



The Hemispherectomy Foundation Brain Matters Newsletter

April 29, 2010



[The Hemi Foundation Dreams on Wings 5K and 1 Mile Fun Run](#)

The Hemispherectomy Foundation and Parker County Physical Therapy will host a 5K and 1-mile fun run/walk on Saturday, May 15. "Dreams on Wings" will honor Aledo's Jessie Hall, a second grader who underwent radical surgery in which one half of her brain was removed. All proceeds from the event will benefit The Hemispherectomy Foundation, a non-profit organization dedicated to providing emotional, financial and educational support for individuals and their families who have undergone or will undergo a hemispherectomy, or similar brain surgery.

"The 2009 Dreams on Wings 5K was a great success! The foundation

Greetings!

This is easily the hardest Brain Matters introduction that I have written since The Hemispherectomy Foundation was created almost two years ago. You see, we lost one of our Hemi Kids recently, and it was one of the children that I had met personally. I knew his mom and dad, and I had great hopes for his future.

It was bound to happen sooner or later, given such a dangerous brain surgery, but still that doesn't help ease the pain. I thought that I had prepared myself for this eventuality, but I hadn't. I guess one can never prepare for this kind of thing.

I want to dedicate this edition of Brain Matters to Srikar's parents, Lakshmi and Ravi. The first article in this edition is written by our Specialty Director Hemimegalencephaly and Cortical Dysplasia, Holly Paauwe. It is a beautiful tribute to a beautiful family, the Potluris.

As many of you read this, Holly's daughter will be recovering from an additional brain surgery. So even as we struggle with the risks of hemispherectomy brain surgery, we also continue to have HOPE in the possibility of a seizure free life, and one lived to its fullest.

There are some INCREDIBLE stories of HOPE in this edition. Miracle children doing miraculous things.

I also look forward to seeing many of you at the Dreams on Wings 5K on May 15th in Texas and the Hemispherectomy Foundation Family Retreat in Indianapolis on July 8 - 11.

And as Always....

Hope in One Hemisphere!



Cris Hall
Co-Founder, The Hemispherectomy Foundation
and Jessie's Dad (Right Hemi, 2008)



Tribute to Srikar Potluri

By Holly Pauwe

May your body rest in peace and may your soul rejoice in Heaven.

On March 21, 2010, our hemi community lost a child, Srikar Potluri. My tears are many and my heart bears a heavy sadness upon it.



Srikar

Srikar underwent a "redo", as we call it in our hemi community, just 12 days before. We all learned that Srikar was not able to pull through this round of surgery and the complications that followed. Now, his family is dealing with loss, not recovery. As a family would be, our community is devastated. So many are in shock and are shedding rivers of tears for this child and his beautiful family. How could we not? As a close and knowledgeable community, we understand the risks of this surgery and the potential for complications. We all knew in our heads that this would happen eventually, but our hearts often have a hard time following and dealing with that which our heads knew. Complications do happen, but usually our children pull through and make a full recovery. For reasons we can't know or explain, this was not the reality for Srikar.

It is difficult to explain how it is that our emotions run so DEEP for a child and his family that in many ways, we only barely know. And it may be hard for some on the outside of THIS world to understand. Yet, the emotions are REAL and they are IMMENSE. But for this surgery, many of our families would not know each other...would never have had the opportunity to meet or may not have even had a common interest to build a friendship upon. Our families are from all walks of life, from different religious (or non-religious) or spiritual backgrounds, of

was able to raise just over \$7000 for the children that we support. Best of all, 10 families with children that have undergone hemispherectomy surgery attended the race! Many families had never met another family that has walked in their shoes! Can you imagine that?," said Kristi Hall, race chairwoman and president/ CEO of The Hemispherectomy Foundation.

The 1-mile fun run will start at 8:00 a.m. followed by the 5K at 8:30 a.m. Both races will start at Parker County Physical Therapy located at 879 E. Eureka in Weatherford, Texas. Individual awards will be given for overall and masters male and female winners, plus the top three male and female finishers in the following age groups: 5 and under, 6-8, 9-11, 12-14, 15-19, 20-24, 25-29, 30-34, 35-39, 40-44, 45-49, 50-54, 55-59, 60-64 and 65+.

Awards will be given for the largest Corporate, School and Family Teams.

Participants can register online at www.hemifoundation.org (no handling fees!) or download registration forms. Early registration ends May 9. The pre-registration cost for adults is \$25 and \$30 on the day of the race. For children under 6-12, the pre-

registration cost is \$20 and free for children ages 5 and under. Teams of 3 or more can register for \$20 per individual. New this year! Sleep in and get the t-shirt! Virtual Runner \$30. Registration forms and checks, made out to The Hemispherectomy Angels, Inc., can be mailed to The Hemispherectomy Foundation, P.O. Box 1239, Aledo, TX 76008.

[For More Info. Click Here](#) or

Contact :
Kristi Hall
Kristi@Hemifoundation.org



[The Hemi Foundation
Family Retreat
Indianapolis, Indiana July
8th - 11th](#)

Registration Deadline:
June 15th

Families registered before
May 15th will be put in a
drawing for a \$1000 Travel
Assistance Award.

This retreat is for
everyone in the family and
is going to be a GREAT
chance for us Hemi
families to hang-out,
socialize, and enjoy the
long weekend together.

different political opinion and thought...still, one shared experience called hemispherectomy levels the field for us all and stands out above any differences we might have over other areas of life. That experience is the one that binds us...as friends, as family, as a community. Every day, we celebrate the successes of our children, we pray for each other, we offer comfort to each other through the struggles, we become the strength that another family needs to get through the surgery, we share our stories of hope with each other, new families and the rest of the world. We ARE family to each other. We ARE friends. We LOVE each other. Anyone that knows me, knows how strongly I feel about these families...how much I care for them...how much they mean to me. And I know the feelings are mutual all around. Ask anyone of us, and we'd tell you that we never would have made it this far without each other...that we wouldn't have the HOPE that we do, the STRENGTH that we do, or even the LOVE that we have without our hemi community. It is easy to celebrate the successes of our families and children. And it comes naturally when you offer another family hope or strength to get through a difficult time. Today though, and in the days to come, we do the hardest thing there is to do, we mourn the loss of one of our own. We cry with Srikar's family and wish that we had some magic words to take away the hurt. We know there are none...yet, we want to find them. For his family, but for ourselves too I expect. Those of us that believe in God and a Heaven, know without a doubt that Srikar is seizure-free and well in Heaven....no doubt doing all the things that his body would not allow him to do on this Earth. And for us, there is solace in that. But, how does a mother and father and family know that and rectify it with the fact that they no longer get to see him, touch him and nurture him. I can't imagine the pain and the emptiness that realization must bring. How can anyone that hasn't felt that type of loss? In the end, all we have to offer them is our unending love and support. But we wish there was something more.

So many of us had the great pleasure of meeting Srikar, his mother Lakshmi, and his father Ravi this summer in Baltimore. This is a gift I feel so incredibly thankful for today and one which I am sure I took for granted on some level at the time. I remember seeing his sweet face for the first time in person... after months of seeing it in pictures, which is the norm. It is hard to put into words what that is like...meeting, for the first time, a child that you have come to "know" and love through pictures and the written words of their parents. It is profoundly moving... EVERY time it happens. And so it was with Srikar. I also remember how gracious and lovely Lakshmi was in coming over to introduce herself, Ravi and Srikar to me and my family. It was immediately obvious that this was a close and loving family... and two parents could not have been prouder of their child. They loved and celebrated every success Srikar had...and with this decision to have a redo...they were fighting for his chance to have more successes. Like so many families before them had.

May they find peace in knowing that they were doing everything they could to help him grow and develop and experience life, though short it was, to the fullest. May they find strength in this community of ours, and in the communities of each of our families. And may they know how incredibly blessed I feel to



Although there will be a few speakers, this event is focused around the word "Retreat". It takes place at the beautiful Jameson Camp in Indianapolis, where you will feel like you are back in kid's summer camp with no cares in the world. Camp Fires and Cabins will take you back to summer camp and build treasured memories. Although you may feel like you are miles from nowhere, this camp is near all the modern conveniences that we need for our special families. And if Summer Camp isn't your thing, you can always stay at a nearby hotel and come out for the family activities. It's close and convenient.



There will be a special surprise this year, as the Epstein Family will be filming The Hemispherectomy Foundation Family Video to be used for Public Relations, Education, and New Family Support.

We hope to see ALL of YOU there in July!

[For More Info, Click Here](#)

have known Srikar and to have experienced, even briefly, the gift of his life. I can't avoid the obvious...as you may no doubt see in all of this. In April, Jon and I and our family will be where the Potluri's were. We'll be handing our child over for her own "redo". Her third redo to be exact. It will take a great and enormous faith to do it...understanding that everything will be done to keep her safe and to get her through recovery without complications...but also knowing that there are no guarantees. There is HOPE and love and a wish for "more" for her that drives this decision for us...yet there is the fear and the worry of that which is unknown...of that which we have no control. Those were the same drivers and fears for the Potluri's. And that makes this loss hit even closer to home. In reality, it could be any of our hemi families.

Please say a prayer for Srikar and his family today, and in the many days to come. Their home is going to feel empty in a way that it never did before Srikar, as will their hearts. Love, friendship and prayer....that is what we have to give them. May those things bring them some sliver of comfort and peace at this most difficult time.



The RE Children's Project

The Wohlberg family had a big reason for starting The RE Children's Project, Grace. Their daughter developed Rasmussen's Encephalitis (sometimes called Rasmussen's Syndrome) at 10 years old. In February 2009 she underwent hemispherectomy surgery and in March 2010 had a second "redo" surgery.



The mission of this organization is to "increase awareness regarding Rasmussen's Encephalitis (RE) for the primary purpose of supporting scientific research directed towards a cure. The organization also supports research dedicated toward the recovery process following hemispherectomy surgery, a life altering surgery that is the only known "cure" for



**International
Hemispherectomy
Workshop
Sept. 30th - Oct. 2nd,
2010
Utrecht, Holland**

*(continue from Previous Edition of
Brain Matters, Article by Stella de
Bode, PhD)*

**"Why Would You Remove
Half a Brain?"**

Stella de Bode, PhD (UCLA)

**Current Position: Assoc.
Prof & Sen Researcher at
the University Medical
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**Specialization: brain
reorganization following
pediatric surgery**

On Our Website



Read [stories of hope](#) about our families on hemifoundation.org

Our Mission

To Encourage and Support impacted families by connecting them with other families who have had a hemispherectomy or similar surgery.

the disease."

On October 6, 7 and 8th the RE Children's Project will be sponsoring a research conference dedicated to RE. The conference will seek to leapfrog our current understanding of RE and identify new pathways for research by incorporating research disciplines beyond neurology into the conference proceedings. The conference attendees will consist of global experts from neurology, immunology, genetics, oncology, multiple sclerosis, and pharmacology who will bring their collective expertise to RE.

If you are interested in finding out more about The RE Children's Project please visit their website at <http://rechildrens.com/> or email Seth Wohlberg at swohlberg@rechildrens.com .



Meet Emma Gibson

By Elizabeth Gibson

Our princess, Emma Elizabeth, had a right functional hemispherectomy on June 1, 2009, after living with uncontrolled seizures for 13.5 months. She was diagnosed with cortical dysplasia in April 2008. Her surgery was done at Le Bonheur Children's Hospital in Memphis, TN. As terrifying as the surgery was to face, it has been our miracle. We went from watching helplessly as our baby had countless tonic clonic seizures and regressed in her development to now... She just turned 2 this past November.



Emma's progress and development have been extraordinary. Once we were home, she quickly learned how to get herself around by scooting on her bottom. She started making new sounds and learning body parts. She is now able to pull herself to stand and has just started walking, although she's still pretty wobbly! She is learning some "modified" sign language and says maybe 30 words (which mom and dad understand best). She has also picked up on learning animal sounds and colors. She is just doing so many wonderful things! It's amazing to see how much progress has been made! We are even seeing developmental appropriate things like temper tantrums, which her dad and I think are quite cute! Parents of special needs

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 hemifoundation.org

[Donate](#)

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[Read about Doctors from the U.S. and Canada who make up our Medical Advisory Board.](#)

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toddlers understand what we mean when we say we love EVERYTHING age appropriate.



Emma loves books and music. She adores her stuffed animals, especially her cookie monster and LOVES watching Clifford the Big Red Dog on TV. She gets PT, OT and speech therapy every week. She and I also do extra "therapy" sessions where we work on stretching, early preschool skills, her sign language, and her speech, PT\OT stuff too. She has gotten quite use to that being part of our daily routine and actually seems to enjoy it!



She is an amazing little girl. She's affectionate and very friendly. She loves her daddy and her grandparents and is a mommy's girl through and through. She loves our dogs and cat very much

too!

In November, she was weaned successfully off her Depakote. She now only takes one medicine, Keppra. There was a time before surgery when she took three anti seizure meds. So being down to one medicine is fantastic!

BEST of all we have been "S word"-free since June 6, 2009! A year ago I didn't even think that would be possible.

We thank God everyday for our amazing miracle named Emma Elizabeth.



Denton's moment of glory highlight of Hawks' season

By Bob Snell, Desert Valley Times

March 16,2010

What was the highlight of the season for the Charles A. Hughes Middle School boys' basketball team? Winning the Garrett Invitational in Boulder City? Sweeping rival Mack Lyon Middle School? Being competitive in its first year playing in the CCSD Middle School league when some thought they might not win a game? Finishing 16-5 overall?

While all of the above were noteworthy, the highlight of the season, hands down, came in the season finale Friday night at the Hawks Nest against visiting Bridger Middle School of Las Vegas.

In a YouTube moment, the Hawks Denton Dorn, a special-needs student at CHMS, brought down the house as well as a few tears to the eyes of those in attendance.

Denton, who is an avid sports fan, was not just an honorary member of the Hawks squad. He was a full-blown member. He had to attend the mandatory 10 practices, just like everyone else, before being issued his No. 50 jersey. He dressed for all the home games and actually made one bus trip with the team a couple of weeks ago.

His teammates embraced him as one of them. He was, and is, a Hawk and darn proud of it.

Everyone loves Denton. He's hard not to get attached to. He always has that smile and he's always ready for a high five walking down the sixth-grade hall or in the student center or on

his way to the gym for PE.

My classroom at CHMS is directly across from where most of Denton's classes are with Mr. Forsyth. I see him every day and he always asks me if I'm going to his game. When I say yes, he gives me a high five.

Denton is a huge Oakland Raiders fan and a big fan of the Utah Utes. Maybe that's why I like the kid so much. He also likes the Colts, Steelers, UNLV Rebels, Oregon Ducks and Duke Blue Devils. I can see liking the Rebels, but those other teams? Denton, Denton, Denton.

He's always sticking his head in the door of my classroom and saying "the Raaaaaiduhs," like Chris Berman does on ESPN. I say it right back to him and he goes away laughing.

He is also a big fan of the Virgin Valley Bulldogs. He attends most of the games, home or away. During Spirit Week, he had his hair colored green and made sure everyone noticed. He was an honorary ball boy for one of the Bulldog football games and he's always going out to shoot baskets between games at Bulldog Gym.

Denton's Story:

Denton was born with hemimegalencephaly and @ the age of 1 1/2 he underwent a hemispherectomy at UCLA Medical Center. He has been seizure free since surgery with the exception of when we tried weaning him from Mysoline, to date he is on Lamictale. Denton has also had a vascular ring repair, ear

tubes, a tympanoplasty and a tonsillectomy. When he was younger he suffered with many respiratory infections requiring him to be in the hospital at least 25 times. It seemed if it wasn't respiratory it was seizures. He has since grown out of his respiratory ailments.

Denton attends middle school in a self contained class room but spends a great part of his day mainstreamed. He is active with Special Olympics and attends the sport of the season once a week for practice. He attends physical therapy twice a week and works with a wonderful lady who takes him into the community for various activities. Together they swim, bowl, play soccer and basketball or go to the library. He loves to bowl and has a high score of 171. He has a fierce love for basketball and this year made the basketball team at the middle school. He was so excited telling us that the only thing he wanted to do was make a 3 point shot and bring the crowd to their feet. He enjoys watching ESPN and will be the first thing that comes on in the morning and the last thing that he watches before he goes to sleep. He amazes us with his ability to recap a days events from ESPN at the shake of a stick.

Every year he goes for a follow up visit to UCLA. Our family has made it a tradition to go to Knott's Berry Farm which is his favorite place to be. He would ride every roller coaster they have but Mom is a little hesitant. If asked what his favorite ride is @ Knott's he would tell you the "orange roller coaster". Not exaggerating at all I would be willing to bet my life on it that we

ride it at least 50 times in one day.

Denton has the ability to bring a smile to anyone's face and can win one's heart with his impeccable love for life. His basketball coach said to me "if all the boys on the team had the love for the game like Denton does, we would be unbeatable". That's Denton, unbeatable and full of love!

To watch Denton's moment of glory click [here](#).



GoodSearch

Want to help the hemi foundation? Check out [Good Search](#) and [Good Shop](#) . Each time you use Good Search (powered by Yahoo) as your search engine, the hemi foundation will receive a donation. Likewise Good Shop is an online marketplace that donates a percentage of your purchase to the hemifoundation. You can choose from hundreds of popular merchants and the experience of shopping through GoodShop is exactly the same as going to the retailer's websites directly.

As always, the hemi foundation is "staffed" only with volunteers so all donations benefit families and research directly.



Dates to Remember:

Hemi Foundation Family Retreat - Indianapolis

Dates : July 8th - July 11th

[Click here for more information](#)

*Registrations Deadline is June 15th.

[To download the registration click here.](#)

**All Families who Register before May 15th will be put in a drawing for \$1,000 Travel Assistance Award.

Contact The Hemispherectomy Foundation

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