The following pages contain Biographies and Contact Information for the speakers and facilitators of the 2012 Hemispherectomy Foundation International Conference and Family Reunion. They are listed in alphabetic order for easy reference during the conference, and for later reference.

The Hemispherectomy Foundation extends a special thanks to the following groups for their participation in making this event meaningful and useful to the families of the Hemispherectomy Community.

The Brain Recovery Project

The CI Therapy Group and Taub Training Clinic

The Johns Hopkins Hospital

The Johns Hopkins Epilepsy Center

Kennedy Krieger Institute

The RE Children’s Project

The Hemispherectomy Foundation Regional Directors

The Hemispherectomy Foundation Specialty Directors

And Especially, Our Hemispherectomy Community Parents, Sibling, Adults, and Children Impacted by Hemispherectomy Brain Surgery.

++ Denotes member of The Hemispherectomy Foundation Medical Advisory Board
Dr. Carson is a full professor of neurosurgery, oncology, plastic surgery, and pediatrics at the Johns Hopkins School of Medicine. In 1984, he was named director of pediatric neurosurgery at Johns Hopkins Children’s Center, a position he still holds today.

In 2008, he was named the inaugural recipient of a professorship in his name, the Benjamin S. Carson, Sr., M.D. and Dr. Evelyn Spiro, R.N. Professor of Pediatric Neurosurgery. Dr. Carson is interested in all aspects of pediatric neurosurgery, and has a special interest in trigeminal neuralgia in adults.

Through his philanthropic foundation, Carson Scholars Fund, he is also interested in maximizing the intellectual potential of every child.

An internationally renowned physician, Dr. Carson has authored over 100 neurosurgical publications, and has been awarded 60 honorary doctorate degrees and dozens of national merit citations. Dr. Carson has written four best-selling books, and his fifth book will be released early in 2012.
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Roxanne graduated from Iowa State University with an Agricultural Business degree, along with a minor in Agronomy. She worked several years for BASF Agricultural Products as a sales representative selling crop protection products. She lives near Jamaica, Iowa with her husband Craig and 4 children, of which two boys who are on the Autism Spectrum and a daughter Rachel who has epilepsy. Rachel was clinically diagnosed with Rasmussen’s Encephalitis, as well as Cortical Dysplasia, which led to a right hemispherectomy brain surgery at UCLA Medical Center on March 26th, 2009. Rachel continues to enjoy living a life of seizure freedom since her brain surgery. She participates in Sunday school, the Calvary Chapel Kids Club, Soccer, Clover Kids 4-H, cheerleading camp and dance which includes tap, ballet and jazz.

In addition of overseeing 13 states as Central Regional Director for The Hemispherectomy Foundation, Roxanne helps coordinate the Virtual Runners for the Hemi Foundation’s Dreams on Wings fundraiser. Roxanne also serves on the Board of Directors for the Autism Society of Iowa, on the Board for the Epilepsy Foundation of Iowa’s Community Council, a Mentor for the Mentor/Peer program for the Brain Injury Association of Iowa and is a member of Heartland Area AEA’s Parent Advisory Council. Roxanne enjoys reading Christian books, participating in bible studies, being a part of the local VIM (Volunteer in Missions) group, going camping, bicycling and coaching soccer.
Dr. Anne Comi received her medical degree at the SUNY Buffalo School of Medicine, then completed a residency in pediatrics at Children's Hospital of Buffalo and a pediatric neurology residency at Johns Hopkins Hospital. Her clinical expertise is in the diagnosis and treatment of the neurologic aspects of Sturge-Weber Syndrome (SWS).

She is a physician advisor for the Vascular Birthmark Foundation and Sturge-Weber Syndrome Community and has served on the scientific advisory board of the Sturge-Weber Foundation. She directs the Hunter Nelson Sturge-Weber Center at the Kennedy Krieger Institute and is Co-PI on the NIH funded Sturge-Weber syndrome project of the Brain Vascular Malformation Consortium.

Her research interests center on studying the pathologic processes involved in the neurologic complications of Sturge-Weber Syndrome, including the effects of chronic hypoxia and glucose deprivation on brain tissue and neurons, as well as the interactions between seizures and impaired blood flow in the brain. Through both clinical and basic research, she hopes to determine approaches to preventing neurodegeneration resulting from chronically impaired blood flow in Sturge-Weber syndrome.
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Technology is one of Byron’s favorite hobbies. Recently he helped teach his 90-year old step-grandmother to use an iPad and keeps his school updated on technology that can be used educationally (admitting that misusing technology is easy to do at school).

He will be a 10th grader at McLean School in Potomac, Maryland where he helps manage the varsity soccer team. His favorite subject is history, and he looks forward to attending college in 3 years.

For the past 2 years Byron has been a blogger for the Pearls Project, a program started by Positive Exposure to help middle and high schoolers rethink beauty. Teachers and students at schools across the country read blogs written by kids who have diagnosed genetic differences. Through discussions and assignments, beauty is redefined and the way visible differences affect perceptions are challenged. The blogs are used in classes such as English, art, philosophy, and science, and Byron has traveled to speak with many of these students. (For sample of the blogs see:  
http://www.positiveexposure.org/pearlsproject  For information about bringing the Pearls Project to your town, contact Rick Guidotti at rick@positiveexposure.org)

Byron is 5 badges and an eagle project away from earning Eagle Scout. He wants the project to benefit Boston Children’s Hospital, and asks the hemispherectomy community for support and advice to develop something that will benefit children who, like him, have spent a lot of time in a hospital.

Byron was 10 ½ months old when he had a left hemispherectomy for Sturge-Weber Syndrome. He would love to talk with families and kids at the reunion. This is Byron’s 6th reunion.
Dr. Stella de Bode is an expert on neuroplasticity following cerebral hemispherectomy. She was recently Assistant Professor at the Rudolf Magnus Institute at the University Medical Center Utrecht in the Netherlands, in the Department of Neurology and Neurosurgery in the Brain Function and Plasticity Section where she studied brain recovery and reorganization in children following cortical hemispherectomy.

Prior to that, she was an Assistant Professor in the Department of Communication Sciences & Disorder, School of Public Health, at the University of South Carolina where her research interests included motor and language reorganization following hemispherectomy. She received her Ph.D. from the University of California at Los Angeles in Applied Linguistics and Neuroscience where the subject of her doctoral dissertation was Language In The Isolated Right Hemisphere: Predicting Language and Quantifying Language Outcomes After Hemispherectomy.

She is a prolific author, having co-authored several research papers on post-hemispherectomy linguistic outcomes, including: Spoken Language Outcomes After Hemispherectomy: Factoring in Etiology; Age and Etiology As Predictors of Language Outcome Following Hemispherectomy; How Normal Is Grammatical Development In The Right Hemisphere Following Hemispherectomy? The Root Infinitive Stage and Beyond; and Language After Hemispherectomy.
Ms. Doerrer received her undergraduate degree in nursing from the University of Maryland-Baltimore. She worked as a registered nurse in the Neonatal Intensive Care Unit at Johns Hopkins Hospital and Howard County General Hospital. She also worked as a school nurse and school-based health center manager in the Baltimore County School System.

She received her Masters degree in Pediatric Advanced Practice Nursing from the University of Maryland-Baltimore and worked as a Pediatric Nurse Practitioner at Health Care for the Homeless, providing both primary care and outreach health care services to homeless children and teens in Baltimore City. She is currently a Certified Pediatric Nurse Practitioner in the Johns M. Freeman Pediatric Epilepsy Center at Johns Hopkins Hospital. She also is a member of the Professional Advisory Board at Abilities Network.
I am a mom to two beautiful girls, Melanie who is 17 and about to graduate high school and Allison, who is finishing her freshman year of high school. I have worked for 20 years at the Erie County SPCA outside of Buffalo, NY as a Veterinary Technician and more recently as the Canine Behavior and Training Supervisor. My husband, Jim, is in Marketing and Communications.

My daughter, Allison, had a perinatal stroke after a long, difficult labor, improper positioning, doctor tried to turn her, finally did a C-section. She seemed fine, APGARs were normal, and my husband held her while I was in recovery. By the time we got me to my room we were met by a Neonatologist who informed us that Allison had stopped breathing several times in the recovery nursery and had been transferred to the Neonatal Intensive Care Unit. CT scan and MRI were done revealing that our baby had suffered a right middle cerebral arterial clot and subarachnoid bleed. We had a wonderful Developmental Pediatrician who, based on the MRI, was able to tell us exactly what to expect: Hemiplegic Cerebral Palsy and she was right on the mark. Amazing!

Allison started having seizures when she was 3 and we spent a couple of years trying different anticonvulsants and combinations of anticonvulsants without success. Allison’s problem wasn’t frequency of seizures, she had 1-2/month, but when she had them they lasted 45 minutes or more and we had to use Diastat (rectal Valium) to stop them at home and made several trips to the ER. Her seizures were Complex Partial, sometimes with loss of consciousness. Our local Neurologist referred us to the Cleveland Clinic and we spent her first week in the Epilepsy Monitoring Unit to determine that she was a perfect candidate for the surgery as her seizures originated from the scarring in her right hemisphere. I was scared. We spent another year trying more anticonvulsants before deciding that the best chance for a normal life and independence for Allison was a Functional Hemispherectomy.

Allison was 7 and in first grade when she had her surgery in 1/2004. She has been seizure free ever since.

Today, Allison is a happy, healthy, 15 year old in a typical classroom with an IQ within the average range. She struggles a bit with Science and Social Studies as these tend to be subjects that require memorizing a lot of facts and she has trouble identifying main ideas from details. She is an avid reader and is doing great at her Foreign Language studies. Math has proven to be difficult as well and we enlisted a private tutor at home for several years. She currently receives Vision Therapy, not for quality of vision but to help her "see" everything on a page with the total left peripheral visual field loss and to process what she is seeing and learning via language and visual components. Allison has participated in Ice Skating and Horseback riding and accompanies me to the gym 2-3 times a week. Socially, well, she is a 15 year old girl with body image issues more relevant than your typical 15 year old girl, but she has friends in school and seems to handle any attention that has come her way due to her "hemi posturing" very well.
John M. Freeman, MD  
Professor of Neurology and Pediatrics (Emeritus)  
Johns Hopkins University School of Medicine

Dr. Freeman is the former head of the Johns Hopkins Pediatric Epilepsy Center, which now bears his name in recognition of his contributions to the field. Together with Dr. Benjamin Carson, he reinstituted the role of hemispherectomy for children with Rasmussen’s encephalitis and other severe, predominantly unilateral, epilepsies.

He is now retired.
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Nicole lives in Akron, Ohio with her husband Jerry and their 3 sons Jayden, Justin and Jaxon. Since she was very young, Nicole has had an interest in working with people. Because of her interests, she earned a BA in psychology and then went on to earn a Master’s degree in Marriage and Family Therapy. She has been a mental health therapist, doing school based therapy, since 2004. She is currently working with middle school students, who suffer severe behavioral issues, in an alternative school.

Jaxon had his first seizure twelve hours after he was born, due to Hemimegalencephaly (thought to be due to an inutero stroke at the time). At 5 months, his seizures became uncontrolled and he was having around 15 tonic clonic seizures a day. Nicole and Jerry took Jaxon to Cleveland Clinic, where they quickly diagnosed him with left hemimegalencephaly. They were then told he would most likely need a hemispherectomy to control his seizures. When he failed his 5th seizure medication at 8 months of age, they decided to go forward with the surgery.

Dr. Bingaman performed surgery at 8 ½ months. Nicole remembers, “We struggled with this decision because Jaxon looked so “normal” on the outside, but knew it was only a matter of time before we would see the decline”. Jaxon was in the hospital for 10 days and had day treatment for 26 weeks following the surgery. He continues to receive PT, OT, Speech therapy, aqua therapy, vision therapy and orientation and mobility. He learned to walk at 20 months and has around 20 words that he uses.

Nicole is completely thrilled with his progress, and is dedicated to helping him be as successful as he can. Nicole says, “He has an awesome charismatic personality that people seem constantly drawn to. We are very proud of our little miracle and hopeful that he will do great things”.

Alicia Grenolds
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Alicia and Rick Grenolds are the proud parents of Georgia (5) and Lillian (2). Georgia was diagnosed with a brain tumor called a choroid plexus papilloma at 11 weeks of age. The tumor was benign and was resected entirely shortly after diagnosis. The Grenolds were told Georgia's biggest risk after surgery would be seizures. Compared to a malignant tumor requiring chemo and radiation, that risk did not seem so daunting at the time. Georgia started having complex partial seizures at 16mo of age. Just before her 3rd birthday, the seizures worsened and transformed into epileptic spasms (infantile spasms in an older child) which quickly proved to be medically intractable. The Grenolds aggressively pursued epilepsy surgery and Georgia ultimately required a right functional hemispherectomy in July 2010 which was performed at Children's Hospital Colorado. She has been seizure free since then.

Professionally, Alicia is a pediatric nurse practitioner also at Children’s Hospital Colorado working with children who have pulmonary hypertension. She is a second-career health care provider who initially worked in medical device clinical research following her graduation from Wake Forest University. She obtained her Masters in Nursing from Simmons College in Boston, MA after realizing that direct patient care was a better calling for her. She feels her clinical practice and ability to relate to other parents of children with life threatening illnesses has been strengthened by her own experience with Georgia. The Grenolds currently live in Denver after meeting in Boston and starting their family there. Alicia and Jane Hittle have recently organized a local Hemispherectomy Foundation chapter for the many hemi families in the Denver area.
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Cris is a loving husband and a dedicated father to his wife, Kristi, and his four children, Matt, Jake, Josh, and Jessie. He grew up in the small, central Texas town of Luling, where he learned at an early age the importance of family, a tight-knit community, and treating people with respect and empathy.

Cris earned a BBA at Texas Tech University in Information Systems in 1988 and an MBA from The University of Texas in Arlington in 1993. At Texas Tech, he was the President of his Fraternity, Lambda Chi Alpha. He was also a member of "Goin' Band from Raiderland". After graduating from Texas Tech, he married his college sweetheart, Kristi Kelley (Hall). Cris is currently an Information Technology Architect with BNSF Railway.

For Cris, his proudest moments have been the birth of each of his four children, and each milestone they have reached on their way to becoming fine youngsters in the community. He enjoys spending time with his family, friends, and church, and SCUBA diving. Cris has dedicated himself to helping children and their families who have undergone hemispherectomy surgeries. His dream is to see The Hemispherectomy Foundation grow in strength so that no child's needs, or their family's needs, go unattended.

Read about Cris’ daughter, Jessie.
Kristi is a loving wife and a dedicated mom to Matt, Josh, Jake and Jessie. She was born and raised in Cheyenne, Wyoming to Gary and Nancy Kelley. Kristi was very active outdoors—riding horses since she was two. During her high school years, she was active showing livestock and was a member of the Cheyenne Frontier Days Dandies equestrian drill team, promoting the famous rodeo.

Kristi attended Laramie County Community College and represented the Livestock Judging Team, allowing her to travel throughout the United States. After receiving her Associates of Science degree, she transferred to Texas Tech where she met and eventually married Cris Hall. Kristi graduated from Texas Tech University in 1987, with a Bachelors of Science in Animal Science.

After their marriage in Lubbock, Kristi and Cris moved to Fort Worth, Texas. Kristi was hired by Alcon Laboratories, Inc.(part of Novartis) as a Laboratory Technician and was soon promoted to Scientist and then Senior Scientist. She has happily worked in Research and Development for over 20 years, and is currently the Manager of Pre-Clinical Safety Systems Support.

Kristi’s hobbies include watching sports and hanging out with her kids. Kristi is dedicated to the children and families supported by The Hemispherectomy Foundation and providing resources and support to families that find themselves facing this radical surgery.

Read about Kristi’s daughter, Jessie.
Dr. Adam Hartman received his undergraduate and medical degrees from Northwestern University. After completing his residency in Pediatrics in the National Capital Uniformed Services Pediatric Residency Program (National Naval Medical Center, Walter Reed Army Medical Center), he served as a general pediatrician in the US Navy for five years (the last as division head of general pediatrics at Naval Medical Center San Diego). He completed his residency in pediatric neurology and a fellowship in clinical neurophysiology/pediatric epilepsy, both at Johns Hopkins. During his residency and fellowship, Dr. Hartman worked in the Epilepsy Research Section, National Institute of Neurological Disorders and Stroke, NIH under the direction of Michael Rogawski, MD.

Now an Assistant Professor at Johns Hopkins, Dr. Hartman focuses on treating children with epilepsy, with an emphasis on those whose seizures have not been adequately controlled with medication. As one of the Attending Physicians in the Epilepsy Monitoring Unit, he evaluates and manages patients in his clinic who may be candidates for epilepsy surgery, including those with Rasmussen syndrome, brain malformations, and perinatal strokes. He is the Co-Director of the Neurology Intensive Care Nursery.

Dr. Hartman’s laboratory is focused on discovering the anticonvulsant and disease-modifying mechanisms underlying several types of metabolism-based therapy for epilepsy, including the ketogenic diet. His research is funded by National Institutes of Health, the Passano Foundation, the Pakula Foundation, and a Johns Hopkins University School of Medicine Clinician Scientist Award.

Dr. Hartman is a coeditor of Treatment of Pediatric Neurologic Disorders, and has authored other research publications and textbook chapters on metabolism-based therapy and epilepsy surgery. He is the Associate Program Director for the Pediatric Neurology Residency.
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Monika Jones is a graduate from the University of California at Los Angeles where she received her bachelor of arts degree in 1989. She then received her juris doctorate from the University of Southern California in 1993 and thereafter practiced law for ten years primarily as a defense lawyer in both state and federal courts, in cases ranging from sexual harassment to trademark infringement.

In 2007 her first child, Henry, was born with true, total hemimegalencephaly of the left hemisphere of his brain. Henry has undergone three surgeries to complete an anatomical hemispherectomy for intractable epilepsy as well as two shunt surgeries.

After his first surgery - a functional hemispherectomy at the age of three months old - Monika and her husband Brad grew increasingly frustrated by the lack of information in the medical and therapy community about how to best rehabilitate their child. Out of this frustration they founded in 2011 The Brain Recovery Project, which in a short amount of time has raised almost $30,000 to fund research programs that specifically address rehabilitation after hemispherectomy surgery. She currently serves as President of the foundation.

Monika is an active member of several online communities who focus on providing information to parents of children who have undergone hemispherectomy surgery and a tireless advocate for these children.
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Dr. Kossoff is an Associate Professor of Neurology and Pediatrics at The Johns Hopkins Hospital in Baltimore, Maryland, where he is a member of the John M. Freeman Pediatric Epilepsy Center and Director of the Child Neurology fellowship program. He is the Medical Director of the Ketogenic Diet Program at Johns Hopkins Hospital.

After completing his undergraduate studies at Cornell University in Ithaca, New York, Dr. Kossoff received his medical degree from the State University of New York at Buffalo School of Medicine and Biomedical Sciences. He completed his residency in Pediatrics at Eastern Virginia Medical School in Norfolk, Virginia, and postgraduate fellowships in Child Neurology, Pediatric Epilepsy, and Clinical Neurophysiology at Johns Hopkins Medical Institutions in Baltimore, Maryland.

Dr. Kossoff is a member of the American Academy of Neurology, Child Neurology Society, and American Epilepsy Society. His clinical and research interests include dietary therapies for epilepsy in children and adults, interaction of epilepsy and migraine in children, infantile spasms, and Sturge Weber syndrome. He is one of the world experts in the ketogenic diet and is the first author of *Ketogenic Diets, 5th* edition, helping to bring dietary treatment today to developing countries, adults, and as a first-line therapy for infantile spasms. He is also the coeditor of the textbook *Treatment of Pediatric Neurological Disease.*
When I was three years old, I was diagnosed with Rasmussen's Syndrome. As a result of how quick the seizures were coming I had my surgery that same year in late 1993. I was so small I don't remember much of the ordeal, but to this day I have grown up no differently than any of my peers the same age.

My parents treated me just the same as my two older brothers when it came to being punished and rewarded for my actions. In school I was always pushed to succeed and find ways for me to achieve academically, physically, and socially. It wasn't until seventh grade that I realized how high I can achieve; it was in that year that I received straight A's in two marking periods (a full semester from August to January) Friends have come and gone in my life, but to this day I am still best friends with the friend I met when I was five years old, Julianne. Most importantly, the physical activity that kept me motivated and pushed me to be the best I can be was dancing.

Dancing is my first love next to my faith. I have been dancing since I was five and kept with it continuously through the end of high school. This helped not only in my therapy sessions every week, but it also made me feel comfortable with myself. I had found my niche that I was good at, even with a paralyzed arm, and some in my foot. I had found something that others would look at and see not my disability, but they would see me. My personality. Since I entered college it has been significantly more difficult to keep up with dance, but I have choreographed a number of dances in this time, and performed one at the last conference I attended in Baltimore in 2009. I also performed a dance two years at a church talent show, where my future husband first saw me. I am now graduated from college, and moving on to the next milestone in my life, and I have dancing to thank for all of it.

Jody is a four-time winner of The Jessie Hall Hemispherectomy Foundation College Scholarship.
In 1993, soon after her 3rd birthday, Lynn's daughter, Jody, suffered her first seizure. During the course of that year, Lynn and her husband, Al, tried one drug after another in the search to stop the seizures that occurred at first once a day, then started increasing in frequency after several months. Once they transferred her care to nearby Johns Hopkins Children's Center, they finally got a diagnosis – Rasmussen's Encephalitis, or Rasmussen's Syndrome, as it is sometimes known. Several months later, Jody underwent a right hemispherectomy at Hopkins. Soon afterward, the Millers started meeting with other families coming into Hopkins for hemispherectomies; this blossomed into a loose support network and led to the beginning of the Reunions held every 3 years in Baltimore.

Al and Lynn have been married since 1984 and have 2 older sons in addition to daughter Jody. Lynn, a dedicated mother, was very involved in all her children's activities – soccer, dance, youth group, etc. Now that all 3 are out of the house for the majority of the year (Jody just started college), Lynn continues to be involved in her church's youth group, as well as other church activities such as evening studies and choir. Al and Lynn recently enjoyed an “empty nest” vacation and continue as well to be very involved in hemispherectomy support.
Dylan Norwood
James Dylan Norwood
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Dylan had a right Hemispherectomy due to a stroke he suffered during his birth. His surgery date was 11/14/1994 at 2 years old. Dylan was having over 100 seizures a day. The surgery was a success and he only had 2 seizures with 48 hours of the surgery and has not had another seizure to this day.

Dylan went to a private school until the middle of 6th grade and then we sent him to our local middle school. He was only in a special ed program for 1 month because they just wanted him to get use to the school before moving him into a regular classroom. Dylan graduated from Hereford High School in 2011 with his class and with a diploma.

Dylan has been very active his entire life and loves to be involved in his community. He’s played rec. sports from 1st grade all the way up to High School. He played basketball, baseball and Football. He played two years of Football for the High School but decided he didn’t want to play Varsity. The High School had a program for kids with disabilities so Dylan played soccer and was on the bowling team for his four years at Hereford. Dylan has been a Boy Scout his entire life and received the rank of Eagle Scout in 2011.

Dylan loves to travel he’s been to England, Ireland, Alaska, Colorado, California, Utah. Dylan also ski’s with an adaptive instructor anytime we go as a family. Dylan has been lucky enough to enjoy the 100th Anniversary of Scouting for the World and for the USA. Dylan wanted his driver’s license and I started the uphill climb when he was 15 years old just like every other boy. It took over 3 years and a lot of work but he got his license and has been driving for a year now. He’s a careful driver and loves driving. He is currently working on getting some restrictions removed from his license to give him some more freedom.

Dylan is currently finishing up his first year at Garrett College in Western Maryland. He lives on campus and is in the NRWT(National Resources and Wildlife Technology) program and he hopes that is years in Scouting will pay off for him to find a good job one day. College has been a struggle but he really wants to try to finish. Dylan has been a winner of The Hemispherectomy Foundation Scholarship and a Hemispherectomy Foundation Camp Scholarship.
When I was seven years old, I was diagnosed with epilepsy. For six years, doctors tried unsuccessfully to control my seizures and eventually I was diagnosed with Atypical Rasmussen’s Encephalitis. On June 6, 2003, at age thirteen, Dr. Carson performed a right hemispherectomy at Johns Hopkins Hospital. Serious infection caused a second major brain surgery only one month into my recovery. I underwent a hemispherectomy re-operation two years later due to ongoing seizures. In 2006, Dr. Carson implanted a shunt because my seizures continued and I started having extreme headaches. Over the next two years, I had three revision surgeries performed locally in Wisconsin due to shunt failures. Thankfully though, I have been seizure-free since 2007.

In 2008, I graduated high school with the rest of my class in spite of all my absences due to seizures, doctor appointments, and surgeries. I went on to pursue my post-secondary education at Edgewood College in Madison, Wisconsin. I graduated this past May with a Bachelor’s of Science degree in Professional Studies in Education with a minor in Psychology. Throughout my college years, I worked as a student employee at the Edgewood College Admissions Office, was an Ambassador for the college giving tours to perspective students, enjoyed volunteering at the local Children’s Hospital, completed several practicums at local elementary schools, participated in many on campus organizations, activities, and clubs, explored the city of Madison on several occasions, and lived independently in an off-campus apartment.

I am thankful for the support and encouragement I received from family and friends and for the financial assistance from several organizations including the Hemispherectomy Foundation Scholarship. Creative thinking and determination have also helped me to succeed. In the future, I plan to use my degree to obtain a job working with children or in the hospital setting. I just refuse to let my limitations stand in my way. I will continue to do the best I can to succeed in all that I do.

My mom, Joan Olsen, has been my number one supporter. She has been involved with individuals with differing abilities as long as she can remember. She has a BS degree in Communicative Disorders with a minor in Psychology. She also has an Associate Degree as an Educational Interpreter Technician. She worked as an interpreter for the Deaf and Hard of Hearing until she turned her focus to getting me and our family through my battle with Rasmussen’s. She then worked part-time as an instructor at Fox Valley Technical College teaching sign language courses and still teaches an introductory course at our local high school. She is also Director of Business Development and Master Trainer at LearningRx, a cognitive brain training center in my home town. A dream of hers is to explore cognitive brain training to benefit post-hemispherectomy patients.

One of the many endeavors my mom and I embarked on was trying to make life easier for me living one-handed in a two-handed world. We have tried several adaptive equipment options along our journey which resulted in our One Handed Gadgets for an Independent Life PowerPoint and Demonstration.

Special thanks to my sister, Rachael Olsen, and best friend, Jennifer Schmalz, for helping to make the demonstration possible. We hope you enjoy it!
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Holly is an Indiana native who grew up in the Ohio River town of Tell City. She received her BS degrees in Environmental Chemistry and Geology from Indiana State University. Holly went on to graduate school at the University of Florida (GO GATORS!) and would meet her husband Jon, also a geologist, there. Following the birth of their first child in 2001 - a son named Caiden - they moved to Indianapolis, where they still reside today. Holly began her professional career with the Indiana Dept. of Environmental Management, where she worked until her daughter was born. With Avery’s birth in 2005, everything changed. Avery was diagnosed with Left Hemimegalencephaly (HME) within 24 hours of her birth. As time went on and Holly met other parents through the webpage and blog she had created for Avery, she realized a real need for a central, all-encompassing, web-based place of hope, support and information for families affected by HME and the related Cortical Dysplasia (CD). As a result, in early 2008, Holly created a web site known as The Hemimegalencephaly Family Support Network that is intended to meet those goals once completed.

Holly was asked to join The Hemispherectomy Foundation team in 2008, representing and assisting families of HME and CD, she was honored to accept. She is passionate about helping other families on this journey get the information they need to effectively advocate and care for their child(ren). The knowledge she has gained in her role at ASK will also serve Foundation families well in regards to resource identification and location.
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Lisa had a right hemispherectomy in 1994, to combat intractable seizures, due to Rasmussen’s Encephalitis. Her surgery was performed by Dr. Benjamin Carson at The Johns Hopkins Hospital.

Lisa is married, and has two beautiful girls named Adeline and Gabrielle.
Cynthia Salorio, Ph.D., ABPP
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Dr. Salorio is a neuropsychologist at the Kennedy Krieger Institute. She is also an assistant professor at the Johns Hopkins School of Medicine.

Dr. Salorio’s clinic expertise is in assessing brain-behavior relationships in children with a variety of neurological disorders. In her outpatient clinic, Dr. Salorio conducts neuropsychological evaluations to assess each child’s cognitive strengths and weaknesses and assist with treatment and academic planning.

Her research focuses on identifying predictors of cognitive, behavioral, and functional outcomes in children with neurological conditions. She is also interested in patterns of behavioral and neuropsychological functioning in children with epilepsy, and the impact of treatment, including hemispherectomy, on these skills.

Dr. Salorio is on the Medical Advisory Board of the Hemispherectomy Foundation, and on the Professional Advisory Board of the Epilepsy Foundation of America, Chesapeake Region.
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Western Region : California, Oregon, Washington, Montana, Idaho, Wyoming, Nevada, Utah, Colorado, Arizona, New Mexico, Hawaii, Alaska

David is an Idaho native and currently lives on the southern Oregon coast in North Bend with his wife Kathleen, and three sons: Chandlor, Patrick and Evan. David and Kathleen's youngest son Evan was diagnosed with infantile spasms, a catastrophic form or epilepsy, when he was three months old. Over the course of several months Evan underwent multiple tests and treatment options, but nothing could fully reveal why these spasms were happening, and nothing could stop them. David and Kathleen found their way to Los Angeles, California where they met with Dr. Gary Mathern, a neurosurgeon at Mattel Children's Hospital UCLA. It was here where they learned more about hemispherectomy surgery, something they had no idea that Evan would soon undergo. The decision was easy for David and Kathleen, as Evan succumbed quickly to infantile spasms, and what little development he had was lost. It was their last chance to save him. On November 23, 2010 at ten months old, Evan had left hemispherectomy surgery. It was revealed that Evan's left hemisphere was severely underdeveloped, causing his seizures. The results of the surgery were almost immediate, and within just a couple days Evan was doing things for the first time ever. Evan has remained seizure free since the morning of his surgery.

In an effort to reach out and help build more awareness, education and support, David created Evan's personal website, [www.evanstauff.com](http://www.evanstauff.com) where he shares more detailed information about Evan's life with infantile spasms and hemispherectomy surgery. David keeps in contact with many families who share similar experiences throughout the entire Western Region of The Hemispherectomy Foundation, as well as many more throughout the United States, and world.

David graduated Magna Cum Laude from Eastern Oregon University with a Bachelor of Science degree in Liberal Studies – History/Anthropology, and stays home now overseeing Evan's care. He spends his time making sure that Evan is progressing through his many therapy sessions, updating Evan's website, and helping The Hemispherectomy Foundation as the Western Regional Director and Webmaster.
Born as the third of four children, I was raised in a small community in Baltimore City, Maryland called Hamilton. Even though I grew up in a large city, Hamilton was a close knit community and most of my family lived on the same block. The local church was the focus of our social activities and my family was very involved. My father ran the Thanksgiving dinner for those too old or infirm to leave their homes or cook for themselves. I spent my youth taking dinners to shut ins and helping elderly people in the neighborhood with laundry and other chores. Year after year, our family dedicated our time and love towards families that were not as fortunate or were shut in due to a disability or hardship.

After my parents passed away, I continued their legacy by being devoting my energies into my activities with the John’s Hopkins Children’s Center; organizing pizza parties, ice cream socials and winter stocking collections for the children. I also wanted to continue my parents’ memory by involving my children, Samie and Nickie, in all of my endeavors with the Children’s Center. My children and I have been so blessed that it is a gift to be able to lend a helping hand to families who have not been so fortunate.

The Hemispherectomy Foundation became my passion when my girls and I saw the Jessie Hall story on the news. Samie, Nickie and I couldn’t help but understand the hardships of parents and children so far from home and facing such a scary ordeal. We just had to become involved and help to relieve some of the anxiety and stress these families were experiencing.

A tax accountant by trade; my organizational skills, dedication, attention to detail and links to the community have enabled me to make an impact in the The Hemispherectomy Foundation’s assistance to children and their families.
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We have treated the arms of children ranging in age from 4-13 after hemispherectomy with CI therapy and have obtained large improvements in each case. CI therapy is a treatment originally derived from basic research with animals that was first used successfully with human patient after stroke and then traumatic brain injury among other conditions involving impairment of movement after substantial damage to the brain. The success with adults led us to apply the treatment to children with cerebral palsy and traumatic brain injury from age one-and-one-half years to adulthood. The results have been as good as with adults in some respects and considerably better in others. This led to our work with children after hemispherectomy. The results have ranged from good to excellent.

CI therapy consists of three main components: 1) intensive training of the more-affected arm on functional tasks using a training technique termed shaping for 3 hours per day (with rest intervals as needed) for 15 weekdays; 2) a “transfer package” of techniques to transfer gains from the clinic to the real world life situation, which takes an additional one-half hour per day (total of 3 ½ hours per day); and 3) restraint of the less-affected arm in a lightweight cast to encourage use of the more-affected arm. The cast is split so that it can be opened periodically to inspect the arm. Children normally adapt to the cast during the first day and only rarely complain about it afterwards. The treatment is administered in the context of play by a warmly encouraging therapist, so that most children enjoy the treatment. For older children, the clearly observable improvement in ability to use the more-affected arm is also rewarding. Parents have a very important role in the therapy since they are shown ways to work with their children to keep their movement improving after the clinic phase of the treatment is over. We are just starting up a CI therapy program to treat the legs in children. This type of treatment will be available shortly.
Beth Usher was born laughing! Her sense of humor and ability to look on the bright side has helped her overcome the effects of Rasmussen’s Encephalitis, a left-sided hemispherectomy at the age of seven and spinal fusion for scoliosis a few years later.

Beth learned at a very young age that laughter can break down barriers, lift spirits and smooth over even the roughest of characters. She has made it her mission in life to make at least ten people smile each day. She is the recipient of Connecticut’s Bloomer Award ~ awarded to people who make Connecticut a friendlier place, a published author and an inspirational speaker.

Beth enjoys her work as a kindergarten aide, a professionally trained clown, a certified laughter leader and a student in the Association for Applied and Therapeutic Humor’s Humor Academy. (She also stalks celebrities, drinks copious amounts of pina coladas and drives her family absolutely crazy!)
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Dr. Vining is Chief of the Division of Child Neurology, Lederer Professor of Pediatric Epilepsy, Professor of Neurology and Pediatrics at the Johns Hopkins University School of Medicine. She is the Director of the John M. Freeman Pediatric Epilepsy Center at Johns Hopkins and Director of the Epilepsy Monitoring Unit. She graduated from Vassar and Johns Hopkins. She then trained in Pediatrics at the Children’s Hospital of Pittsburgh and in Developmental Pediatrics at the Kennedy Institute/Johns Hopkins. She trained in EEG under Dr. Niedermeyer at Johns Hopkins.

Dr. Vining has focused her research efforts in three areas: surgery for epilepsy in children (especially hemispherectomy), the ketogenic diet, and the impact of epilepsy and its treatment on the child. She has continued to nurture a very comprehensive approach to caring for the “whole child and the family” that has been a hallmark of the Hopkins epilepsy program over the decades. Her background in developmental disabilities has greatly influenced her approach to children with epilepsy, recognizing that co-morbid problems greatly influence outcome.

She has written more than 100 peer-reviewed articles, editorials and book chapters. She is the co-author of a book about epilepsy, Seizures and Epilepsy in Childhood: A Guide. At Hopkins, she has also been a leader in many programs that focus on issues facing women in medicine. She has been active in the American Academy of Pediatrics, serving on their National Meeting and Scientific Exhibition Planning Group.

She has served on numerous American Epilepsy Society committees including: the Scientific Program Committee, Continuing Medical Education Committee, and the Year Round Education Committee (Pediatrics). She has also served the Epilepsy Foundation, locally and nationally, in a variety of capacities.
Lisa had seizures at birth and during her first year of life. She had a right hemispherectomy at John's Hopkins Hospital January 1986 at the age of one years, she is now 27 years old. Dr. Freeman, Dr. Vinning, and Dr. Carson at Hopkins thought that if she had the hemispherectomy surgery she would have a chance. We were so blessed that the surgery helped Lisa.

She has accomplished so much and has grown into a beautiful young woman who has done amazing things. Lisa has just finished a three year program at The Horizon's School in Birmingham Alabama. This program deals with Independent Living Skills and Job Training.

Lisa is currently in Birmingham and contracting with the school to continue her work there. She plans to move back home to Houston and live independently.
Seth Wohlberg
Founder
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Seth Wohlberg founded the RE Children's Project in 2010 to accelerate medical research into Rasmussen's Encephalitis. Toward that end, the RE Children’s Project has sponsored global research symposiums and funded several ground breaking research projects in an attempt to increase our understanding of the disease.

Seth's daughter Grace had her first seizure in 2008 and had hemispherectomy surgery in 2009 at John Hopkins and additional surgery at UCLA in 2010. Seth works on Wall Street in the hedge fund business at Far Hills Group, LLC where he has been a partner for the past 11 years. He lives with his wife, Deb and they have a 19 year old son who attends the University of Massachusetts at Amherst.