelsey to open up. her mother asked us for play dates because her daughter would talk around Kayci. this camp was awesome for Kayci, someday she would cry because she didnt want to leave. I thank you from the depths of my heart for allowing my baby to experience fellowship, fun and new friends.

Thank you!
Chiquita and Kayci Clemmons

= = =

My daughter Emily was awarded a scholarship to attend a camp for special needs children last summer. I can't begin to tell you how much that money meant to us. It was more than money it was an opportunity to have Emily be a normal kid with a normal camp experience. It was a blessing to have you guys help us to pay for it. Emily has gone to this camp for a few years and it was paid for by a grant that she received. That money ran out last year and we were not aware of it until it was too late to come up with \$600. You saved us from a disaster. If not for that money to send Emily to camp I would have not been able to interview for and get

offered a job. I would not have been able to attend the required training for this job. But because Emily was safe at her day camp with people I trusted, I got a great job that fits my life and still gives me time for both of my kids. Emily's therapies, doctor appointments, ARC meetings, not to mention all the activities of my 5 year old, leave me with little time to work except when my kids are at school. We also met Melissa, a counselor at Emily's camp, who has become our go to person for babysitting! She is great with Emily and Katelyn. She is studying to be a special education teacher so it's a perfect fit! This year we have put away enough money to pay for the camp in full. I hope that some other child has the opportunity to benefit from the camp tuition assistance that Emily received last year. Thank you so very much!

The Swanson Family
Brad, Kristi, Emily and Katelyn



Making a Difference

Thank You to The following for your support and fund raising efforts:

Sunshine Glenn - Garage Sale

Nicole Beno - Garage Sale

Dear Hemi Foundation,

I Hope all has been well for you guys. I wanted to let you know that my church did do the donation drive in August and into September. We have a lot of stuff for the Hemi Hug program. Our plan was to drive it down and meet you all. I have been very sick, and I am now on medication and feeling lots better.

I would like to go ahead and mail this stuff to you guys. Also we raised some money along with the donations and I wanted to know if you would like for me to buy gift cards or just send a check. We do not mind either way. My church talks as though they will do this each year and if so hopefully we could meet in 2011. Attached is a picture of Alex with all the donations that was collected. Could you please send me the address that you would like these items mailed to.

Thank you,
Veronica Cales



**New Hemi Foundation YouTube Channel
"Celebrating Our Kids"**

by Jack Epstein

We'd like to introduce a new You Tube channel devoted to our amazing children.

<http://www.youtube.com/user/OurHemiKids>

People constantly wonder what their kids will be like after surgery. With that in mind, we'd like to fill this channel with great videos (of any quality) of your kids and their accomplishments! Learning to ride a bike/trike, reading,

walking, first words, first steps after surgery, first foods, etc. But, we can't make this channel great without you!

Please send videos, preferably short examples of your kid's accomplishments, to Hemi Dad Jack Epstein (jepsteen@mac.com). You can use the various file transfer websites like yousendit.com or megaupload.com. Or, if that option doesn't work for you, send Jack an email, and he'll give you an address to send a disc. We'll upload as many as we can to the channel ASAP. If possible, also include a short description, in this format:

<your child's name>, <age>, <when/what surgery>, <what they're doing>

For example, Levon, 4 years old, Right hemi 2008 loves to recite The Pledge of Allegiance.

Let's help people considering the surgery see what our kids can do!



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 volunteered their time to serve in various aspects of the operation of The Hemi Foundation.

Nicole Fuller - Eastern Regional Director

Chris Jones - Website Team

Saasha Huston - Website Team



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 Cris@HemiFoundation.org.

Current Volunteer Opportunities:

Website Developer

Website Proof Readers and Testers

Newsletter Writers and Reporters

Newsletter Editors

Newsletter Proof Readers
Newsletter Designers

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!"



Contact The Hemispherectomy Foundation

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



Try it FREE today.