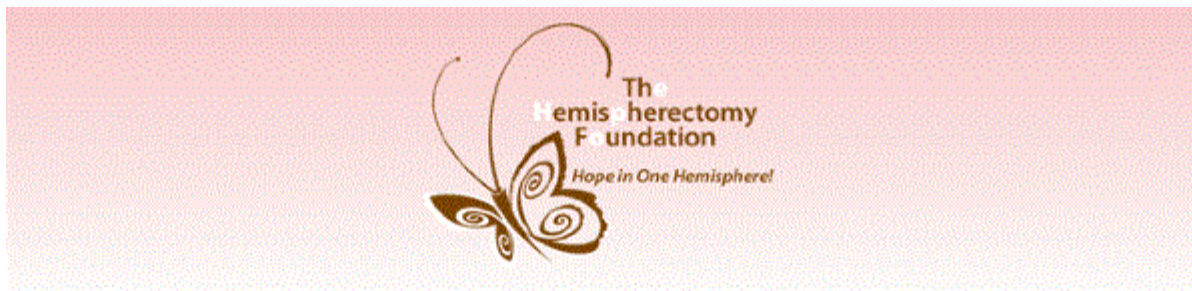


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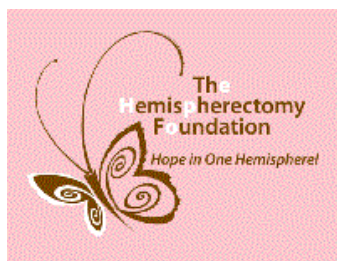
published by the Hemispherectomy Foundation

October 2014 - Revised (with video links in tact)

In this issue you'll find a recap of the Hemispherectomy Conference this past July in Anaheim, CA as well as an overview of the very first Robocamp at Rancho. The Hemi Golf Tournament was a huge success in Cedar, MN and we've got the 4th Annual Hemi Jam coming up in November in Lawrence, KS. Read on and see what else is new....

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HemiCon 2014

Recap by Monika Jones

The 2014 Hemispherectomy Conference and Family Reunion was held at the Paradise Pier Hotel at the Disneyland Resort in July of this year. Families from as far as Australia gathered to share stories, make new friends and, learn from professionals.

Day One

Amanda Caldwell (a.k.a. "DJ Red"), a young woman who had a hemispherectomy several years ago, opened the conference with a funny and engaging introduction. A college student and radio disc jockey, Amanda received the Founders' Award from The Brain Recovery Project for her outstanding contribution to neuroscience. By participating in three research projects to date, with several in the pipeline, Amanda is likely the most studied person in the world after hemispherectomy surgery. (Follow DJ Red on Facebook [here](#).)

[Dr. Karen Pape](#) gave the keynote address where she discussed



**We need your help in a
BIG way.**

We need YOU to help US to get the word out about the United Way. We are so excited that the United Way is now allowing donations to be directed to The Hemispherectomy Foundation, and we need you to help us communicate this exciting news. Even if you don't participate in United Way, changes are you have relatives and friends that do, so please pass this message along to them.

Please **copy and paste the red paragraph below** and post on Facebook, Twitter, Instagram, in emails, text messages, etc. Together we can make this the Hemi version of the 'Ice Bucket Challenge'. Consider yourself nominated!

"When you donate to United Way, please ask that they direct your pledge to an organization that is near and dear to our hearts. The Hemispherectomy Angels, EIN 262864993 (this is the Hemispherectomy Foundation's official name and ID). Also, please visit www.hemifoundation.org and read about the children they help and the work they do. Use password 'butterfly' where needed. Thank you from hemi families everywhere!"

Thanks!!

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how to minimize maladaptive habits while maximizing neuroplasticity. In a presentation similar to her [TEDx talk](#), she discussed the importance of studying the outliers in any community to better understand how their outcomes are achieved. She warned the audience that maladaptive practices, such as neglect of the hemiparetic arm, can develop early, and it is easier to prevent them than correct them later in life. Suggestions from Dr. Pape included:

- A [water exercise program](#) that uses a [neutral buoyancy wet vest](#) in a swimming pool to encourage proper bilateral leg movement, as much as 5-6 days per week for very poor gait. See an example [here](#);
- Proper alignment should be a top priority before strength and agility. See her blog post on alignment [here](#);
- Constraint therapy, treadmill training, and any other intensive program are ineffective without proper alignment first. Use kinesio tape or vests to help with alignment;
- [Stabilize](#) the wrist and thumb before beginning any intensive practice;
- Hand splints and braces should be brightly colored or covered with brightly colored tape to help the child be more aware of their hemiparetic hand;
- Any new skill can only be effective through constant repetition;
- Intensive programs are better than the traditional therapy model of three sessions of therapy per week. Work with your insurance company to save weekly therapy sessions for use in an intensive program, instead.

Drs. [Cynthia Salorio](#) and [Patricia Walshaw](#), pediatric neuropsychologists, next addressed the importance of neuropsychological testing. Neuropsychological testing will help the parent and school understand the child's strengths and weaknesses. Parents were cautioned not to rely on standard IQ tests alone, because the common problem of slow processing speed post-hemispherectomy will bring down the overall IQ score. Instead, focus on the specific components of the IQ test with particular attention to those the child performed well.

After hemispherectomy surgery, cognitive areas affected include:

Brain Matters Newsletter Archives

VIDEO: Hope in One Hemisphere



VIDEO: The Differences in Hemi Procedures, Seizure Recurrence and Underlying Conditions Dr. Gary Mathern



VIDEO: What Can You Do With Half a Brain Dr. Gary Mathern



Parents at HemiCon 2014 learn about special needs trusts in a breakout session



Carolyn Pinto, Kylie Hockley and Team Australia at the Luau Dinner

- [attention](#);
- [effort](#);
- [focus](#);
- [working memory](#);
- [long term memory](#);
- [emotional regulation](#); and,
- [planning](#) (including [executive function](#) and [motor planning](#).)

Because the remaining hemisphere will not automatically pick up the cognitive functions of the lost hemisphere, a good assessment should include recommendations for targeted interventions for the challenges listed above.

After lunch together, families enjoyed free time by the pool, Disneyland, and gather for impromptu dinners together in Downtown Disney.

Day Two

Day two opened with an introduction from Rebecca Kopp, a young woman who had a hemispherectomy over twenty years ago. She discussed her challenges as a preschool aide as well as her struggles with math, but also encouraged the audience to believe in their dreams and “never give up.”

A panel of specialists next discussed common issues after hemispherectomy surgery. [Dr. Michelle Van Hirtum Das](#), neuro-anatomist and neurologist, introduced the audience to the anatomy of the brain.

[Dr. Gary Mathern](#), pediatric neurosurgeon, discussed hydrocephalus in detail and concluded that it is a very poorly understood condition. It can be a problem with absorption of cerebrospinal fluid, production of cerebrospinal fluid, or a combination of both. Symptoms can include headaches, vomiting, poor balance, seizures, and lethargy. Although anatomical hemispherectomy is associated with a greater incidence of hydrocephalus, it also occurs after functional hemispherectomy. When an audience member asked him when a parent should stop worrying about the possible need for a shunt, he replied “never.” Hydrocephalus can be a problem at any time after surgery. He encouraged parents to familiarize themselves with the large



Roommates Cassie Mills and Tracey Blackman attended HemiCon without the kiddos in tow



Monika Jones presents Amanda Caldwell with an award from the Brain Recovery Project for her Outstanding Contribution to Neuroscience



hemispherectomy hydrocephalus study (see [here](#).)

Drs. [Raman Sankar](#) and [Don Shields](#) gave presentations similar to those at the 2011 conference, which can be seen [here](#). Dr. Anna Haddall discussed precocious (early onset) puberty as something parents should be aware of, as it is relatively common in children with neurological issues.

The conference then split off into separate sessions. Drs. [Mark Borchert](#), [Alain Ptito](#), and [De Anne Fitzgerald](#) discussed vision after hemispherectomy surgery. Because of the nature of the surgery, there is a loss of an entire field of vision (right or left) – not simply a peripheral vision loss. Some children develop [exotropia](#) post-operatively, either because the brain is unable to control the movement of the eye or the child is trying to compensate for the field loss by moving the eye outward. Some parents elect to do strabismus correction surgery, while others have had success with vision therapy or patching. Prism glasses, which shift the field of vision, have been used by some children with some success but require training.

Dr. Ptito discussed blindsightedness in the lost visual field and also conducted data collection on the subject from many young adults and children at the conference. Simply put, for many persons post-hemispherectomy, they are able to see black and white in their blind field but do not know it consciously. A recent, similar talk by him on the subject can be seen [here](#).

Dr. [Lucinda Baker, Ph.D.](#), discussed neuromuscular electric stimulation (NMES.) NMES provides 1) sensory input, 2) muscle strengthening, 3) modification of “tone”, and 4) motivation (to help the hand to move.) Voluntary movement, supplemented with NMES, will give an additional boost to movement and is highly recommended. Equally as important is meaningful activity; in other words, make sure the activity is interesting to the child, is triggered by the affected hand or foot, and the more repetitions the better. Orthotist [Spencer Doty](#) discussed Kiddie Gait’s [new carbon fibre AFO](#) (ankle foot orthotic) which slows down the step with flexibility and can be combined with a supra malleolar orthosis (SMO.) He also encouraged parents to have the child watch a video of someone walking while the child was watching, a strategy supported by mirror neurons of the brain which was discussed at

Everyone enjoyed the
Polynesian Dancers



[Click here to view more pictures from of the 2014 Hemi Conference and Family Reunion](#)

RESOURCES

Financial
Looking for financial resources to help with medical expenses, adaptive aids, therapies, etc? Visit our Financial Resource Page and you'll find a list organized by geographical region

Specialists and Support
use password: butterfly

We have a network of helpful specialists at our fingertips available to answer questions, including

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Occupational Therapist
Vision Expert
Hemi Foundation Specialty Directors
Hemi Teen and Young Adult Panel

In addition you'll find
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Family Blogs
Prayer Requests
Yahoo Support Groups
Facebook Support Groups
Information on
Conditions/Diseases

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length at the scientific conference.

Dr. [Nisha Pagan](#), Ph.D., discuss intensive mobility training after hemispherectomy surgery. It is used to improve gait and balance, and is comprised of two weeks of three-hour sessions per day, with approximately 400-600 repetitions per session. Current research has shown that progress can be made even several years after surgery.

Drs. [Robert Kay](#) and [Nina Lightdale](#), orthopedic surgeons, discussed common issues after hemispherectomy surgery. All children post-hemispherectomy should be scanned regularly for [hip subluxation](#), which is often not revealed until it is quite severe. Limb discrepancies of 1-2cm are often well-tolerated and orthotic devices can usually address this issue well. Neglect of the hemiparetic hand is extremely common, however, children can manage and adapt well to one-handedness. Even for the child with limited hand mobility, they can benefit greatly from tendon and elbow surgery. Children with acquired pathology (such as Rasmussen's encephalitis) over the age of five are the most challenging to treat in terms of arm and hand function.

Saturday night included a spectacular luau with performances by [Tupua](#) and the [International Children's Choir of Long Beach](#).

[Not all topics discussed at the conference are discussed here. A special thanks to Carolyn Pinto (Hemispherectomy Foundation, Australia) and Anthony Fleming, for their contribution to this article.]

*****SAVE THE DATE*****

**2015 HEMISPHERECTOMY CONFERENCE AND
FAMILY REUNION
JULY 10-11, BALTIMORE, MD**

Hemi Golf Tournament 2014

By Shanna Sabet

As a 'Hemi Parent', I know firsthand how difficult it can be to accept the cards that life has dealt to our families. Moving past the initial stages, when one of the questions we ask the most is 'Why

password: butterfly

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This year the **Hemi Golf Tournament** proudly welcomed 40 golfers, and an additional 60 supporters, and raised XX for the Hemispherectomy Foundation

UPCOMING EVENTS

Hemi Parent Meet Up
Sat, Nov 1, 2014
Westford, MA

Parents of children who have undergone

my child?' takes strength and determination. One 'Hemi Mama' decided to honor her daughter and the surgery that saved her life...through golf.

Hailing from Minnesota, Kori Kielty started the Hemi Golf Tournament 4 years ago as a call to increase awareness and raise funds for the foundation in the name of her daughter Abby, who began having seizures in the summer of 2010. Abby was initially given an incorrect diagnosis of Acid Reflux, but shortly after, the family connected with a knowledgeable neurosurgeon and Abby's family learned what had really been happening to the young girl. She was having seizures due to Hemimegalencephaly, which involves an enlargement of one side of the brain. On November 1, 2010 the Kielty's family and friends gathered together at St. Paul Children's Hospital, as little Abby went in for her Hemispherectomy.

Fast-forward to the present day, where we find Abby as a thriving 4 year old, and her parents Kori and Rick continuing to raise awareness for the surgery that saved their daughter's life.

"I think if every family did a little fundraiser, that would be the best thing," said Kori. "We are raising money for a cause that actually reflects our own family."

This year, the Kielty's hosted the 4th Annual Hemi Golf Tournament on Saturday, August 23 at Hidden Haven Golf Course in Cedar, Minnesota. In four years the golf tournament has grown from 20 golfers to about 40, and there is also a 'dining only' option for those who aren't keen to hit the links, but would still like to participate. All in all, the event pulls in nearly 100 participants who golf, dine, and enjoy a little competitive bidding on items during the event's silent auction.

"This year the amount of prizes is insane," said Kori. "We have all kinds of things like Hockey tickets and 'Girls Night Out' spa gift certificates."

In fact, around 30 silent auction prizes and 50 raffle prizes were awarded during the event. They even had a notable prize which found one winner taking home 50% of a special cash prize, with the other 50% of the proceeds benefitting the Hemispherectomy

hemispherectomy surgery and their friends and loved ones are invited to attend a casual reunion on Saturday, November 1, 2014 at the Westford Regency Hotel in Westford, MA. This reunion is intended for adults only, as we have no children's activities planned and we will be likely gathering in a pub setting. This is a time to meet face to face, share stories, advice, laughter and support for each other.

There is no cost to participate, however each person is asked to pay for whatever they intend to eat or drink, and if they'd also like a hotel room simply make a reservation. Please RSVP to Tracey Blackman at tracey89a@charter.net or 203-915-3874, or visit our [Facebook event](#)

Hemi Jam
Sat, Nov 22, 2014
Lawrence, KS

The bands are being finalized for the fourth annual Hemi Jam which will be held on Saturday, November 22 at The Granada in downtown Lawrence at 7PM. We are especially excited because one act is someone from our very own hemi community. George DeMott, is coming all the way from Las Vegas to take the stage at the Granada.

Check out www.georgedemott.com! The night includes three live bands, silent and live auctions, dancing and fun.

Tickets are \$15 and all proceeds benefit the Hemispherectomy Foundation. If you plan on attending, there will be a block of rooms available for Friday and Saturday nights. Email info@hemijam.org

Foundation.

For more information on the Golf Tournament and the Kiely Family, visit their Caring Bridge site at caringbridge.org/visit/abbykiely.

Robocamp at Rancho!

By Monika Jones

This summer, seven children several years post-hemispherectomy participated in the first robotics camp ever. Fondly known as the Magnificent Seven, these kids received intensive physical therapy specifically targeted at their hand, wrist, and ankle (areas most affected by hemispherectomy surgery) as well as overall locomotion. But fun was in the mix too, in the form of recreational yoga classes and other activities aimed to encourage camaraderie and improve social skills.

This exciting and innovative program initiated by [The Brain Recovery Project](#) (a strategic partner of the Hemispherectomy Foundation) at the [Rancho Los Amigos National Rehabilitation Center](#) in Downey, California, promises to be the platinum standard for 21st century neuro-rehabilitation for children with disabilities. By providing two weeks of intensive, robotics-assisted therapy in a camp-like environment - rather than the sterile setting of a hospital - children participate in a program that targets their specific neurodevelopmental challenges. Grouped with children with similar disabilities, they get to hang out with kids "just like them" in a fun and engaging environment.

Why Rancho?

Rancho Los Amigos National Rehabilitation Center is a leader in neuro-rehabilitation. With their team of highly trained therapists and professionals, and through their research partnerships with the California Institute of Technology (Cal Tech) and the University of Southern California (USC), Rancho is on the leading edge of rehabilitation research. Their research collaborations are helping [paralyzed people walk](#) with exoskeletons or control robotic hands with brain computer interfaces.

What's So Special About Robotics?

for details. We'd love to see you there, but if you are unable to attend, stay tuned because we will be broadcasting the event LIVE online. For a suggested minimum donation of \$10 you will be able tune into the event from afar. Please like our [Hemi Jam Facebook page](#) to hear the latest as this special night gets closer.

**Hemi Lighted Forest of Hope
October through March
6565 Ashley Drive,
Cheyenne, WY**

The Hemi Lighted Forest of Hope in Cheyenne, Wyoming, is a celebration of LIFE and HOPE for children all over the world, who have had their lives turned upside down, in a battle against intractable epilepsy. These children all underwent radical brain surgery in HOPE of living a life seizure free. A tree will be lighted for each child who has undergone Hemispherectomy Brain Surgery and who has registered with [The Hemispherectomy Foundation](#). These trees and lights represent a celebration of each child's HOPE for a life without seizures.

Lights can be seen October 15 through February 28 from dark through 10:30p each night. Hay rides and hot chocolate begin Sunday after Thanksgiving and to through New Years Eve.

Any questions please call Gary at 307-630-6641 or e-mail us at papa@hemiforest.com.

**Hemispherectomy
Conference and Family
Reunion**

Today's robots sense the patient's capabilities and provide suitable assistance; in other words, they help the child only as much as they need it by being highly responsive to their movements.

Robotics also provide hundreds of repetitions per hour - far more than any human therapist can get out of a child in a typical therapy session. And the best part of robotics is that the child actually wants to engage the robot through the video game interface. This makes therapy fun while at the same time focusing on the specific physical motions that need to be improved.

"Putting blocks in a box over and over and over again just isn't fun for a child" says Monika Jones, President and co-founder of The Brain Recovery Project. "And these kids are sick and tired of being in a hospital setting. I've always thought that there should be a camp where they can receive the very best, most innovative therapy in a fun environment. It's certainly the least we can do for them after such a drastic procedure. We're lucky to have Dr. Luis Montes, Director of Pediatrics for Rancho, on our board of directors. He was the one who introduced us to the concept of robotics and to Dr. Mindy Aisen. Dr. Aisen and I had an 'aha!' moment at lunch one day when we decided that we would develop a camp for kids post-hemispherectomy on these robots."

The program was technically a proof-of-concept research study to determine whether intensive therapy could be provided in a camp-like environment. "One thing is certain. This proof of concept 'experiment' was a smashing success" says Dr. Mindy Aisen, Chief Medical Officer of Rancho. "The brain is a learning machine throughout life. This is critically important to remember when working with children or adults with any brain disorder. At any time in life there is capacity for plasticity in the human brain to lay down new memories and new motor skills. Just as the elite musician or athlete can hone specific motor skills, the child whom has had a large portion of their brain removed CAN acquire new motor skills by using intensive, engaging, task specific practice. This summer for the first time these children received the most intensive task specific practice possible in a 2 week period: 3 hours per day of exoskeleton assist as needed robotic therapy coupled with video games to keep them immersed and motivated, as well as other generally enriching motor and cognitive programs."

Did The Children Experience Motor Improvement?

July 10-11, 2015
Baltimore, MD

The Hemi Foundation website will be updated soon with conference details

[Double-Tree BWI Hilton](#)

Sasha Sabet works on arm kinematics using the Interactive Motion Technologies ARM Interactive Therapy System



The entire team of Robocamp participants and therapists at Rancho Los Amigos



WELCOME

Please welcome the following new Directors to the Hemi Foundation Team

- Lisa Koesterer - Director, Pediatric Stroke
- Mary Silva - Assistant Director Pediatric Stroke
- Karen Sicillano - Assistant Director, Pediatric Stroke

And also Tracey Blackman - Publisher Brain Matters

Data collected, including fMRI, is being analyzed now to determine whether the program improved each child's function. Angie Wathan, whose daughter Josie participated in the program, is certain her daughter's arm function and gait have improved. "Josie is using her left arm more. She has full range of motion all day long and appears to be moving her left arm more frequently. Before, within two hours, she had limited range of motion and would neglect it. And her gait is better. She has not fallen or tripped since camp. Before, she would trip or fall multiple times a week.

Her entire left side is looser. She wants to go back to camp next year and talks about how much fun camp was. The dancing is always the first thing she talks about."

Dan Huston, whose son Gibson participated in the program, says "we have definitely noticed an improvement in his gait. His local [physical therapist] has also seen an improvement in his gait and hip flexors. This is something they have always worked on during [physical therapy], but Gibson seems to be performing better now."

Sandra Webb, whose daughter Hannah also participated in the program, says "[Hannah] is more aware of and more willing to use her affected side. I think that is due to a combination of using it so much at camp and because when she did use it, she was supported and encouraged by the others regardless of how well it worked. We have carried over Remy's (the clinical manager) suggestions for shoulder realignment into our [occupational therapy]."

Some children, however, did not have noticeable improvement in gait. "We don't see any improvement [in gait]" reports Cris Hall, whose daughter Jessie participated in the program. However, "[i]f you look at the camp holistically, it is a great benefit, especially from the social aspect" say Kristi Hall, Jessie's mom. Jessie says, "I can't wait to go back!" "Really, the social side was the biggest thing for Jessie. She loved hanging out with all of the other kids." Dr. Aisen agrees: "[t]he fact that they enjoyed the experience and 100% want to return is a huge success."

The impact the program had on the therapy team was an unexpected result of this program. "Robocamp was an incredible experience for all of us and it was more successful that I had even hoped" says Dr. Susan Shaw, Assistant Professor of Neurology at USC and epileptologist with Rancho. "I give great kudos to our

Newsletter

If you are interested in volunteering for the Hemi Foundation, please email crishall@hemifoundation.org. Volunteer opportunities can be on any of [our teams](#).

CALL FOR CONTRIBUTORS

We're always looking for meaningful content for our Brain Matters newsletter, especially articles and stories written by our very own Hemi community members. If you have a story you'd like to tell, please email hemi@traceyblackman.com and we'll include it in an upcoming issue. If you have a subject you would like to see covered, email that as well and we'll try to find someone to write it for us.



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Hemi Foundation's Website

staff – who, by the way, are some of the best out there – who worked really hard and cared so much about each person. Yet besides staff and equipment, a successful rehabilitation program needs a third ingredient, which is the people doing the therapy. I knew this was going to be a great group of kids, but I didn't realize just how utterly amazing they would be. They had such great attitudes, determination, and fortitude, and the best smiles you can imagine. It was wonderful to hear them proudly tell me they just beat their high score, to see them concentrating so hard on their robot task that they don't want to look up at me, and to watch them encouraging each other and becoming great friends. Robocamp 2014 really sets the stage for developing more camps based on this concept, and I am looking forward to it."

Will The Camp Be Offered Annually?

"The Brain Recovery Project is fully committed to making sure that this program is an annual event. And not just at Rancho, but at other facilities across the country like Research Institute of Chicago in Indianapolis and Blythesdale Children's Hospital in New York state, where these pediatric robots are now available" says Monika Jones. "Next year we will offer more therapy more specific to each child's needs and test robot against robot, consider adding neuro-modulation as an arm of the treatment (to assess whether such treatment enhances robotic therapy) and even more rigorously collect and analyze the program" reports Dr. Aisen. If the decision was left up to Remy Chu, Clinical Manager at Rancho and Adjunct Professor at USC, the answer would be Yes.

"Robocamp was such an amazing experience. Getting to know all of the Magnificent Seven and their families was truly an inspiration. The kids' energy and enthusiasm was contagious and has fueled my drive to combine intensive therapy and technology in helping others regain meaningful outcomes. I am happy to report that preliminary data seem very promising, a confirmation that we are definitely heading in the right direction. Special thanks to the Brain Recovery Project and the Hemispherectomy Foundation for your partnership in this exciting venture."

Funding

Funding for the camp was provided by Rancho Research Institute. The Hemispherectomy Foundation provided \$3,500 to cover each family's co-pay, and The Brain Recovery Project

initiated the program and covered the expenses for meals, transportation, and other costs. Downey Women's League donated rooms in their Housing of Medical Emergencies temporary residential facility.

How Can I Help?

This two-week program costs approximately \$40,000 to fund seven children. At this time, The Brain Recovery Project is actively seeking individual, corporate, or private foundation support for this program. Contact Brad Jones at brad@brainrecoveryproject.org for more information.

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 www.hemifoundation.org

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