

STORIES OF hope

The Sturge-Weber Foundation

The stronger the wind, the tougher the trees



features

AJ	3
APRIL.....	4
ADIEN R	5
ADIEN W.....	6
BEN	7
BRAD	8
CHLOE	9
CHRISTOPER	10
COEN.....	11
CONNOR.....	12
CYNTHIA AND BOB	13
DEBROAH	14
GABRIEL.....	15
HARLEY	16
JACK	17
JAIDEN ANDREW	18
JASON	19
JEFF	20
JENNA	21
JOSE SEBASTIAN	22
JOSHUA	23
JULIE BETH.....	24
KATIE	25
KENNIDEE	26
LAKSHMI	27
LINDSAY	28
LIZZY	29
LYNDON.....	30
MADDIE H.....	31
MARISSA	32
NOAH.....	33
OGUZ KAGAN	34
PAIGE	35
PEARL.....	36
SAMANTHA	37
SAVANNAH.....	38
SYDNEY	39
ZANDER	40

on the front cover



on the back cover





aj

“We feel very fortunate to be AJ’s parents, as he has taught us so much about courage, strength and life on this journey. Along the way, the support we’ve received from family, friends, and the Sturge-Weber Foundation has been extremely remarkable.”

On December 22, 2008, we became the proud parents of Allen Joshua (AJ). As first time parents, we had a lot to learn, even more so when it was explained to us the birthmark on the right side of AJ’s head and face was actually a port wine birthmark. We were told AJ would need to see special doctors, and we immediately began our search for the best doctors available.

Through a referral from a family friend, we found a fabulous dermatologist at Children’s Hospital of Wisconsin, in Milwaukee, who specializes in pediatric birthmarks. AJ has had eleven laser surgeries to lighten his birthmark, and we’re thrilled with the progress he’s made thus far. He has also had several procedures with a pediatric ophthalmologist due to the involvement of the port wine birthmark in and around his right eye. Fortunately, AJ’s eye pressure levels have been in the normal range and he does not have glaucoma.

On August 1, 2010, AJ had a series of seizures and was flown by Flight for Life to Children’s Hospital where he was diagnosed with Sturge-Weber syndrome. Our lives were turned completely upside down! Doctors experimented with different medications, and after a week, we were told that SWS is a progressive disorder and AJ’s case was referred to as a “hard control”. After two weeks at Children’s, AJ went home on phenobarbital and Keppra, yet we were told he would not be able to remain seizure-free on medications alone. Doctors at Children’s Hospital believed AJ would need a hemispherectomy in order to effectively stop the seizures.

We were scared and uncertain not knowing what the future would hold, but we knew we had work to do to help AJ fight his battle. We began a second opinion search for the best facilities and doctors in America. After extensive research, and with help from the Sturge-Weber and Hemispherectomy Foundations, we sought opinions from two other top-notch medical facilities. We made the most important decision of our lives in choosing Cleveland Clinic, praying for a miracle. Thankfully, we came in contact with excellent doctors. They studied AJ’s medical records, ran more tests, and determined AJ did not need a hemispherectomy. Instead, they recommended a temporal/occipital lobectomy.

On January 13, 2011, AJ underwent a successful surgery at Cleveland Clinic without any complications. After five days in the hospital, we returned home to Wisconsin with our smart, energetic, happy-go-lucky little boy.

We travelled back to Cleveland in August for follow-up testing and the doctors said everything looked great. We can’t thank them enough for the future they’ve given our son! We are truly blessed!

AJ continues to develop normally and has been seizure-free since the surgery! He has adjusted well to the loss of his left peripheral vision in both eyes, which we knew would happen as a result of the surgery. Doctors told us AJ will never notice any loss of vision, because he had this procedure done at such a young age.

We feel very fortunate to be AJ’s parents, as he has taught us so much about courage, strength and life on this journey. Along the way, the support we’ve received from family, friends, and the Sturge-Weber Foundation has been extremely remarkable. Together we hope to continue to raise awareness of SWS and help AJ and others win this fight. Live Strong! GO AJ GO!

april

My name is April Michele. I was born on December 13, 1976 in Louisville, KY. I am 34 years old and a member of the Cathedral Church. My disability is Klippel-Trenaunay-Weber syndrome, which I was born with.

As a child, I had a great upbringing with a very supportive and loving family. My family and friends never treated or looked at me any differently.

My school years were great and when I graduated from DuPont Manual High School in 1995, I received my diploma with much pride and satisfaction. I attended technical school for two semesters but secured a full time job and stopped school to begin working. I have had three jobs in my lifetime; the longest job I held was for eight years as a Support Specialist with a major health care insurance company. I had to stop working due to health issues in 2007.

When I was younger the doctors told my mom that I would never graduate high school, hold a job, live independently or drive a car. I am very proud to say I have accomplished all of these things including driving and owning my own car.

I feel I have achieved a lot in my lifetime because I have tried to live life to the fullest and as normal as possible and with GOD on my side, ALL THINGS ARE POSSIBLE. I have some limitations, but I don't let that stop me from doing what I have to do. I am a strong and independent person. I don't ask anyone for anything unless I absolutely need it. At this point in my life I would like a job that I could work at part-time and continue on with my life and enjoy being "JUST ME!"



"I feel I have achieved a lot in my lifetime because I have tried to live life to the fullest and as normal as possible and with GOD on my side, ALL THINGS ARE POSSIBLE. I have some limitations, but I don't let that stop me from doing what I have to do."



aden r.

Hi. I'm Aden and I was born with a birthmark on half of my face. (I don't really notice it now because I have laser treatments once or twice a year.) When I was 2 months old my parents found out that I had glaucoma. Then, I was diagnosed with Sturge-Weber. I've been on eye drops ever since.

I had my first eye surgery at 4 months to place an Ahmed valve in my affected eye. (I had a second one placed in the same eye when I was 5.) The next day while at the glaucoma specialist's office I had my first seizure. Luckily, we were at Jules

Stein Eye Institute, which is right across the street from UCLA Hospital. My parents still remember how scared they were running across the street while I was seizing in their arms.

Since then I have been on seizure medication. At that point I was seeing five doctors:

- A pediatrician
- A pediatric neuro-ophthalmologist
- A glaucoma specialist
- A dermatologist
- A neurologist

When I was 7 a CAT scan showed that my retina had detached. Now I see a retina specialist too. I can't see out of my left eye and don't have good depth perception but I have better than 20/20 vision in my right eye. I take three medicines and an eye drop twice a day.

I'm 15 now and enjoying life. I have a great family who are fun to be with. My mom and dad, my brother and sister, and my grandparents all encourage me to do anything I want to do. And we are really lucky to have The Sturge-Weber Foundation to help with my medical issues and to just lean on sometimes.

I enjoy school and playing strategy type games. I like to read all kinds of different books. I especially liked the Harry Potter series and the Lightning Thief series. I also like golf. To me golf is a game of fun, patience and practice. I'm on the school golf team this year and practice is just starting up.

Thanks for reading about my life...so far.

"I'm 15 now and enjoying life. I have a great family who are fun to be with."

aiden w.

Aiden was born in February 2004 with a large birthmark on his face and scalp. The doctors called it a port wine stain and warned that Aiden might have glaucoma as the birthmark was also in his right eye. When he was just 2 months old he had his first eye surgery.

At three months Aiden had his first seizure and soon after was diagnosed with a rare neurological brain disorder called Sturge-Weber syndrome. When multiple anti-seizure medications failed to control his seizures, his doctors recommended a brain surgery called hemispherectomy. On August 21, 2008 Aiden, just 4 years old, underwent 11 hours of surgery to remove the right half of his brain.

Aiden has been seizure free since that operation. He has learned to:

walk independently

- feed himself
- drink from a straw
- draw circles
- walk up a flight of stairs

Aiden could not speak before his surgery. Today he has a growing vocabulary. Best of all, Aiden was taking 7 anti-seizure pills a day; now he doesn't take any pills and he has kept his sweet, loving personality.



Aiden is a champion of hope and he is one of the thousands of reasons we're here.



Brad

Back in 1988 and 1993, Brad Cunningham of Roodepoort, South Africa, was in the local magazines and newspapers a lot.

Through the diligence of his mom, Trudi, Brad's story was put in front of the public in newspapers and magazines throughout the region. Photos then show Brad with his mom, dad Trevor and sister Danielle, his dog Mauser, his school chums, Mark and Jeffrey, and his tennis coach.

Brad was born in 1985 with a PWS that covered most of his face. He developed glaucoma at about 18 months of age. At the time of the articles, Brad had already begun laser treatments, traveling to Geneva, Switzerland four or five times before treatments were available in South Africa.

Photos at the time shows a smiling, determined kid sometimes wearing sunglasses and a baseball cap. The articles were a big step in an attempt to reach and educate insensitive adults. Trudi reported at the time that Brad's schoolmates were appropriately inquisitive but not mean. When he told them his PWS was a birthmark, they said, "Oh" and that was that. Adults encountered in public were another story.

His mom and dad had decided that it would not help him to be sheltered and always told him "Yes, you look different., but you must learn to stand up for yourself."

In 1993, as a result of one magazine article, he became the student of a well known tennis coach who admired his determination and motivation. Now, 10 years later, we visited Brad and his family via email as he is about to turn 18 years of age. This is Brad's letter to us.

In South Africa we have 12 grades before entering university, so next year will be my last school year. Our school year starts in January of every year, and finishes in December. I am currently in grade 11 at Allen Glen High School. I take 7 subjects (only 6 are compulsory). My subjects are English, Afrikaans (a language similar to Dutch), Mathematics, Add Maths, Physical Science, Technika Electronics and Computer Science. I am currently one of the top 3 achievers (academically) in our grade – my position varies between me and my two best friends (Mark is still one of them). My average has not dropped below an "A", and I am hoping to keep it that way in the future.

I still play tennis, but not as seriously as in my earlier years, but still good enough to kick my dad's butt on the tennis court every so often. I now play squash (similar to racquet-ball) for my school. This year I played at the number 2 position for my school's first team and for two years in a row I have received half colors (the second most prized sports award given at school.)

Mauser my Labrador is sadly not with us anymore. He succumbed to old age. He has been replaced by Teddy, a Cocker Spaniel/Labrador and Lia, a German Shepherd (alias "Hell-Hound") who thinks I am her chew toy – her teeth marks on my forearms can attest to that!

I have a part-time job as well. I work at a Science and Experiment shop near my house where I have been working for almost a year now. It is a shop that specializes in science and electronic equipment and I help people with anything I can, assisting with school projects for persons coming to the shop most of my working hours.

Dealing with public reaction really hasn't been too difficult for me. I learned a long time ago not to care what people who don't know me think of me, and this has helped. I don't really get hassled too much by long glares, and most people just ask me about my face - a question that really doesn't bug me, they hear the answer, and carry on in their own ways.

I have been with my best friend Mark ever since I can remember (we started together at kindergarten) and we are even in the same high-school. He continues being my best friend. I still speak to Jeffrey, but we have drifted apart over the years.

After school I hope to become a computer programmer. Programming has become a hobby for me and I can see myself still doing it 20 years from now.

On the Sturge-Weber side – God has been good to me.

I no longer suffer from epilepsy and have been off my medication for almost 2 years now. My eyesight has remained stable over the years due to continued surgery (the last surgery was in August last year). Although the surgery may seem extreme and daunting, it really does work. I can vouch for that!

It is quite an honor to be asked for my input about a disease that plagues so many and I hope to help inspire all those that suffer from it in any way I can.

ben

We are delighted to introduce you to our son, Benjamin. He is absolutely one of the happiest kids you'll ever meet – he brings joy through his infectious smile to everyone he meets.

When Ben was born, on August 25, 1994, we noticed the birthmark on his face. It was only a few hours after his birth we noticed it actually covered over 80% of his body. In addition, the right side of his body was significantly larger than his left side – you could almost draw a line down the center of his body. At that time, of course, we didn't know the journey we had just begun. We spent the next few months undergoing all sorts of tests to get to a diagnosis – what was going on with our little boy? We saw neurologists, geneticists, and radiologists (Ben's kidney on his "larger" side was also larger than the kidney on the "smaller" side). At the age of 2.5 months Ben underwent a bone marrow extraction – in an attempt to understand his low hemoglobin count. That brought visits to an oncologist.

When Ben was 3 months old, his uncle, then a medical resident, came by to see him. Uncle Jim mentioned that children with a port wine birthmark on their face were at a higher risk for glaucoma. We had all spent so much time and effort working on the rest of him we missed this fact. A quick visit to his pediatrician, followed by an examination by a pediatric ophthalmologist confirmed our fears! Ben had glaucoma in both eyes. He underwent surgery on his left eye at the age of 4 months, and on his right eye at the age of 5 months.

Over the course of the past 17 years, Ben has had multiple eye surgeries, including the positioning and repositioning of shunts to help maintain his eye pressure. Despite these efforts, and a daily regime of all sorts of glaucoma medications, he's lost the vision in his left eye. While he's legally blind in his right eye, he can still see well enough to hit a ball not only over the fence, but over the roof!

A visit to Mayo Clinic in 1997 confirmed Ben has an overlap of Klippel Trenaunay and Sturge-Weber syndromes. We were told that if seizures didn't begin by the age of two, they probably won't be an issue for him. Ben, never being one to play by the rules, had his first seizure at 26 months! Since then, life has been a roller coaster! Throughout the years, Ben has had a brain hemorrhage, and three strokes! He's recovered from all this, and more, thanks to an amazing team of doctors, specialists, therapists, and his own determination and tenacity. He NEVER gives up!

Today Ben is 17 years old, and a junior in high school. While he is in a self-contained special education classroom, he does attend one or two classes a semester with other kids in the school. He LOVES PE – and has managed to get straight A's in that class! He's made an incredible number of friends, and has some wonderful peer buddies that keep him engaged and involved with other kids his age. He likes to listen to music, dance, shoot hoops, and swim! Ben has, and continues, to teach us and others, what is really important in life: Live every moment; laugh every day; love beyond words!



"Ben has, and continues, to teach us and others, what is really important in life: Live every moment; laugh every day; love beyond words!"



chloe

This is Chloe Elizabeth, our miracle baby that doctors told us we would never be able to conceive. Born on March 4th 2009, it was the happiest day of our lives. She entered the world with what we thought was bruising starting from her right eyelid, all the way in to her scalp. My husband and I realized after about a week that Chloe wasn't bruised, she had a big, red birthmark or a port wine stain. No biggie, at least she was healthy!

Her seizures started when she was 3 months old and after 3 agonizing days and numerous tests at Loma Linda Children's Hospital, Chloe was diagnosed with Sturge-Weber syndrome. Having never heard of this, our family had lots of learning and research to do. Her seizures have continued to date but are being controlled with two different medications. It has been trial and error to find the best combination and dosage but it's a learning process as Chloe grows.

Now two and a half years later we are still learning and dealing with SWS. She has an ophthalmologist who routinely checks for glaucoma and so far so good with no signs of it. We just live every day and try to give Chloe as much of a normal life as possible. Actually, she does have a 'normal' life, just a bit different than most kids. Despite everything Chloe has been through in her short life, she is the friendliest little girl around. She absolutely adores her eleven year old step-brother, Ryan, and loves jumping on his bed with him and messing up his video games.

She is truly amazing and has touched the hearts of everyone she's met. My husband and I are the luckiest parents around to have been given this little angel. We will continue to face obstacles as Chloe grows, but that's ok. The obstacles we've faced so far have made us the strong, patient, loving people we are today. Chloe is our miracle!

"The obstacles we've faced so far have made us the strong, patient, loving people we are today. Chloe is our miracle!"

christopher

Christopher was born four weeks premature on July 13, 2005. At birth his entire face was all red and purple; they told us that it was a bruise or birthmark. We were never informed of what Sturge-Weber syndrome was or what might happen until the following day, the doctors came into the recovery room and told us that he was "a strong little boy, different but strong." I got the impression that the doctor was just as unsure of the prognosis for Christopher as we were.

Christopher had his first Glaucoma surgery when he was 6 weeks old and his second at 7 weeks. It was at that time that we were informed that Christopher had bilateral Sturge-Weber syndrome in all aspects including brain involvement. Christopher began having seizures when he was three months old, which were well controlled for about a year. He has been on four medications to control his seizures which have all been unsuccessful thus far. Christopher is currently having severe vision impairment, and was recently diagnosed as being legally blind in his right eye. Christopher has undergone numerous eye surgeries and has been hospitalized for seizures and strokes on too many occasions to count, at times I felt that I should start receiving my mail at the hospital as it was more our home than our actual house was. Christopher has recently begun having multiple seizures daily that we have been unable to control with medications and we are in the beginning stages of possible surgery.

When Christopher was born our entire family had never heard of Sturge-Weber syndrome and it was the most terrifying thing in the world to not understand or know exactly what's wrong with your child. It still amazes me everyday how strong he is, most times stronger than I am. Christopher is our "little miracle man" he has overcome so much during the last five years and has touched the hearts of many. We thank God everyday that we have been blessed to be the parents of this wonderful child. Christopher has given everyone he knows a new perception and appreciation for life which has made me a better person, and for that, I am truly grateful to "my little angel".



"Christopher is our "little miracle man" he has overcome so much during the last five years and has touched the hearts of many."



coen

“He loves to play with his brothers, loves music and loves being outside looking at birds. He is a huge basketball fan. He is so full of life and has an amazing personality.”

Coen was born July 26th 2008, a normal birth, a healthy 4.6kg. The port wine birthmark over the right side of his face was the first thing we noticed. We were told within hours of Coen's birth that he may have Sturge-Weber syndrome and we will need to have tests done. I was so hurt and very sad for my little boy, I spent the next few days thinking of what I did wrong to have done this to my son. Coen had a CT scan the next day and then we were referred to our neurologist a few weeks after.

For the first 3 months of his life he was developing very well. He then had his MRI and that's when he was officially diagnosed with Sturge-Weber syndrome.

Coen went on for 2 more months seizure free. At 5 months Coen was playing happily in the living room when I noticed his left side of the face was twitching. I took him to the hospital as it lasted about 10 minutes, and that was the first and only for the day, so we were sent home. The next day was Christmas and he went seizure free. It was a wonderful Christmas, his first. The following day the seizures started up again, but this time they were more frequent and lasted a lot longer. We stayed in the hospital for 2 months trying to get his medication right.

Because of the constant seizures and paralysing affect they had it caused aspiration problems which led to pneumonia. Coen had to have a NG tube put in which then led to a gastrostomy.

Coen's seizures progressively got worse and lasted for as long as 2 hrs. His meds stopped working. We then were told that Coen would need a hemispherectomy. We had no other choice, we were watching our baby boy waste away in front of us, and we just knew we had to do this.

The surgery took place in September 2010. It was a day filled with a lot of emotion. I saw Coen 10 hrs after I left him with the anaesthetist. The surgery was a complete success and he looked amazing. My fears were quickly diminished and he quickly showed me that he was going to be just fine. I would absolutely encourage anyone thinking of having this surgery done to just do it. It was the best decision we as parents have ever made, and now we have a happy healthy seizure free son who is developing slowly but surely.

Coen today is 3 yrs old, and starting to say words. He can understand everything we say, is walking with assistance, loves to laugh and have fun. He loves to play with his brothers, loves music and loves being outside looking at birds. He is a huge basketball fan. He is so full of life and has an amazing personality. This Coen didn't exist only a few months ago due to the high dose of anti epileptic medications, and crippling seizures. He was always sedated and spent most days sleeping.

I am truly a lucky Mum to have had the opportunity to help my son. I will be forever grateful and will never ever forget the families that don't have that as an option. I have friends that have to deal with these horrible seizures for life. I am so thankful every day to have a happy healthy baby boy.

conner

Connor came into this world on February 15th, 2011. He was born with a port wine birthmark that covered the entire left half of his face. No one really told us what it was when he was born. A week after he was born we went and saw his pediatrician. He was the one who informed us that this could be SWS. My heart sank, as if I did something wrong while carrying him.

We ended up seeing the neurologist the following week; they ordered an MRI, and to our surprise the MRI was completely normal. On July 15, 2011 Connor had his first seizure. This was the worst day of my life. He ended up in Children's Hospital where he stayed for two weeks. While we were there he had another MRI, which showed SWS in both hemispheres of his brain. We were then told he would need a hemispherectomy on the left half so he can try and live a normal life. To this day, everything is great. My child has some vision problems, and he can't walk without a brace, but he is God's gift and we were so blessed to have him. I would never change anything about him.



"My child has some vision problems, and he can't walk without a brace, but he is God's gift and we were so blessed to have him. I would never change anything about him."



Cynthia & Bob

Our Cynthia was 25 years old when we learned about The Sturge-Weber Foundation...it was in a 'Dear Abby' newspaper column! It was 1989 and we traveled from our home in Alexandria, VA to attend the SWF Conference in Pittsburgh, PA. And there we discovered, for the first time, Cynthia was not alone in this journey of life.

That was our AHHA moment – finding Karen Ball who had started a foundation for all the angels born with this syndrome that has helped so many of us through the journey of life with a SWS child.

Today we still feel like Cynthia, at 51, is one of the pioneering members of the Foundation. She has worked for the government as a mail clerk for 33 years. She shares an apartment in an assisted living complex near our home with her friend Bob Tidler. Bob is 63, and was also born with SWS. He retired from a government job after 38 years and continues to work 2 days a week at the Safeway and 2 days at the Library. They have been together for 4 years now learning to be independent and doing very well...with a little help from us here and there. They are a blessing to each other.

This is the living story of champions, as told to us by Nina and Donald Weber.

“Our Cynthia was 25 years old when we learned about The Sturge-Weber Foundation...it was in a 'Dear Abby' newspaper column!”

deborah

This is my mother, Deborah. She was born on June 28, 1954 in Aiken, South Carolina. She was the first born child of my grandparents, with a brother and then a sister to follow. After being diagnosed with Sturge-Weber as an infant, she spent most of her childhood in and out of hospitals and doctor offices. So she did not get to graduate high school. Soon my mom met a man by the name of Leslie and they fell in love. They married on September 30, 1973. On June 21, 1974, my brother was born with me to follow 3 years later and then my sister 7 years after me.

I grew up never thinking much of my mom's condition. I never really noticed her port wine stain, except for when new friends would ask me. I only remember watching her run a family and run our home just like any other mother. In 2000, my mother had a stroke. I remembered being very scared that I would lose her or that she would not be the same. It took her a few months to start walking like she used to and to start talking without slurring, but she overcame the stroke. As my grandmother started to become disabled, the family made a decision to move my grandmother into a home that was a few feet behind my parents home. My mother spent the next few years, 24 hours a day, caring for my grandmother who had Parkinson's. She also continue to take care of her own home and my father.

With everything my mother experienced with Sturge-Weber and having 3 kids and then caring for her elderly mother, she has proven to be one of the strongest women in the world. She didn't graduate from high school with a diploma or go to college, but she is the smartest woman I know. She has learned to face adversity in her life and has taught her children how to see the world in a different view than most kids learn growing up. She taught her children that even though you may have a medical condition that can affect every part of your life, don't let it. You are only as weak as you allow your medical condition to make you. My mother, Deborah, is a strong, smart, loving and brave woman. God bless her and God bless all the people with Sturge-Weber syndrome.



"I grew up never thinking much of my mom's condition. I never really noticed her port wine stain, except for when new friends would ask me. I only remember watching her run a family and run our home just like any other mother."



Gabriel

Our story began 7 years ago when our third child Gabriel was born on Oct 5, 2002. Everything about my wife's pregnancy was normal. She ate a balanced diet, and got plenty of rest and exercise and did not consume any alcohol. We were so happy to welcome our newest family member. Gabriel was a big baby at 10lbs.

He completed our family with three children, a girl and two boys. He was so cute and looked very similar to his big brother, however, we did notice Gabriel appeared to have a large bruise covering the left side of his face and a large portion of his body. We soon learned from our doctor that this was not a bruise but a birthmark called a Port Wine Stain. The medical staff were concerned that Gabriel may have a condition called Sturge-Weber Syndrome.

We were consumed with worry and grief over what this diagnosis would mean for our new baby boy. We were told only of the worst case situations and the information we were receiving from doctors was all "doom and gloom". We were given text books to read with short blurbs on the disease. We also had to keep happy faces for our other two children who would ask us, "why is he all red, Mommy/Daddy?". Of course they were too young at the time to understand, so we just explained this is how God made him extra

special. The next two weeks we had numerous doctor appointments and finally after a trip to our local Children's Hospital, the IWK in Halifax, Nova Scotia, Gabriel's diagnosis was confirmed. He indeed did have Sturge-Weber Syndrome.

Our world was turned upside down and we didn't know which end was up. I can clearly remember walking out of the hospital in a dazed state. I was trying to absorb and comprehend what this would mean for our new son and our family. I can remember being overcome with grief and I cried my eyes out when I was alone. The first week of my son's life was the lowest I have ever been. I never asked why or felt sorry for myself but was just so worried about the unknown.

However, this changed when I did a Google search on Sturge-Weber and found the Sturge-Weber Foundation in New Jersey, USA. They had plenty of information about Sturge-Weber and photos of individuals who had birthmarks similar to our Gabriel. We contacted the toll free number and spoke with staff members. It was at this moment we gained hope. We learned in joining the online Support Forum that life can be good with Sturge-Weber even though it can have its challenges.

Finally, there was some positive news about a future for our son. We went from feeling hopeless to feeling we were no longer alone. I can remember feeling like I was walking on air, my hope and faith was renewed all because of the SWF. They truly made the difference in our journey.

Gabriel is such an amazing little boy. He has endured a great deal in his short life. He has had two eye surgeries to lower the pressure in his eye caused by glaucoma. He has had seizures and 5 stroke-like episodes which resulted in him being hospitalized and unable to use his right side. He continues to take numerous medications, anti seizure meds and eye drops. We fly to Montreal every 4 months for pulse dye laser surgery to have his birthmark treated. Left untreated Gabriel's face will grow larger on the left side and with further complications.

Through it all, Gabriel is the happiest little guy you could ever want to meet. He never complains or asks why, he just goes with the flow. Gabriel's speech is delayed by his condition but he is very bright and understands everything. As a result of having a son with a special condition he has taught our family a great deal about acceptance. We are better people because Gabriel is in our lives. We are drawn to people who look different or who have special conditions. I guess you could say we feel an instant connection to them. I think how we all share the same challenges one way or another. Having a son with Sturge-Weber has taught us to be organized. We are on top of all his medical information (thanks to the support group). Being organized and prepared for the unknown gives us some sense of control.

Gabriel's siblings are amazing. All three children are very close and have a very special bond. I am so proud of all our children and as much as we teach Gabriel, he has taught us so much more. Like all families, we don't know what tomorrow brings, but we stay positive all the time. Worrying does no good. Every day that Gabriel is healthy is a good day. We live everyday just like anyone else, only we have a son with special needs. Sometimes it means juggling schedules or making special arrangements, but it has become second nature. We are hopeful for the future and we are so blessed as a family. Life is good!

harley

My name is Harley and I was born on January 14th 2010. I have a rare condition known as Sturge-Weber syndrome. This syndrome affects about 1 in every 100,000 infants born. I have a large port wine birthmark on the left side of my face which extends all the way to the back of my neck and a little on my chest as well as a small spot on my right cheek. I have glaucoma in my left eye and seizures. I experienced my first seizure when I was one month old; it was just a twitch in my right arm. My seizures mostly consist of focal ones but I have had grand-mal as well as petit-mal.

I have been developing normally for a child of my age, and only experience a little weakness on the right half of my body which makes it harder to walk and crawl (but I butt scoot like it's my job). I'm followed by a neurologist, ophthalmologist and have laser treatment to help lighten my port wine birthmark. My mom, dad, and big brother Gavyn are my biggest fans. It was very scary for my mom to hear the word hemispherectomy, but once she started researching and hearing all the positive stories of other families who went through the surgery it made it easier. Right now my glaucoma is controlled by medications and pressure is fantastic. My seizures seem to be controlled for awhile then we have to adjust meds. So far the doctors feel I'm not a candidate for the hemispherectomy at this time but are continuing to observe and run tests to help in any decision that may have to be made.

Note From Mommy: I don't know what the future holds for my little girl, all I do know is we have a great team of doctors, a wonderful family, and rare and wonderful support system in the Sturge-Weber Foundation. It is so much easier when you know you're not alone when something is bigger than you are. Never stronger but bigger.

Harley was born ten days early, due to the fact that I had developed a condition known as cholestasia in which the gall bladder is working incorrectly which causes bile to over flow into the blood stream. It can be fatal to mother and baby so the only cure is delivery. My pregnancy was very normal and healthy otherwise. I did everything right so it was a huge surprise when Harley was born and we were told there might be something wrong with her. I was in the hospital for four days and during that time I saw a lot of different doctors of different specialties, and this is when I met Harley's neurologist who uttered those three very familiar and scary words Sturge-Weber syndrome. When I started researching the syndrome it became very real and scary. There were words I didn't understand let alone know how to pronounce and then came the ones I understood very well. It took a lot of time, doctors' appointments as well as researching and talking to other parents in my shoes to realize I could work with this. We could survive it and put up a winning fight.



“ It is so much easier when you know you're not alone when something is bigger than you are. Never stronger but bigger.”



jack

“The progress of Jack has astonished us all! We will forever be grateful to the team of doctors and nurses who gave us a second chance for our son.”

It was Mother's Day 2008, when our son, Jack, began complaining of a headache and throwing up. Within 24 hours he had his first seizure at the age of 3½ years old. He was rushed to the hospital by ambulance where he spent the next several days. The diagnosis of Sturge-Weber syndrome devastated us all. We knew nothing about this syndrome or the effects it would have on our son. Prior to this date, Jack was a vibrant, happy and healthy young child. He had no port wine stain. Jack tried several medications alone and in combination of each other for a period of time. From outward appearances the meds seemed to be controlling the seizures, however, based on his EEG's and MRI's, the seizures and/or polyspikes persisted. The fear was that if Jack continued to have these polyspikes the damage resulting from prolonged use of meds and the seizures would be severe. Although Jack appeared to all who came in contact with him as a healthy child, he was actually highly medicated and was experiencing adverse side effects to his medications. In June 2009, Jack's seizures became more frequent. We were told that the left side of Jack's brain had developed atrophy and had severe scarring. The recommendation by our neurologist was that Jack would be a likely candidate for surgery.

We were scared and excited at the same time. Scared at the thought of such a major surgery and excited at the possibility of a “cure” for our son. It was a terrifying time in our lives to be told that our only son was being recommended for brain surgery. Because we live in Carrollton, Georgia and there was no pediatric neurosurgeon nearby that was as familiar with SWS, the decision was made to proceed with surgery in Detroit at the Children's Hospital of Michigan. The doctors believed that Jack's seizures were originating from the left temporal lobe. The damage was so severe on the left that it was their opinion Jack's right side had already begun to take over the left side functions. Although Jack would regress slightly after surgery, the risks of surgery were far less than the risk of continued use of medication and seizures.

In November 2009 Jack underwent brain surgery to remove his left temporal lobe, his left occipital lobe and part of the parietal lobe. We were scared to death to say the least. Our faith in God and support from family and friends allowed us to get through this most difficult time. The progress of Jack has astonished us all! We will forever be grateful to the team of doctors and nurses who gave us a second chance for our son. Jack is seizure free and has been weaned from all but one medication. Jack's brain tissue was donated to the University of Maryland Brain and Tissue Bank for Developmental Disorders in Baltimore.

Jack will turn 6 years old on November 1, 2010. He is in kindergarten and is progressing on track developmentally. He continues speech and occupational therapy weekly. He plays baseball, soccer and basketball. He is a miracle. We thank God for our little miracle each and every day. Our hope is that Jack's story will inspire and touch those faced with such a difficult decision as brain surgery. Thank you for allowing us to share!

We documented our journey on the caringbridge website. www.caringbridge.org/visit/jackgodwin.

jaiden andrew

Jaiden Andrew came into the world on November 06, 2008. At three months of age Jaiden was diagnosed with Sturge-Weber syndrome. Ironically, the same day of the MRI he had his first onset seizure. Jaiden has all the associated conditions of the disorder which are port wine stains, seizures, glaucoma, and developmental delays. He also has port wine stains on various parts of his body and was diagnosed with Klippel-Trenaunay syndrome because of the staining on his limbs. He recently has been diagnosed with hypothyroidism and has begun taking medication to treat that.

Jaiden's MRI confirmed that he has bilateral brain involvement. Both sides of his brain are very significantly involved with abnormal blood vessels, calcification, and his brain is not growing well. Comparison of MRIs showed that over time there has been shrinking of his brain.

It has been a real struggle to control Jaiden's seizures. He has been hospitalized approximately 12 times to date for seizures and associated complications. In August of 2009 he experienced status epilepticus. Basically his seizures were uncontrollable and to give his brain a break he was induced into a coma which lasted nine days. Currently he is on four seizure medications and is on an aspirin regimen.

Jaiden has glaucoma in both eyes. In November 2009 he underwent surgery on his left eye and had an Ahmed valve implanted because his pressure went up too high. His right eye is currently controlled with two eye drops. He is severely visually impaired due to the glaucoma and his neurological condition. Jaiden has been classified as legally blind. It is hard to engage him visually. He doesn't track objects but he is believed to see lights and might have some visual field cuts. He receives vision therapy weekly.

Jaiden started receiving laser treatment to the port wine stain on his face. With treatment his port wine stain are becoming notably lighter. He will be receiving laser treatment about every few months for years to come.

Developmentally, Jaiden is very delayed. As a result of his underlying condition Jaiden suffers from hemiparesis. He uses his left side better than his right. The things that he can do is roll over, get up on all fours, and hold a 2 ounce bottle with his left hand. He can also make his way around the room in his walker. Jaiden receives physical and occupational therapy weekly.

It is known that Jaiden will have struggles throughout his lifetime and that he will need assistance. But for right now, whether Jaiden makes strides in his development or not, I'm comforted in the fact that he is usually content and he is easily consolable. He laughs out loud, at what I don't know, most of the time but it's "Jaiden's world" as I call it and he might be the luckier one because his world might be better than ours.



"It is known that Jaiden will have struggles throughout his lifetime and that he will need assistance. But for right now, whether Jaiden makes strides in his development or not, I'm comforted in the fact that he is usually content and he is easily consolable."



jason

Jason, born in Green Bay, Wisconsin, was born with Sturge-Weber Syndrome 30 years ago, a time when the medical journals had only one paragraph about SWS. He graduated from Southwest High School, and continued on to earn a horticulture certificate degree from Northeast Wisconsin Technical College. He utilizes his education experiences in caring for the landscape of his rural home in Abrams, Wisconsin. In addition to lawn care and gardening, Jason is the caregiver to his cat, 3 dogs, and 2 horses.

In order to help him through tough times and the struggles of SWS, Jason is the author of a book entitled, "Dealing with Sturge-Weber Syndrome, A Reason Not to Give Up". In addition to the book helping Jason cope with his personal despair, the book has raised awareness to hundreds of people and has been a source of inspiration to others.

He is an accomplished business owner, the sole proprietor of a company he started called JR's EnviroCycle. Only 4 years young, Jason has increased his clientele from 1 (his family) to 100 families and businesses. Jason continues his journey by raising awareness through his business endeavors and donates 25% of his business profits to the Sturge-Weber Foundation.

When Jason is not being an advocate of SWS, he enjoys fishing with his dad, clay pigeon shooting with his brother, and going to the stock car races with his uncle.

"In order to help him through tough times and the struggles of SWS, Jason is the author of a book entitled, 'Dealing with Sturge-Weber Syndrome, A Reason Not to Give Up'."

jeff

When Carol asked me to speak at this session she suggested the title: "Along The Road." She said "Talk about your experiences with the Foundation, your strengths and resources. Basically, describe the journey of SWS".

Just a few little things like that eh? I think I was asked because I have white hair. Actually it does mean that our family's journey will give you a historical view of how things were and how they've improved over the years. I would so like to motivate, inspire, create hope, share laughter, and have you feel empowered as you leave here.

The best way to do that is to just be, to be with you, to share stories. I believe that in sharing, we realize our kinship, and find common experiences in our journeys that connect us and help us feel less lonely.

Before I start these stories, I'd like you to know that each person in my family has been behind this effort. They've searched their hearts, answered my questions about their thoughts, feelings and experiences, and have had the Grace to risk this kind of honesty and exposure.

And why would they and I do this? Well, maybe it's one of the gifts of living with Sturge-Weber. I think we really are more open and courageous because we've learned we need to be.

Forty-two years ago, when my husband Noel was 30 and I was 23, our first child, Jeff, was born. It was a difficult birth, breech, and he was taken immediately to the nursery.

Later, a nurse brought him to me to hold for the first time. There was a big black X marked across each cheek. Shocked, I asked what those X's were for. The nurse answered, "There's something wrong with your baby and they're trying to figure it out." There's no good way to find out your baby has problems.

Two-and a half weeks later, a specialist was able to tell us he thought Jeff had a syndrome called Sturge-Weber. He told us the little bit he knew about the syndrome, gave us a referral to the Well Baby Clinic at UCLA, and suggested we might consider institutionalization.

Our Baby!? We didn't even know yet who he was. I think that moment is when my internal "mother bear" came into being. On the exterior I remained fairly calm and quiet. But inside, I was fiercely determined that our baby would have every opportunity possible to develop and thrive. When Jeff was a month old, Noel's Pop said, "This baby isn't seeing." We couldn't believe it. "He's only a month old; how can you tell? He was our first child, remember.... To Read More Please Click [HERE](#).





jenna

“Meeting someone for the first time can be awkward – I worry about what they will say or wonder what they are thinking. But, I know in my heart that facing these challenges has made me a stronger person.”

Hello, my name is Jenna. I am 25 years old. I was diagnosed with SWS at 2 months old. I have glaucoma in my right eye and a PWS that covers 70% of my body. I had eye surgery when I was 8 months old, and continue to see the same doctor for yearly checkups. Thankfully, the pressure in my eyes has been normal and stable for years. I had a couple of laser treatments in grade school, but my parents chose to stop them and let me decide whether or not I wanted to continue. I chose to stop lightening my birthmark and I have never regretted that decision.

I have been fortunate in that I've never had any seizures or learning delays. I did experience some motor delays and attended therapy at 14 months old to learn how to walk. I excelled academically and graduated third in my high school class. I went on to college and earned a Bachelor's degree in Psychology and I am currently working towards my Master's in Applied Psychology.

Life with PWS can be challenging. People will stare and make rude comments. Meeting someone for the first time can be awkward – I worry about what they will say or wonder what they are thinking. But, I know in my heart that facing these challenges has made me a stronger person. My birthmark has taught me to be patient, compassionate and resilient. My sense of humor has allowed me to look back and laugh at some of the difficult times I faced – like when I worked at a restaurant and a gentleman asked if I had been making red Jell-O or the time a sweet old lady informed me that lotion would cure my rash.

I have learned to look at my birthmark as a source of joy – it sure has made life interesting! I have embraced my unique look and enjoy entertaining friends with my color-changing “chameleon” skin. I hope that others will find comfort in my story. I am living proof that a child with SWS can become a happy, confident, well-adjusted adult.

jose sebastian

Guitarist, singer, actor and bowler. Positive, fun, silly, joker and an inspiration, are words that would perfectly describe Jose Sebastian. He's friendly and fun, loves hugs and kisses, video games and Mario brothers. Apart from the birthmark that covers almost all his face, he's just a regular guy. The difference is that Jose is 75% blind, slightly limps and doesn't use his right hand. Yet, he manages to play the guitar, bowl and be an actor in the local drama studio. To see him laugh, joke and share, one would never realize how much he's been through. Jose never crawled, he couldn't walk, couldn't speak and couldn't eat things other babies and toddlers ate because a grain of rice would make him gag and choke. That changed with therapies, but at the age of two, because of uncontrollable seizures, he had half of his brain removed. I was told he could be a vegetable. Beating all odds, Jose graduated first honors from middle school and is doing as well in H.S. When he was 5, at the sight of a new day dawning he said with total happiness and amazement: "Look ma, the blue sky is coming!" That's how he approaches everything he does, with wonderment and joy. He teaches big lessons in simple things. People are attracted to his positive, happy and soft personality. He's an inspiration.

He was six years old when I had to take someone to the clinic. While I was in with the patient and the doctor, I left him in the kid's room; (a supervised playroom for the children to be while parents are in with the doctors). After a while, the playroom attendant went to the room to get me, she was excited and I was afraid something bad had happened. She said: "I had to tell you this!"

I asked: "What did he do?" She said: "He was playing with blocks and a little girl went to play with him, they were having fun and getting along fine. Out of the blues the girl asked him: "why is your face red?" We all gasped, waiting, and a dead silence filled the room. Jose looked at the girl and said: "my face is not red!" the air could have been broken with a knife. The silence was then broken by Jose's laughter. He looked at the girl and said while still laughing: "Oh yes! Yes it is! But you know what? It's perfect just like that!" The girl looked at him and said: "Oh, ok!" and they kept playing!" I guess he's known the secret all along, we're all perfect just the way we are!

Thanks Jose, you ARE perfect!



"I guess he's known the secret all along,
we're all perfect just the way we are!
Thanks Jose, you ARE perfect!"



joshua

“... OUR go-to source of information has been The Sturge-Weber Foundation and their email Support Group.”

As a volunteer adoption advocate for special needs children all over the world, I received the following from The Shepherd's Crook. Just one more plea for one more family for a needy orphan:

Three-year-old boy; - Large red birthmark on upper body and part of face; - Left ear abnormality; - Mental development is normal; - Possible Weber syndrome (not confirmed); - No history of seizures; - He is a social little guy, but can be shy at times”.

In the process of trying to help this child, China recalled his file, making him unadoptable. A series of incredible coincidences followed, and we soon realized WE were the one family for this one extra special boy when we were able to get his file released again!

It took another 14 months to finally arrive in China and meet him for the very first time, but Joshua has now been home 8 months, is 5.5 yrs old, and just started Kindergarten a few days ago, which he is VERY excited about. The “large” red birthmark is huge indeed... covering approximately 60% of his skin above the waist. Despite now documented brain anomalies, high risks of glaucoma and seizures, and deep port wine stain in many areas, Joshua is a very happy, healthy, social, LOUD, active, delightful young man who has added sunshine and joy into our lives. His initial EEG is normal, and he has only shown possible seizures one week in 8 months. His affected eye is light sensitive and often swollen almost shut in the mornings from the fluid in the stain around his eye, but there is no glaucoma at this time! He has a few odd neurological kinks, but is rapidly learning English and seems quite smart. His 100% port wine stain engulfed arm is swollen and a little longer than the other arm, but not to the extent it could have been if the stain had reached his lymphatic system.

Sturge-Weber syndrome and K-T syndrome remain possible, but unconfirmed, diagnoses at this time. But OUR go-to source of information has been The Sturge-Weber Foundation and their email Support Group. They have been absolutely invaluable sources of information and support for us with these very rare syndromes. We would have had a much harder time learning how to best care for Joshua without them. We have a ready source of been-there-done-that parents when we get the scary test results, or the puzzling symptoms. We sure appreciate their encouragement and support!

julie beth

I was born on April 15, 1969, the third of four children in the Clarke family. After my birth, Mom wondered why the delivery room became so quiet. No conversation was occurring between the doctor and nurses. Finally, the obstetrician told Mom there was a problem. When she saw me, the extensive port wine stain on my head, face, neck, right shoulder, arm and hand was shocking. The doctor said a pediatrician should be consulted to learn more about my condition.

When I was six weeks old Mom took me for my first check-up with the pediatrician. He examined me but was unable to tell her anything about my condition. He noticed my enlarged left eye and referred us to an ophthalmologist. That doctor knew immediately that I had congenital glaucoma and advised monitoring the ocular pressure frequently, saying I might need surgery if it got worse. During my second visit to the pediatrician we finally learned that my diagnosis was Sturge-Weber syndrome as a result of his research in medical textbooks. He told us that I might also have seizures in addition to the other problems.

Fortunately my progress was normal for the first seven months of my life. I was thriving and achieving all the developmental milestones. Monitoring the ocular pressure in my left eye happened periodically but in November the ophthalmologist recommended surgery to relieve the pressure. Then the bottom fell out! I experienced my first grand mal seizure in the hospital the morning I was scheduled for surgery, so it was postponed. I lost my ability to roll over, sit up, and had a left sided paralysis called hemiplegia. The hospital physical therapist taught Mom some exercises to do on my left side to prevent atrophy of my muscles. It worked! Eleven months later I regained most of my strength and walked independently at 18 months, but I'm still coping with some hemiparesis. Seizures continued with considerable frequency so my neurologist prescribed a combination of phenobarbital and dilantin. At eight months I was declared ready to undergo a surgical procedure called Goniectomy for glaucoma in my left eye. It was considered successful for about five years. Then at age six the doctor decided a second procedure called Trabeculectomy was needed. It, too, was successful. During my late teens I developed "sympathetic" glaucoma in my right eye but I'm happy to say that my glaucoma has been well controlled with three prescription eye drops for 15 years.

My seizures have been sporadic. For a seven year period, between ages three and ten, I was seizure free. Then they reoccurred when I was a teenager with different manifestations: tonic clonic, partial, and Jacksonian March. Several anti-convulsant medications were prescribed over the years, but seizure control has been difficult. In 2009 my current neurologist recommended a Vagus Nerve Stimulator (VNS) implant. Mom did some research, including contacting other SWF parents, before deciding to go for it. On May 6, 2009, the implant surgery was performed and now I can honestly say the VNS is helping to prevent and reduce my seizures.

SWS has been an impediment to completing my education and having a socially and emotionally rewarding life. I am very grateful for the love and support of my family, the services of dedicated staff at my residence and dayhab, and the SWF for being there, helping me to realize that I'm not alone.

Thoughtfully written by Julie and her mom. Janet



"SWS has been an impediment to completing my education and having a socially and emotionally rewarding life."



katie

Katie, our daughter, is almost nine years old and has Sturge-Weber syndrome. She was diagnosed shortly after birth. She doesn't let it get her down, most of the time. What annoys her are stares and silly questions like "what happened to your face honey?" or "did you get hit in the face?" which she gets quite often. She would prefer they ask her straight out why her face is red. She learned at an early age that not all people are kind, but she has also learned to deal with it (better than her mom and dad).

Except for doctor's appointments, medicine, and laser treatments, Katie leads the life of a regular nine year old. She has many friends, does well in school, and participates in many activities such as karate, swimming and dance. She wants to go to the University of Kansas-she loves those Jayhawks!

We went to our first SWS conference this past summer. We brought back so much useful information, but the best part was that Katie made many new friends. Katie has never been around others with SWS for any length of time. It was comforting for her to not be the only one. She was just starting to wear make-up to hide the redness and now she hardly uses it at all.

It's a new school year with new issues. We don't know what the future holds medically for Katie, but we do know she will be just fine in any endeavor she attempts because she is secure with who she is and what she has. Her future looks very bright.

"We went to our first SWS conference this past summer... Katie has never been around others with SWS for any length of time."

kennidee

Kennidee blessed this world on October 13, 2003 and came in with a ball of energy. When she arrived the doctors informed us that she had a birthmark that covers almost 90% of her face and mentioned the possibilities of Sturge-Weber syndrome. I did what every parent would probably do and started researching on the internet and of course was bombarded with all different forms of information, both good and bad. Her pediatrician scheduled her for an ultrasound of her brain to see if she had any additional signs of the syndrome. The ultrasound showed nothing and later I found out that it wouldn't have shown the right information anyway. At the age of 6 months she had her first seizure that lasted about two hours. The emergency room doctors were concerned because only one side of her body was actually seizing. The seizures continued for about a week with each one lasting anywhere from an hour to two hours. Finally her medication was adjusted enough and they were under control. Kennidee experienced paralysis on the right side but through therapy has completely recovered.

Her seizures remained under control until September 2009 when she started experiencing random falls. She broke her nose and busted her lip several times. From this her doctors determined she was having drop attack seizures. Our journey then took us to Cook's Children's Hospital in Ft. Worth, Texas for a five day evaluation. They determined that she has partial complex seizures that start on the left side of her brain and travel over to the right. Previously all of her other scans only showed seizure activity on the left side. These new scans showed signs as well on the right side of her brain. Currently medication is controlling her seizures again. Kennidee is evaluated every 6 months for signs of glaucoma and so far we are in the clear.

To date, Kennidee is a very happy and healthy child and is continuing to strive and grow. She loves fishing, riding her bike, playing soccer, and working in the garage to help fix things. She is truly a blessing in my life and I believe she blesses every one she meets.

The Sturge-Weber Foundation has been an amazing tool to connect with other families that are experiencing some of the same medical, physical, and emotional battles that can accompany the syndrome. Thank you to all for your continuing support.



“To date, Kennidee is a very happy and healthy child and is continuing to strive and grow.”



lakshmi

“...it is not easy to be growing up in today's world where young girls and boys are so preoccupied with their appearance and deeply troubled even by a minor pimple or a freckle.”

I was born in a government hospital in Mumbai, India, in 1953, full-term, followed fifteen minutes later by my sister, both of us with low birth weight. We were the youngest of five children.

I was born with a port wine stain on my face. My twin sister did not have it. I am not sure if it was diagnosed as Sturge-Weber syndrome at that time. I was diagnosed with glaucoma at 14 years (in both eyes) by which time the optic nerve in my left eye was damaged. I wore glasses and had to make weekly trips to my ophthalmologist. Many years later with medication, my trips became monthly and then quarterly and finally annually after undergoing surgery in both eyes.

I am very fortunate that I have no history of seizures and have led a fairly normal life. And the health problems (probably related to SWS) that cropped up periodically could be dealt with through medical interventions.

My growing years were easy and happy thanks to my family, especially my very progressive parents. Thankfully I grew up in an era when looks were not a priority. Family acceptance and values are very important in leading a normal life and my parents made sure that I was not made to feel any different from the other siblings. I never thought I was different, and luckily was not subjected to taunts and jibes, not even by children – who can be quite cruel. I was never given special treatment – nor was I viewed with sympathy – at home or at school. I was accepted as myself by my school and college mates, neighbors, friends, relatives and colleagues.

However, it is not easy to be growing up in today's world where young girls and boys are so preoccupied with their appearance and deeply troubled even by a minor pimple or a freckle. The cosmetic industry thrives by promoting such inane values and the youth of today are such easy prey.

I overcame many health problems including poor eyesight and a congenital heart defect to become a trained librarian and worked in academic libraries including a medical library. I focused on documentation of development issues, working with not-for-profit organizations and developing simple and appropriate information systems. I have compiled/edited over 25 books at international level and travelled widely on work. I have also been actively involved in the health and women's movement since 30 years.

Worried that I may lose my eyesight I started learning instrumental music a few years ago to help me occupy myself should there be a time of complete darkness. Now I have reduced my work and travel but I continue to be active in social issues and my routine includes daily yoga and swimming.

My life has been full of what can be called “miracles” – the miracle of support from family and friends who did not view me as different which gave me courage and confidence. However, the most notable miracle in my life has been my own strength in overcoming challenges and living life fully, in the professional and social worlds. For this I am grateful to my family and friends. And I always remember that things could have been worse. I believe in miracles and more importantly, I believe in making them happen.

lindsay

My name is Lindsay, and I was born in Toronto, Canada in 1984. I was diagnosed with Sturge-Weber syndrome very soon after I was born. I have glaucoma in my right eye, but I don't have any seizures. I have had several eye surgeries over the years and am still followed by an ophthalmologist and retinal specialist. I started laser treatments at the age of 5 and have had over 35 treatments so far. Even though I've had many laser treatments to lighten my birthmark, I know it will never go away completely; and that's ok! I am happy to be me, even though it is not always easy being different.

When I was 14, my family moved from Ontario to Alberta (like moving from Michigan to Montana for my American friends!). It was difficult at first, but eventually I made friends and got involved in activities again. I think it is important to find activities you enjoy and get involved. It helps to make friends and build self-esteem.

I started dancing when I was 5, because my mom wanted to help me come out of my shell and meet other kids. I continued dancing all the way until University, where I completed a Bachelor of Arts in Dance in 2007. Soon after, I realized that I wanted to keep dance as a hobby and not as a career. After spending a few years working on my French in Québec City, I went back to school and got a degree in Translation (French-English) in 2010. I just started my first permanent job as a translator, and I couldn't be happier!

I am so grateful to have such supportive and loving friends and family. They have always encouraged me to follow my dreams in life. I am also thrilled to be part of the SWF family. I attended my first SWF Conference this summer in Orlando. It was such an emotional, inspiring, and uplifting experience. I had always wanted to meet other people like me. I would recommend it to everyone!



"I started dancing when I was 5, because my mom wanted to help me come out of my shell and meet other kids."



Lizzy

“Throughout the 11 years of Lizzie’s life, and despite over 100 seizure and “stroke-like” episodes...Lizzie has grown into a beautiful, happy, funny, stubborn, determined and fearless young lady.”

Lizzie was born on June 8, 2000. The first person to suggest that something was “different” about her was the duty nurse in the nursery. She noticed redness on the left side of her face. The on-call pediatrician at the hospital mentioned the possibility of “a rare syndrome which is typified by a port wine stain within the trigeminal area of the face.” He explained that along with the birthmark, there would likely be glaucoma, seizures and brain damage. When asked what seizures were, he said, “They basically fry the brain.”

Okay, then... Thus began our journey of discovery. Instead of reading through individual accounts found on the internet, we were incredibly fortunate to find and contact the Sturge-Weber Foundation. Immediately, they gave one of the best pieces of advice that we ever received: Find a family doctor/pediatrician who is willing to work with (and refer us to) a “team” of specialists to help manage the myriad issues that are often interconnected with this syndrome. The Foundation provided concrete information that we could use to help chart a course of action, and offered support from their compassionate staff, and a connection to an amazing internet (support group) family. We can’t really imagine families who didn’t have the SWF to call when the diagnosis was delivered. This year, the Foundation helped with travel expenses so that we could attend our first Sturge-Weber International Conference in Orlando, Florida. Lizzie was finally able to meet and get to know others with SWS, and we now feel more educated and hopeful about her future! It was truly a wonderful experience for our family.

Another invaluable piece of advice came from an experienced SWF member. He used the term “The Velvet Hammer Approach” to describe an effective way to deal with medical and educational systems, and those who work for them and with us. You have to remain rational and clear during all interactions because if you don’t, you lose a measure of credibility; to make sure your ducks-are-in-a-row (questions are ready and clear); and to make sure before you leave the appointment or meeting you get answers that are understandable and can be followed up. And, above all, don’t take no for an answer!

Throughout the 11 years of Lizzie’s life, and despite over 100 seizure and “stroke-like” episodes, hospital stays, glaucoma surgeries, laser procedures to reduce the size and thickness of her birthmark, hundreds of doctor visits, countless blood draws, radiological procedures, and thousands of pills...Lizzie has grown into a beautiful, happy, funny, stubborn, determined and fearless young lady. She is active in dance, Girl Scouts, chorus, and swimming. When recently asked what she was afraid of, she replied, “Nothing.”

Along with the staff at the Sturge Weber Foundation, the neurologist at the Kennedy Krieger Institute, the ophthalmologist/surgeon at Children’s National Medical Center, who saved her vision, and our local family doctor, who has so adeptly helped us navigate her healthcare, Lizzie is blessed with another immeasurable gift. Her loving, patient and devoted sister, Rosie, maybe more than any one person, prayer, or doctor, has helped bring the light, strength and optimism that has helped shape who Lizzie is.

We like to remember the mantra of the doctors at Children’s National Medical Center, who kept telling us when we so badly wanted answers, “Let’s see what she shows us.”

No one can tell us what to expect, and that’s the hope and reason to keep believing that anything is possible.

lyndon

Lyndon came bounding into this world on April 17, 2000. The doctors informed us he had a severe bruise on the right side of his face. After a few days it was determined it was a port wine birthmark, not a bruise. We were also informed at this time, there was a chance he could have something called Sturge-Weber syndrome. Of course, it's not a well known or understood syndrome and we didn't have any idea what we were in for. The internet soon became a friend and enemy with all of its wealth of information.

Not being aware, our adventure was just beginning. Lyndon had his first seizure three days before his first birthday. The worst seizure came when he was 14 months old. This time the seizure was so out of control they had to put him in an induced coma, just to keep him from seizing. After a long hospital stay, Lyndon had a lot to overcome for he was back to a 3 month old state, not walking until he was three and not talking until he was five. Now we can't get him to slow down or stop talking. Lyndon has had many procedures, glaucoma surgery, numerous laser treatments, 10 radiation treatments for a tumor that was detaching his retina in 2009, and countless doctor appointments (which most of us know all about). Through all this he just keeps smiling.

Lyndon has had many struggles but has always taken the challenge head on. Due to all his setbacks he is developmentally delayed for his age, but that doesn't ever seem to stop him. It's funny how kids look at things differently. Lyndon's older sister, Ashley, has never once looked at her brother as having a disability; he is just her annoying little brother. He always has an upbeat attitude and we don't feel people even notice the port wine birthmark once they get to know him.

We try and keep him very busy with many sporting events through Special Olympics (basketball, bowling, equestrian, gymnastics, poly hockey, speed skating and track). He also takes drum lessons, cheers with a special needs squad, plays Challenger baseball and ice skates with the Gliding Starts. He loves to spend time with his friends at school, but homework is definitely not his favorite thing.

Lyndon has been seizure free for almost 3 years. He has done nothing but amaze people with what he has accomplished over the years. We praise God everyday for how far he has come. With God, family and good friends, anything is possible. The strength that Lyndon has shown could be a lesson to us all. We wish everyone could think like our SWS kids do, "That we are all perfect just the way we are."



"Lyndon has had many struggles but has always taken the challenge head on."



“... I know that it will be Maddie's courage and determination ultimately leading her to further accomplishments and true happiness.”

maddie

Maddie and I wandered the aisles of a local bookstore this afternoon, savoring the carefree summer day. Lost in my thoughts, I was quickly brought back to the present as I heard my little dolly's voice. “Mom?” she called. “Yes, Maddie,” I responded as I glanced over at the children's section. “I love you!” she exclaimed. Another treasured memory.

While my head swirls with snapshots of scenes taken during Maddie's life, I wish I could share them with the twice-crowned mother who cradled her newborn and pondered all of life's uncertainties. I was that mother, embracing Maddie, staring at the six-foot stork that graced our front lawn and announced her arrival. At that time, my mind was blurred by insecurities. I wanted to flash forward, to read the last several chapters of Maddie's story, to be comforted knowing that everything would be alright in our world.

A close friend shared that this was an impossibility, and furthermore, would deprive me of the joys that awaited. It took me quite some time to appreciate that her philosophy had merit. After all, my little girl had been diagnosed with Sturge-Weber syndrome and was battling seizures. Mothers at the park were worried about scrapes and bruises, yet I worried about Maddie's hemispherectomy surgery on the horizon.

Thankfully, and with the support of my Sturge-Weber Foundation family, I have emerged a stronger woman who has found peace with navigating each day as it unfolds, treasuring the many gifts along the way.

My wish is that by sharing Maddie's successes, I bring hope to other families and provide encouragement to dream big for our children. At eight years old, there is so much to celebrate! Maddie can:

- Run after her sisters, Rachel and Olivia
- Snuggle contently before drifting off to sleep
- Play tennis, serving one-handed
- Hoola-hoop
- Read!
- Write a love note
- Catch a fish on her princess rod at the pond
- Remember where Grandma hides the candy
- Courageously perform at the school talent show
- Independently swim the length of the local pool
- Recognize when a friend needs a hug
- Get into mischief
- Blow a bubble with gum
- Say her prayers
- Give 100 kisses a day

These days, as I wonder about the future, I am excited by all the possibilities! While we are certain to encounter uncharted challenges, we will tackle them as a team. Our family members will take turns guiding, yet I know that it will be Maddie's courage and determination ultimately leading her to further accomplishments and true happiness.

I'm so very blessed that I was chosen to be her mom! Stay tuned to learn more as she grows and I eagerly anticipate hearing about your child's proud moments too!

marissa

March 23, 2009 began like every other morning. I was a week overdue but still working. I headed to work and about half through the day my water broke and I headed to the hospital. I was in labor for 20 hours when it was determined that it was time for a c-section and soon Marissa would be with us. At 11:00 am on March 24th Marissa was born 7 lbs 10ozs and 20.5 inches long. My husband and I were so excited; Marissa was a perfect 10 year anniversary present. Once I was back in my room I heard the nurses talking with the doctors about the red mark on her face. Immediately I asked to see her again and her right eye was swollen almost shut. I learned that it was a port wine birthmark. Everything settled down for the evening and the next morning I was visited by the pediatrician, neurologist, and the dermatologist and the grim news came about Sturge-Weber and what it could mean.

We had a CAT scan and found that there were no calcifications on the brain. We came home and we took her to the eye doctor as well. We were lucky no glaucoma and nothing at that time was wrong with the brain. So we began to have her laser treatments. In January of 2010, things turned for the worse. On the 19th, Marissa started with seizures. She had about 20 of them within 24 hours. We spent a week at Children's Hospital and when we came home she was still having silent seizures. In April we learned that even the silent seizures have been controlled with medicine and though the left side of the body has delays she has started to walk and will be running before we know it.

That was her Sturge-Weber story...but the real story is Marissa is an ANGEL sent to us from God. She has been the connection of our family that has brought all our worlds together. Her baptism alone brought people from as far north as Syracuse, NY and as far south as Florida. When she was born with SWS we decided to never take one day for granted. If you would see the house it is a shrine to our Marissa. She has gotten to know all her grandparents and great grandparents, aunts, uncles, and cousins. Her great-grandfather is exactly 90 years older than Marissa. No matter how bad a day he is having, the moment she comes into the room he lights up and all his woes go away. She goes to daycare every day and has two therapists that work with her at daycare once a week. The worst thing they ever say is they never know when she is sick because she is always happy. I never thought I could admire and adore someone so little and she always just bounces back with whatever we throw at her.

At the end of the day, I am humbled for she has gone through so much more in 18 months than I have in my life and she still wakes up everyday with a big smile and says "Hi" which just melts my heart. I don't know if she will have seizures again or if she will be diagnosed with glaucoma in the future but I am eager to see where our adventure takes us and what else she will teach us on our journey.



"I never thought I could admire and adore someone so little and she always just bounces back with whatever we throw at her."



“This has been an eventful season of life, but by God’s grace we are ready to tackle anything that comes our way!”

noah

We would like for you to meet our little Noah. He is very special to us! He’s not special because he has an odd syndrome with a funny name, but because God has blessed us with him. He has been such a blessing to our family. He has touched people with his smile that we would have never met if it wasn’t for him!

Noah was born in 2007 in a little town called Powell, Wyoming. We thought he had severe bruising when he was born, only to find out around a week later that it was a port wine stain birthmark. We also noticed a “bulging-cloud covered” eye which we dismissed at first thinking something happened during his birth. Around 1 week old, I told the local doctor about his eye. He did not see what I saw but said he wasn’t an eye expert and sent us to his local optometrist. It was there when we first heard the term Sturge-Weber syndrome, PWS birthmark, and glaucoma. He sent us to Billings, MT to confirm it and they did. Since Noah was so tiny, the doctor in Billings wasn’t really equipped to give him the medical attention he needed so they sent us to Primary Children’s Hospital in Salt Lake City, UT. It was ironic to me, that just days earlier, I was commenting to the local doctor of how busy I was feeling. I was bringing him to the hospital daily for jaundice and I told him I didn’t know how parents with bigger medical issues could keep up! Before I knew it, I felt like we were in a whirlwind of seeing specialists when all I wanted to do was hold my baby at home. Our family of four other children was heading to Utah (500 mile one-way trip) every two weeks for his eye for about the first four months of life. Although Noah has not had any seizures, he has had four eye surgeries before 14 months old and it looks like he will have another one in the near future. At one time he was on seventeen eye drops a day! His vision in one eye is extremely poor.

We’ve been through numerous laser treatments on the extensive PWS which covers most of the face, scalp, chest, back, arm, hand, backs of both legs, and bottoms of both feet. He’s been blessed with a lighter colored birth mark (unless he gets cold, then it turns deep purple). Most people think it’s a rash or an allergic reaction, a wind or sunburn, or they suggest a cream. . .hehe. This has been an eventful season of life, but by God’s grace we are ready to tackle anything that comes our way!

There are two things I remember, just like it was yesterday. 1.) When I read about Sturge-Weber my mind filled with fear. My parents just happened to be visiting the new baby and my mom took me into the bedroom and prayed while I cried. I believe that God has touched Noah because of prayer. 2.) When I was trying to figure out if Noah truly had Sturge-Weber, I had emailed Anne Howard, from the Sturge-Weber Foundation, some pictures of Noah’s birthmark. I had asked her if she felt it was really a PWS birthmark. . .her first response was “Congratulations, you have a beautiful baby.” Thank you!

oğuz kağan

April, 28, 2010. There was a baby scream, and I saw him, my little boy, my little angel was born. Nothing was important to me anymore, but my little son. The doctor said, "There is a birthmark at his eyelid and forehead, but that's not so important because when he grows up the birthmark will be erased." I said, "Who cares?..My little boy is with me, who cares the rest..will erase or not." She didn't tell me about the risk that my son can have a rare syndrome called Sturge-Weber. She also didn't tell me that we had to have an MRI about the birthmark.

When he was six months old, there's something happened that I can't understand. He had a cold and sore throat. Suddenly I realize that he was trying to gulp. I think he had sore throat because of his illness and tried to nurse him, but he didn't react. I realized that his leg was shaking. We took him to the hospital in minutes. I was crying and trying to realize what was happening to my son. When we went to the hospital **Oğuz Kağan** didn't have any reaction to anything. The right part of his body wasn't moving, the left part was flopping like trying to rescue himself. His head was just looking to the left side, not moving to right side. The doctor looked at him and asked me if we had any MRI. I said, "No."

Then she began to tell the other doctor that my son had a birthmark at the left side of his face, and the right side of his body had cramp. I thought, "It's none of your business that my son has a birthmark or not, just do your job!" How could I know my son had a rare syndrome beneath that birthmark? That night my son was at the same situation about 2 hours and the doctor didn't do anything for him. She just said, "He is between asleep and awake, and it's just about his sore throat and cold." After 2 hours my son was good, and the doctor let us go home.

The next day we decided to take **Oğuz Kağan** to the university hospital which is bigger than the other one. When we entered of the door of hospital's emergency department, and told doctors about last night, the doctor asked if my son had any MRI about his birthmark or not. And she asked if the other doctor did anything while my son wasn't connecting with us. At this time I understood that something bad was happening. She told us about the risks of Sturge-Weber syndrome. I didn't hear about this syndrome before, I even didn't understood how to spell its name. That moment was too scary for us. I was just crying and angry at other doctor who told us that my son was between asleep and awake.

Now, **Oğuz Kağan** is eighteen months old, thank God, his seizures are under control by two different medicines. Until now he had just a few seizures that we can count. He's full of energy, full of life. He smiles all the time. I see a little man in him, who is so strong against his syndrome, who is enjoying every moment of life – like joking with life. He taught us to be strong, to be hopeful.

Our story began like a nightmare, I hope it will continue with the success of my little angel.



"Our story began like a nightmare, I hope it will continue with the success of my little angel."



paige

“It has been two years since Paige was officially diagnosed with Sturge-Weber syndrome. We are so blessed that she has remained seizure-free since leaving the hospital.”

We would like to introduce you to our spunky, little “bundle of energy”, Paige. She came into our lives in June of 2002 and was absolutely beautiful! She was born with a fairly light, but quite extensive port wine birthmark on her head, face, neck, arm, and leg. We were shocked and frightened to hear that she may have a condition called Sturge-Weber syndrome. Paige had an MRI as an infant and it did not show any brain involvement. We breathed a sigh of relief, but still watched her closely. Over the years, Paige met all of her milestones and was developing normally. We were thankful that we only had to deal with the “cosmetic issue” of laser treatments to lighten her birthmark. (She has had about 15 treatments since the age of 6 months.)

Fast forward to August 31, 2008...it was Labor Day weekend and we were spending the weekend at Grandpa's lake house three hours away from home. Paige became ill while watching the holiday fireworks display. She ran a fever and vomited through the night. We made the decision to go home the next day and her condition worsened. We headed straight to the emergency room. Paige suffered a stroke-like episode and ended up spending 19 days in the PICU. She was unable to speak, move her right side, walk, or sit up. It was during this time that Paige had 3 seizures and was officially diagnosed with Sturge-Weber syndrome. That is when the REAL journey began...just two short weeks after starting kindergarten! Paige gained her physical abilities back rather quickly, but went through speech therapy for six months. She suffered from speech aphasia and short term memory loss which required her to re-learn many things. We were amazed by her patience, determination, and sense of humor through it all.

It has been two years since Paige was officially diagnosed with Sturge-Weber syndrome. We are so blessed that she has remained seizure-free since leaving the hospital. She is a typical 8 year-old and keeps us very busy (along with her big brother, Kyle). She is filled with confidence and loves to be the center of attention (which sometimes annoys her brother). Paige is always on the move. She is involved in Brownies, gymnastics, soccer, and various school clubs. She loves playing with her friends, putting on dance shows, and wants to be a teacher when she grows up. We are so proud of how Paige handles her condition and she never lets it get her down. This journey has taught our family what is truly important and we are confident Paige is going to do great things with her life...she already has!

samantha

It takes a certain amount of courage and backbone to show up to the unknown. After you do you'll be forever changed. Pearl and George showed up for Samantha and were forever changed.

Samantha Davidson is twice blessed. She has a loving grandmother who has also been her devoted parent since she was 5 months old.

Pearl and George of Milford, DE assumed custody of their granddaughter Samantha shortly after her diagnosis of SWS in 1966. Pearl and George raised and cared for their granddaughter, on their own, until 1988 when they learned about the Sturge-Weber Foundation. Samantha was 22.

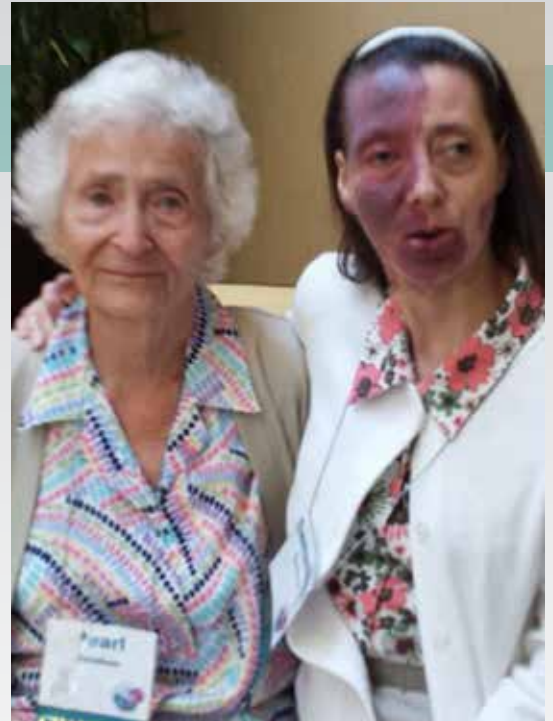
In 1990 they traveled to Pittsburgh for their first International Conference. Here, they met Kathy Keffer Capozzoli who helped them as they began learning all they could about Sturge-Weber. They've become life-long friends and have attended many regional events together.

Like so many children with SWS Samantha has faced many medical and educational challenges: the doctors appointments; the endless medical forms to complete; the research studies to review; the special education programs that helped her through high school. Pearl has continued to accept them, as a single parent, since George's death in the mid-1990s.

Samantha is an avid letter writer, often sending the SWF office friendly floral notes and seasonal cards. Her handwritten advocacy letters to her local and national politicians are always personal and heartfelt. She recently wrote to Senator Thomas Carper to support continued funding for rare disease research. Together, Samantha and Pearl embody the partnership that The Sturge-Weber Foundation has with the people who call on us.

"Sometimes it takes another's strength to help you walk along and to lift the fear away... You know I'm gonna see you through. This I know We Weren't Meant To Go Alone", excerpted from our 2013 Conference theme song by Steph Shaw.

P.S. Earlier this month Samantha celebrated her 47th birthday. And, she and Pearl attended the 2013 International Conference in Denver, flying for the first time!



"Sometimes it takes another's strength to help you walk along and to lift the fear away... You know I'm gonna see you through. This I know We Weren't Meant To Go Alone"

excerpted from our 2013 Conference theme song by Steph Shaw.



savannah

“Our minds raced to picture what our little girls’ life would be like in the future. What would this mean for her? What did we do wrong?”

Savannah was born September 28, 2009 at 8:14 pm with lots of dark brown hair, blue eyes, and very round cheeks. Savannah was also born with a lot of redness all over her body along with some bruises, due to her being wedged between my pelvic area for so long during the labor. We were able to see her for about 15 minutes, in an incubator, before they transferred her to the NICU where we would spend the next 6 days. Over the next few days we learned Savannah had glaucoma in her right eye, and the redness all over her body was a port wine birthmark that would not fade like the bruises would. I can remember the doctors sitting us down to tell us that Savannah had Sturge-Weber syndrome like it was yesterday. Philip and I tried to hold back tears as the doctors described what SWS was and how it may affect our little girl. Our minds raced to picture what our little girls’ life would be like in the future. What would this mean for her? What did we do wrong? So many thoughts and fears filled our heads.

The last year and a half has been a whirlwind of doctors, hospitals, and therapist appointments. We finally seem to be starting to get settled in our own routine and feel more comfortable with the decisions we are making for Savannah. She now has glaucoma in both eyes. She has had 2 right eye surgeries and 1 left eye surgery. And at the present time her pressures have been fairly stable since October 2010 with Cosopt and Xalatan eye drops. Savannah started having seizures when she was 4 months old. We have worked with her neurologist closely, but we still continue to see seizures occur every couple of weeks. Thankfully we are only seeing 2-4 seizures a month right now. Savannah takes Trileptal, and Felbatol. Savannah also has hypothyroidism, which she takes Synthroid for. We have OT, PT, and speech therapy once a week. Since we started OT, the therapist found Savannah to have sensory integration issues. So we use different sensory activities to “wake up” her left side, because of the weakness she has on her left side. We have to stimulate her body by different activities to get her to eat a meal. If we don’t, she will not eat. Savannah has had developmental delays from the start. She didn’t smile until she was 4 months old or laugh until just 20 months. Savannah is now saying mama, dada, and baba. She has been sitting since she was 14 months old.

Savannah likes to smile, to babble and roll across the floor. She absolutely adores her big brother Conner and her daddy, and will do anything she can to get their attention. Every child is a wonderful blessing, but until you have a special baby like Savannah, you may take for granted that first smile at 6 wks or perhaps their first word or even perhaps the knowing recognition of family. Savannah is our daily reminder to us to take one day at a time and to take each precious day slowly. We know we may have several challenges in front of us, but we will face them with her. Savannah is our beautiful little girl.

sydney

Meet Sydney. Our little 4-year old is cute, funny, social and can we say a tad dramatic. Her likes include Dora, Strawberry Shortcake, zebras and her older brother, Ryne. Her dislikes include Santa, the Easter Bunny, getting her hair brushed and ketchup. Sydney's story sounds like so many of her fellow Sturge-Weber friends. She was born on April 6, 2006 and little did we know what started out as a bruise on her face would turn into so much more. From the moment the nurse came into our room and said the redness on Syd's face was a port wine stain and not just a bruise, our lives have truly never been the same.

Our wonderful pediatrician, Dr. Rosa, came into our room that night and warned us that there was a chance she could have a syndrome that sometimes accompanies port wine stains called Sturge-Weber but tried to reassure us that we would cross that bridge if we had to. We hoped for the best and prayed we wouldn't have to learn what Sturge-Weber was but unfortunately Sydney had her first focal seizure in May when she was just over a month old. An MRI in June would confirm our fear and diagnose her with SWS. Syd's diagnosis was extremely hard to accept. This is the kind of thing that only happens to other families, not yours.

Dr. Rosa referred us to St. Louis Children's Hospital and when Sydney was only two weeks old she met her pediatric dermatologist, Dr. Bayliss, and her pediatric ophthalmologist, Dr. Lueder, for the first time. An eye exam under anesthesia would show that Syd had glaucoma in her left eye. For the next two years of her life, the 2½ hour trip to St. Louis would become a regular occurrence. The laser treatments began that August when she was only 4 months old. Now four years later, Sydney has undergone two glaucoma surgeries, two strabismus surgeries, sixteen laser treatments and numerous MRI's, PET scans, and eye exams under anesthesia.

We feel truly blessed to be surrounded by our wonderful families, friends, doctors, co-workers and employers. These people have been so supportive of Sydney from the beginning and we wouldn't be able to get through this without them. Some days are still harder than others but having a strong support system makes all the difference.

We are also grateful to the Sturge-Weber Foundation. We don't even want to think about where we would be without them. After reading a copy of *Branching Out* a few years ago, we decided to enroll Syd in the Sturge-Weber study being conducted by Dr. Juhasz and Dr. Chugani at the Detroit Children's Hospital in Michigan. We learned more from the doctors there than we could have ever hoped for. The entire staff working with the study is wonderful and we are so thankful to them for what they did for our family. We strongly encourage other SWS families to take part in that study.

We are very thankful that Tegretol keeps Sydney's seizures under control. She has minor speech delays but other than that is developing right on schedule. She was enrolled in our school district's Early Learning Program when she turned 3 and attends pre-school daily. Her favorite part of school is riding the bus but we won't tell her teachers that. Syd tried t-ball and swim lessons for the first time this past summer and we know this is just the beginning of what she is capable of.



"We are also grateful to the Sturge-Weber Foundation. We don't even want to think about where we would be without them."



Zander

“As soon as he could hold his head up without help he started to use those icy blues to humorous effect. I can honestly say that I’ve never seen an infant stare a grown man down until I met Zander.”

My heart broke the moment Zander was handed into my arms and I saw his face for the first time. Our doctor hastily assured us it was just a bruise that would fade quickly, but I knew immediately that he was only trying to soften the blow by denying the obvious.

I wish we had known then what we know now. I wish we had known that we had just met the most relentless, indomitable little person that we would ever encounter, and I wish we had known just how much mischief we were in for. At least if we had, we might not have worried ourselves into sleeplessness for so many nights.

It wasn’t until several days after we brought him home that I realized just how beautiful he was, from his adorable cleft chin to his perfect lips, and those eyes! Admittedly, we were terrified to take him into public at first. The stares, gasps and whispered comments as we walked by were hard to take. We felt an overpowering urge to protect him from it all, but over time we began to realize we didn’t need to. As soon as he could hold his head up without help he started to use those icy blues to humorous effect. I can honestly say that I’ve never seen an infant stare a grown man down until I met Zander. He was a serious little guy in the beginning, with hardly a smile and such a great deadpan stare that eventually people started keeping a more respectful distance. If they stared at him, he stared back fearlessly. It got to the point that our friends would joke about him being an adorable bully.

Now it’s been two years and he’s lightened up considerably. It’s all we can do to make it through the day without him pulling a prank or two at our expense, and there is nothing he enjoys more thoroughly than harassing his older brother, Adrian, who takes it good naturedly and occasionally returns the favor. It’s not uncommon for him to flash you with a thousand watt smile and run away, in the hopes that you’ll give chase and if he’s lucky, tickle him.

The word “can’t” doesn’t even exist in Zander’s world. If there is an obstacle in his way -or heaven help them, a person- he will get around it at all costs. If we had to pick a favorite quirk about him though, it might be his mind. We never dreamed he would be counting by twos, fives and tens, and already reading his name at the ripe old age of two.

In short, Zander is a tiny conqueror. He has only grown more beautiful with each year, and I can’t help but wonder if maybe his PWS was simply Nature’s way of keeping things fair. He may walk into every room as if he owns it, but if you’re one of those lucky people he loves, he might just deign to stop and snuggle for a moment. Only a moment though, don’t get greedy.



STORIES OF hope

The Sturge-Weber Foundation

The stronger the wind, the tougher the trees

PO Box 418 | Mt. Freedom, New Jersey USA 07970-0418

P 800-627-5482 or 973-895-4445 | F 973-895-4846

swf@sturge-weber.org | www.sturge-weber.org