

BranchingOut

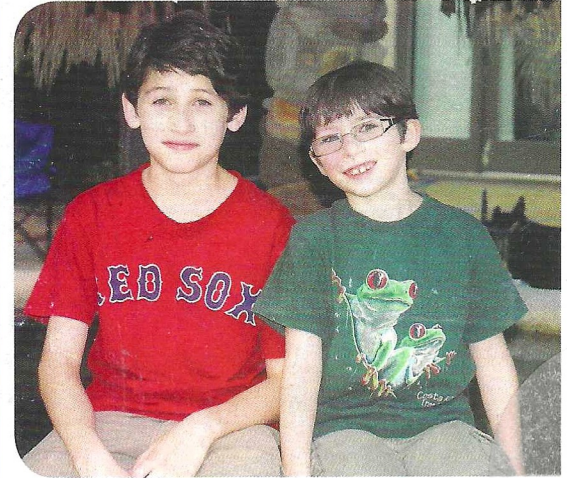
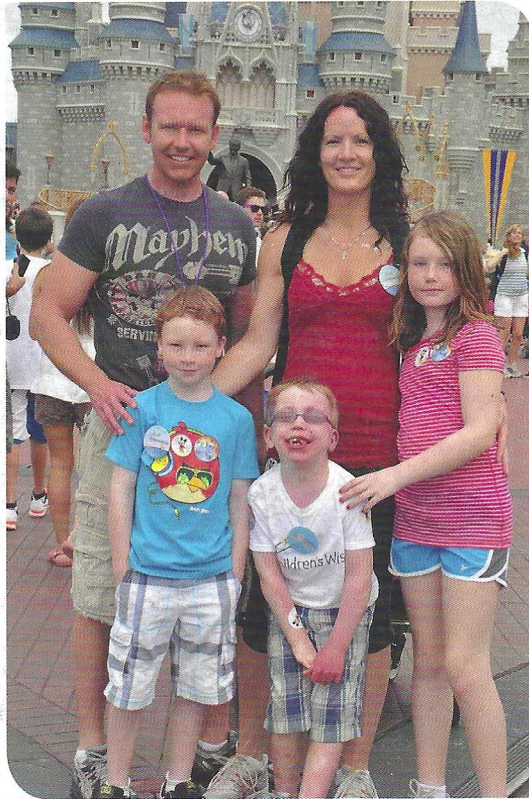
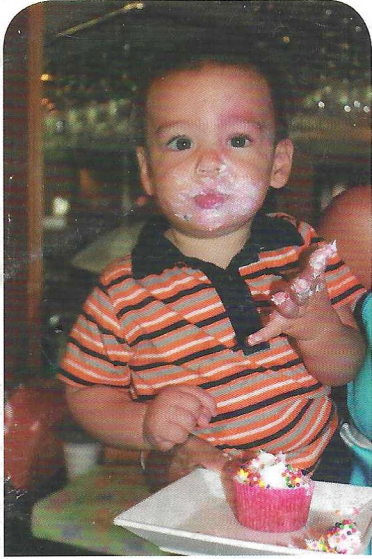
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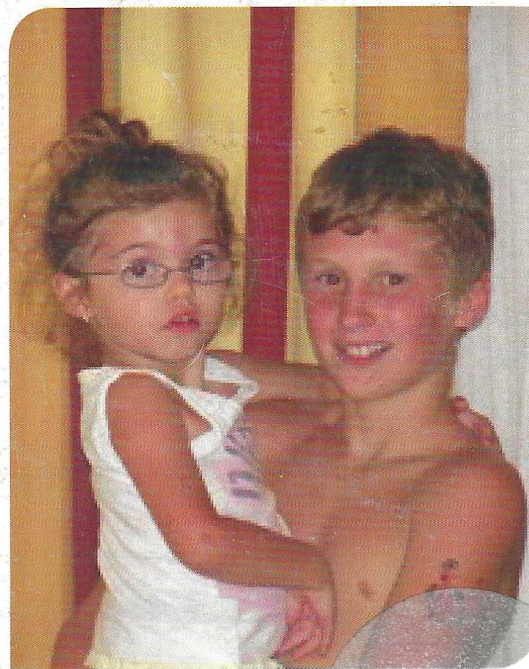
August 2012

The Sturge-Weber Foundation

Single Copy \$3.75 • Free to SWF Registered Partners



Rays of
SWF



Summer
Sunshine

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On the cover: SWF family photos from the Terrell, Dalton, Clark, Walsh, Richardson and Findlater families.

If you have opinions, questions, or articles for Branching Out, we would like to hear from you. Please fax, mail, or e-mail your material to the SWF office (swf@sturge-weber.org). We reserve the right to edit all materials.

The SWF is a member of the National Organization for Rare Disorders (NORD), American Brain Coalition (ABC), The Coalition of Skin Diseases (CSD), and the Association for Research in Vision and Ophthalmology (ARVO).



On the SWF Road Again

by *Karen L. Ball, SWF,
President & CEO*

I keep hearing that Willie Nelson song in my head... On the Road Again! It's that time of year again where I hit the road to meet our members and engage stakeholders to collaborate with the SWF. We improve the quality of life and care for those living with SWS, KT and birthmarks with every opportunity to connect! In our last survey, 79% of you reported research was a top priority. I engaged Dr Charles Swindell to work with the SWF to stimulate research and identify drug compounds to improve therapy and quality of life. The Board of Directors has shifted resources accordingly. We're fired up and we hope you are too! Look for opportunities in this issue to participate in the research you ranked as a #1 priority!

Dr Swindell has formed a SWS clinical trials working group with **Dr Steve Roach** at the helm. Dr Swindell reports in this issue on the progress being made to establish a framework for clinical trials and to find new drugs that will improve our loved ones care. The BVMC Sturge-Weber project is moving right along and is identifying some interesting trends and leads for future research. The SWF is reaching out to new stakeholders such as the Drug Information Association (DIA) and increasing awareness through a network with key stakeholders such as the DIA, FDA and NIH. These relationships will be beneficial to the clinical trials working group and more importantly to your loved ones.



The SWF comprehensive programs and services, while focused on research, are really centered on support and networking! We LOVE to meet and greet; connect and advocate; and spread smiles across the miles! Great fun meeting the 2013 SWF International Conference Committee in Denver! We all are so excited to host the International

Conference in Denver July 23-25, 2013. Y'all come and let's kick off the SWF's 25th anniversary year with a bang where it all started lo those many years ago! There's also a Boston Educational Forum in September and in the planning stages one for Chicago. These forums give you the ability to connect on a local level while the International Conference brings together an army of families and researchers with the

latest news...either way we're better together!

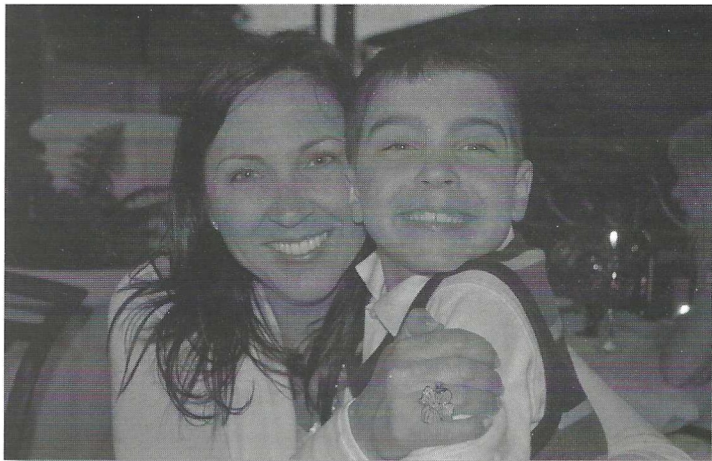
Greta McLaney and Buddy Petrillo joined me in Miami for an on-site visit to select this year's venue to toast and roast a well respected dermatologist during the annual dermatology meeting to be held in Miami March 1-4, 2013. The SWF looks forward to welcoming attendees to the elegant Ritz Carlton in Miami Beach, FL for our winter fund raiser. Enjoy the rest of your summer!

With faith, hope and love,

A handwritten signature in cursive script that reads "Karen L. Ball".

Karen L. Ball

SOUNDING BOARD: Pamela McIntyre



Pam and her husband Dan of North Reading, MA joined the SWF in 2006 after twins Ryan and Ava were born in 2004. Pam and Jessica Melo met through the SWF and collaborated in the cookbook "Cooking Up a Cure" as a fund raiser. They have since been running in the Falmouth Road Race, now for the 3rd year.

Our family will be celebrating an important milestone in July, our son Ryan, who was diagnosed with SWS at 6 months of age, has been seizure-free for two years. This coincides with my nomination to the Sturge-Weber Board; two wonderful life events occurring at the same time. Ryan is now seven years old, enjoying his childhood with his twin sister. Her typical childhood development is a daily reminder of the contrasting differences in development, and continued challenges, that Ryan and other children with SWS face.

I am honored to be nominated to the Board of Directors of the Foundation and look forward to continuing to support the wonderful legacy of dedication and hard work provided

by volunteers over the years to help carry out the Foundation's mission. I am especially eager to learn more about the progress in research that the foundation has collaborated on in conjunction with the Brain Vascular Malformation Consortium.

I am inspired by CEO Karen Ball's continued heartfelt commitment to serving the Sturge-Weber community. I am grateful that she had the foresight and perseverance to overcome the obstacles associated with building out a non-profit entity. This year's 25th anniversary of the Foundation, with over 6,000 members, is a tremendous accomplishment achieved through her dedication and vision. On behalf of the SW community, we are all deeply thankful to her for making the resource of the Foundation available to all of the families across the world.

In addition to the medical aspect to the Foundation's mission, there is also the communication aspect facilitated through the Foundation's network. This has been a powerful resource for me, as it is where I met another SW mom, Jessica Melo. Our supportive friendship and combined effort has motivated us to raise over \$75,000 for the Foundation by having a cookbook sale and running in the Falmouth Road Race as a team.

I look forward to contributing to the Board, and am particularly excited about helping to facilitate Boston's first Education Forum this September with the help of Jennifer McCrave at Children's Hospital Boston. This invaluable experience will capitalize on all of the wonderful doctors in Boston who are willing to spend the day with parents.

In appreciation

While we welcome a new Board member, Pam McIntyre, we send our warmest appreciation to two retiring Board members, who will now be moving to Honorary positions.

Linda Larach Cohen has been a Board member since 2008 and with her family, husband Rolando and kids Roberto, Marco and Francesca, has been an energetic and generous member, running the two Players Club SWF benefits in NYC and the recent Wine Tasting.

Woody Crouch joined us in 2005, after attending the International Conference in Hershey, PA. After the death of his infant grandson, Michael, he stepped up to provide advice and insight for Board and admin activities of the SWF. We know you will still be here, Linda and Woody, so this is not good bye, just a big thanks.



MEMBERS' MILESTONES

Jeff Gilbert Sky Dives

On May 20, Jeff Gilbert, who has SWS and is blind, stepped out of a plane and sailed into the blue, a dream he has had for a long time. This happened in Perris, CA when he went tandem skydiving with Sky Dive Perris. It is all captured on Youtube for you to enjoy. Search "Jeff Gilbert's Tandem Skydive" and after about a 2 minute intro you will see Jeff going on the ride of a lifetime.

The Dalton Family's Wish

Gabriel Dalton of Prince Edward Island, Canada was granted a wish from the Children's Wish Foundation. In May, Sam and Mary and kids, Gabriel, Sophia and Xavier (see cover photo) spent a week at a not for profit resort Give Kids the World in Orlando. They had a whole week to enjoy Disney World and Sea World.

They met other families who had children with various conditions. "We all had things in common and it was great to be around them. Now we have a CD with all our photos and memories". Gabriel has a special star in the tower of angels where it joins 150,000 stars



Maddie Haubert in Talent Show

Lisa Haubert proudly reports that 7 year old Maddie participated in her school's talent show in May. She sang the Toy Story theme song "You've Got a Friend in Me". Lisa says "My courageous little girl stood on stage in front of at least

150 people and was tickled pink at her accomplishment. Following her performance, she announced "I did it! I did it! Mom, are you proud of me?" Naturally, my tears said it all. Our children are so amazing"

Maddie's evening talent show performance was so inspirational, that she was asked to sing again at a later date during a school-wide assembly to celebrate the uniqueness of all children. "Tears filled our eyes as the entire school clapped and cheered for Maddie. She was beaming with pride and we will cherish this memory always."

Reaching New Heights

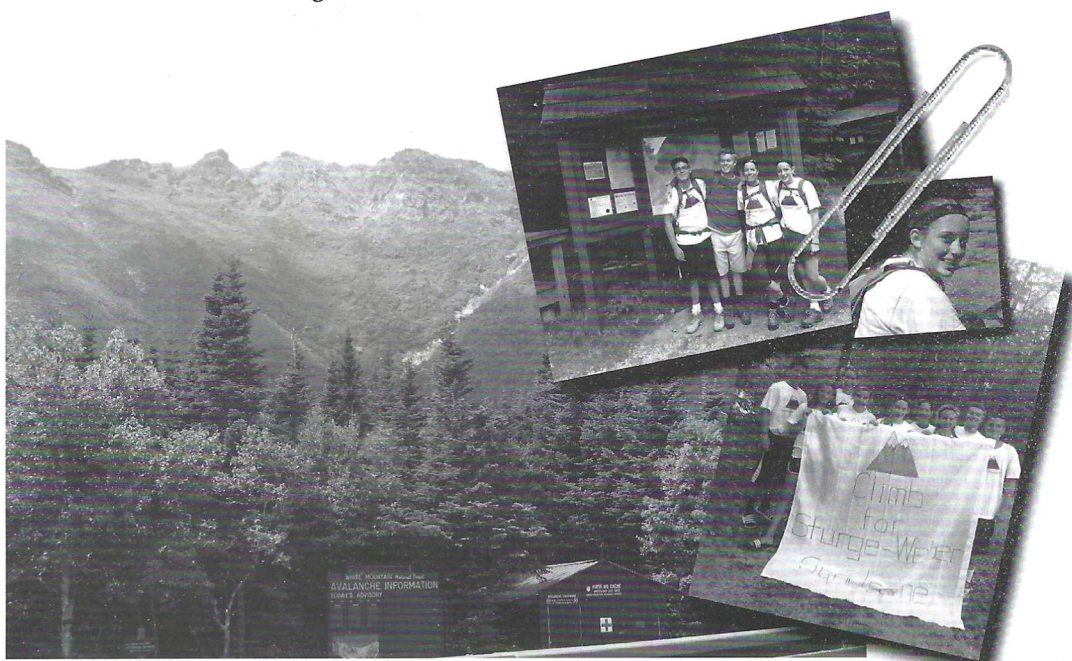
Sarah Argersinger writes: "I am very pleased to let you and the Foundation know that on Wednesday, July 18, 2012 we met Emily Argersinger's goal in support of Sturge-Weber syndrome of climbing to the top of Mt. Washington in New Hampshire's White Mountain Presidential Range. Emily is 13.

Mt. Washington is the highest mountain east of the Mississippi and is famous for erratic weather and wind gusts. We thought it fitting. "The stronger the wind, the tougher the trees."

Our amazing group from Ann Arbor, Michigan consisted of Emily's brothers Davis Argersinger, 17, and Danny Argersinger, 15, friends Anika Szuszman, 14, Analee Szuszman, 12, Aydan Szuszman, 11, Luke Furlong, 16, and Stacey Szuszman (Mom to Anika, Analee, and Aydan) and me, Emily's mom. We climbed to the summit via the Tuckerman's Ravine Trail. It was challenging and awesome! I am so proud of Emily and this group of kids and grateful to my friend Stacey for helping me make Emily's dream a reality. Emily was inspired to establish a fundraiser after visiting the Foundation website and learning about a golf outing for a boy named Jachin in Wisconsin. She so badly wanted us to take

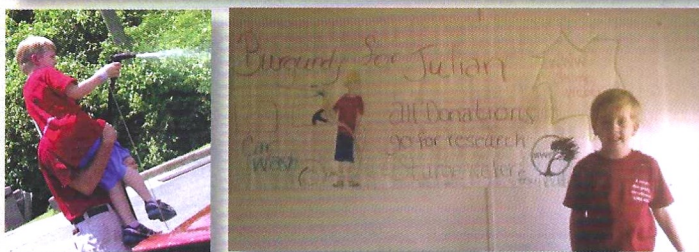
her there to be a part of Jachin's fundraiser and we just couldn't do it because of work, school, etc. One of these days I will let the people in Wisconsin know how their efforts inspired Emily who then inspired the rest of us!

These are photos of Emily on the way up, Emily and our group celebrating after the climb, my three children and I before the climb, and a photo we took of the mountain when we were half way up at a place called Herman's Hut. I am hopeful that Emily's fundraiser will continue to grow."



MONTH OF AWARENESS ROUNDUP

Each year in May, SWF members do whatever they can, wherever they are to bring SWS and port wine birthmark conditions into the spotlight. These are only some of the events our wonderful members held.



WENDY STEELE, HER FAMILY, COMMUNITY AND ALLIANCE TAEKWONDO GEARED UP FOR MONTH OF AWARENESS

Wendy is spearheading great things in Springville, AL! Wendy and her sons hosted a car wash to raise awareness and funds. They created & sold "wear burgundy for Julian" t-shirts and got Julian's Taekwondo school involved in raising funds and awareness at their school. The "wear burgundy" shirts were featured on Alliance Taekwondo's Facebook page during the month of May.

WINGRA SCHOOL, MADISON WI

Each year the school runs a school store selling supplies as well as juice and snacks at lunchtime. The activity has two purposes. One is a math activity where students learn about profits, price setting, calculator skills. The other is to involve the students in the community outside the school. One of the students, Maxwell Isenberg, suggested the SWF as the recipient of May's proceeds because his brother Walton, has SWS. The students unanimously agreed with him. Thanks, Maxwell, for being a great big brother.



CANDY BAR SALE

Kaydie Hill and her brother Eric were ready to spread awareness and raise funds by selling candy bars during Month of Awareness this year. Kaydie and Eric were proud to raise \$93 for the SWF. Kaydie is a strong little girl, getting out there to help after having a right side hemi brain surgery in March!



JACHIN JORDAN GOLF OUTING

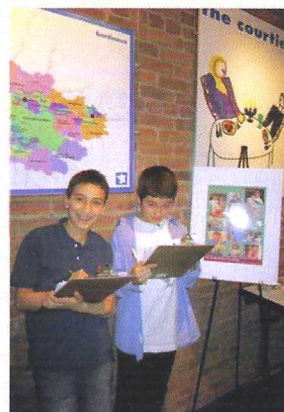
Jonathan Jordan and his family hosted their 5th annual golf outing at Bishop's Bay Country Club on the north shore of Lake Mendota, WI. Morning and afternoon golfers enjoyed a great day of golf, wrapping up with dinner. As always, Jonathan did a great job recruiting golfers, raising awareness and raising funds for the Sturge-Weber Foundation. This year the golf outing raised \$20,057!

CALVARY UNITED METHODIST CHURCH, MILFORD, DE

Richard Roberts organized a fundraiser in honor of Samantha Davidson at their church in May, 2012 and raised almost \$898.00! Parishioners received SWF informational brochures and the Sunday school students received coloring books to learn more about SWS. Samantha and her grandmother Pearl are church members and have been with the SWF since the beginning in 1987. Samantha also created awareness in her community through an article in the Milford Chronicle.

MARCO CHEERS FOR THE STURGE-WEBER FOUNDATION

Rolando & Linda Cohen hosted a wine tasting in NYC on May 17th in support of SWF programs and in honor of their son, Marco at the Moore Brothers Wine Company who graciously donated the wine, space and staff for the event. Cupcakes donated by Petite Treat Cupcakes were an additional treat. Big brother Roberto and a friend manned the reception table very effectively. Dan Miles, MD of the SWF Center of Excellence at NYU, dropped by to join the crowd. Their event raised over \$20,000!



BAKE SALE

Maddy Tiffany, 11, and her friends planned and ran a bake sale to support the SWF in honor of her brother Charlie, who is 9. The Tiffany's company, DCT, matched the proceeds and made a generous \$400 donation. They presented the check to Karen Ball at the San Diego Educational Day on March 18th.

THE WOMEN'S CLUB OF WHITE PLAINS FOUNDATION



April Tunno, Heather Adessa and the Women's Club of White Plains Foundation in NY supported the SWF by hosting a "Shop for the Cause" night on June 14th and raised \$1740. The event was attended by members of the Women's Club and the White Plains and Westchester communities. The Club's motto is "Women for Women – Women for Family – Women for Community". For close



to 100 years the members have been raising funds to support nonprofit agencies throughout Westchester County and beyond. The SWF is fortunate to be a recipient this year.

BAKE SALE IN NEBRASKA



Megan Loudon and family had a bake sale in a small park in Tekamah, NE on a day when the town was packed with people celebrating graduations. They had mountains of baked goods to sell and reached many people who did not know

about SWS. The pastor of the Baptist Church helped out by bringing sandwiches and coffee. One of the local police officers had his kids home baking cookies all morning for the sale. It was an amazing day, raising \$300. They are gearing up for a spaghetti dinner in the fall.



ACES FOR ARAYAH IN FL

Annie and Sam Vititoe held a benefit poker tournament in honor of their daughter on June 23 which was a first for an SWF fund raiser. In addition to raising awareness among a new segment of the community, they raised \$350.



HOT YOGA IN MA



Pam McIntyre had her yoga class in North Reading host a 75 minute special class as a benefit for the SWF in July. People with all skill levels of yoga were invited with a suggested contribution per person, raising over \$800. In addition to a good relaxing workout, the participants learned about SWS - good exercise for the brain and good for the soul.

SYOSSET NY SCHOOL DISTRICT AWARENESS DAY

Linda Sobolow, proud grandmom of 6 year old Noah Broklawski, held her annual awareness table in Syosset where she works in the school district's Special Services department. She shared printed materials and information and also raised \$200.

VOLLEYBALL TOURNAMENT IN BOWLER, WI

Valerie Fehrman and her sister Sabina hosted a volleyball tournament on April 21st to benefit the SWF and raised \$280. Valerie's daughter, Katelyn was able to participate in the tournament. She had a wonderful time playing volleyball while raising awareness and funds!

You can check out several of these stories and news articles in the "Get Involved" section of the SWF website.

Drug Information Association (DIA)

The Sturge-Weber Foundation was one of 21 organizations nominated and accepted for the DIA's 2012 Patient Advocate Fellows program in conjunction with the annual DIA conference held in Philadelphia, PA **June 23-28**. The DIA is a multidisciplinary association of almost 18,000 members in 80 countries whose mission is to advance the discovery, development and life cycle management of safe and effective medical products.

The Fellows program, shepherded by **Donna Mayers, Volunteer Services Program Lead** met for a full day to learn more about the DIA's operations and activities. **Susan Cantrell, DIA Director of North America**, reported on the DIA and North America's activities. **Heidi Marchand and James Valentine** reported on the office of Special Health Issues at the FDA.

The annual meeting complimentary registration and annual membership will greatly benefit the SWF as we ramp up our clinical trials initiatives and engage new stakeholders in our endeavors. **Mennato Forgione**, VP Business Development for Ce3 a clinical trials company, and SWF member **Klaus Rose**, MD, former Novartis Global division, are old friends of the SWF and assisted with introductions for potential future collaborations. The SWF is grateful for the opportunity to have participated in the program and looks forward to continuing the friendships and optimizing the business leads generated during an eventful week!



Brain Vascular Malformation Consortium (BVMC)-Sturge-Weber Project Annual Report

The annual BVMC meeting was held in Santa Fe, NM **June 19-21** and hosted by the Angioma Alliance and UNM this year. **Beth Baca, Phillip Evans, Leslie Morrison, MD and Amy Akers, PhD** did a wonderful job with logistics and playing hosts. The three projects reported on their respective progress, enrollment and brainstormed about future studies

benefiting brain vascular malformations. **Dr. Doug Marchuk and Dr. Anne Comi** reported on the SWS Project that we have 114 enrolled with a minimum of 300 participants needed for Aim 1 (registry). There are several urine samples collected for Aim 2 (MMPs) and they have registered with the NDRI to obtain brain tissue samples for study in Aim 3 (DNA).

Three cheers to the SWF members! **Callyn Hall, DMCC**, reported that 50% of the contact registrants who have signed up to be contacted about any upcoming research trials

that could benefit those living with SWS...50% come from the SWS project. Thank you for responding to the SWF's call for participants! The SWF has now been given the green light to assist even more in patient enrollment. As you call or email, we will be asking you to participate in the

registry enrollment so we can meet the goal of 300 minimum participants.

Showing insightful results in research projects is key to continued funding. We need to maximize the BVMC Sturge-Weber project and the two other projects' findings to obtain further National Institutes of Health (NIH) funding. The project is making it now even easier to participate by enabling oral consent! What's oral consent you may ask? Well, the SWF will first screen you based on set inclusion project criteria. Then, one of the participating Centers of Excellence will contact you or you will contact them and verify diagnosis. Once verified your data will be stored at the RDCRN in Florida with the other participants so the scientists can continue to study SWS. Already, the findings are exciting and each one of you participating can be proud for having improved our collective understanding of SWS!

Sleep Study

in cooperation with Boston Children's Hospital.
An initial on-line survey is in progress
that will address sleep and headache
issues for children between the ages of 2 to 18.

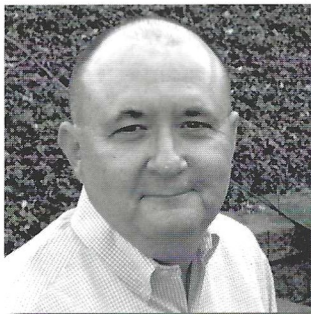
What you can do to register

If you or your child has a diagnosis of SWS and can document it, and you are willing to participate, please call us. We will give you the names and location of centers that would be convenient for you.

We can contact the Center with your information and they will finalize the registration OR

We will give you the location and contact information for you to make the initial contact.

The Sturge-Weber Foundation Clinical Studies Working Group



Charles Swindell, PhD

When I first discussed this project with Dr. Steve Roach at Nationwide Children's Hospital in Columbus, Ohio, we agreed that a vigorous discussion among the Foundation's clinical advisors with a special interest in and experience with clinical research was well worthwhile. The principal objective of this effort would be to identify

opportunities to investigate new potential treatment options, but other questions related to clinical care could be addressed, as well. I am happy to say that the work of the clinical studies working group has now been kicked off and Steve has agreed to serve as convener.

In addition to Dr. Roach, the clinical trials working group currently involves Drs. John Bodensteiner, at the Mayo Clinic in Rochester, Minnesota, Anne Comi, at the Kennedy Krieger Institute in Baltimore, Maryland, and Csaba Juhasz, at Children's Hospital in Detroit, Michigan. We plan to add additional clinicians to represent the diverse medical specialties involved in the treatment of Sturge-Weber syndrome. Although we are only in the very initial stages of this project, my hope is that this group will conceive and plan clinical investigations that the Foundation may be able to help facilitate, and that ultimately will provide key data that could improve the care and quality of life of those with Sturge-Weber syndrome.

Since we are on the subject of clinical research, it is a good time to remember how important it is for patients and families to consider participation in clinical studies and patient registries, like the Foundation's registry and the BVMC registry. Clinical advances cannot be made without patient participation. While involvement in clinical research may not be the right thing for you or your family, we do ask that you keep yourself informed about these opportunities and consider participating whenever possible.

NDRI

The National Disease Research Interchange is available for your participation at all times. This is the organization that collects and banks tissue samples from surgery and makes them available to researchers.

You can see where SWF members fit into this valuable program. If you or your child is scheduled for surgery – major (brain surgery) or minor (gum reduction) – you are encouraged to register with the NDRI. You have to call or email them to begin the process. Then you have to give signed informed consent. The NDRI is located in Philadelphia but they work with hospitals all around the country to collect and bank the excised tissue that is a by-product of the surgical procedure.

The SWF website has an article and photo stories about the value of this generous act. Look under Research then Tissue Donation on the Home Page. Many SWF families have taken advantage of this opportunity. It costs you nothing. But the rewards are great for the rest of our community.

NDRI – National Disease
Research Interchange
8 Penn Center 1628 JFK Blvd
Philadelphia, PA 19103
800 222-6374 ext 222
www.ndriresource.org
dremer@ndriresource.org

First Giving Pages

As easy as 1-2-3 and Good for You.

The SWF is fortunate to have individuals dedicated to raising funds and awareness in their First Giving Pages among their communities and circle of contacts. As events are ever changing on the SWF's First Giving Page, our thanks and sincere appreciation is steadfast.

Did you know Emily Argersinger climbed Mt. Washington in July? Emily is 13 years old and feels blessed she doesn't face the challenges many children face with SWS so she is challenging herself to climb and raise \$1 for every foot? She has already raised \$3100. You need to check out her story.

Continued on page 10

DEVELOPMENT DOINGS

Continued from page 9

Or that Sandy Fox has raised over \$1600 in honor of her daughter Alexis? Alexis was a Cover Baby on the last issue of Branching Out. Sandy's coworkers have jumped on board and have even submitted company matching gift forms. Can you believe the fantastic efforts of our Falmouth Road Race Team? Collectively they have raised over \$22,000 this year to date. The race is scheduled for August 12th and we wish the team the best of success on race day.

Since 2008 we have raised over \$125,000 through First Giving pages created by members, just like you. Check it out at www.firstgiving.com/swf today and see the many ways people are helping raise awareness and vital funds to support Sturge-Weber Foundation programs. Thank you to everyone involved. We cannot do it without you!

Advocacy

Kathy Capozzoli, RN attended the AAD Dermatology Research Agency Consensus Conference in Washington DC in June. As an RN with a son who has SWS, and someone who has known the SWF since 1987, her comments and evaluation are extremely valuable.

Dr. Sheila Friedlander, co-director of the SWS Center of Excellence at Rady Children's Hospital in San Diego, was the only pediatric dermatologist invited to participate. Kathy says Dr Friedlander was wonderful in making a case for how research into vascular anomalies would make the AAD a more respected field instead of just being seen as "cosmetic doctors".

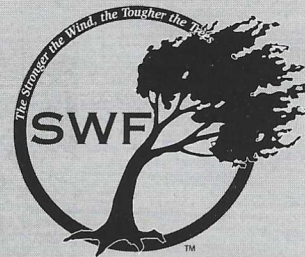
While the meeting did not choose to focus on vascular malformations and research, Kathy feels that representing the concerns of SWF families was a good first step for the SWF to be accepted as a knowledgeable and vocal voice in the dialogue.

Remembering Loved Ones

Judy McGee sends word of the death of her grandson, Timothy Munsey in North Carolina. Timothy was almost 12 years old and had lived with Judy since we was 2 months old.

You can always catch up on the Volunteer Happenings on the SWF website, www.sturge-weber.org

SWF BOSTON EDUCATION FORUM



The Sturge-Weber Foundation

Date: Saturday, September 22, 2012

Time: 10:00 am - 3:00 pm

Buffet Lunch

Location: Boston Children's Hospital, Waltham

Cost: Free, reservation required

Reservation: Contact Anne Howard at
ahoward@sturge-weber.org or
call 800-627-5482

Child care not provided

FEATURED SPEAKERS

You are invited to an educational forum! Specialists, from Boston Children's Hospital who have experience and knowledge of Sturge-Weber syndrome and Port Wine birthmark conditions will speak and answer your questions.

Mustafa Sahin, MD, PhD Neurologist

Marilyn Liang, MD, Pediatric Dermatologist

Douglas Rhee, MD Ophthalmologist

Masanori Takeoka, MD, Neurologist and Epileptologist,

Katrina Boyer, PhD, Neuropsychologist

Kitty Petty, M.Ed., M.A., LMHC, Educational Consultant

*Karen Ball, President & CEO,
Sturge-Weber Foundation*

SAVE THE DATE!

SAVE THE DATE! JULY 25-27, 2013

Join My Family in Colorado for the 2013 Sturge-Weber Foundation Conference

I'm so happy the Sturge-Weber Foundation International Conference is going to be held in my home state of Colorado! In 2012 my daughter Nevaeh and I had the opportunity to travel to Orlando; it was an amazing experience. Please make plans to attend as the conference is not an event to be missed. You will gain the information and support needed to be your (or your child's) best advocate. You will walk away with a support network that sees you, not your condition. Adults and conference veterans will have the chance to mentor teens and share your wisdom with families who have never attended a conference. You'll find that no matter if you have been to one, one or dozens, this year's conference has something for you. We look forward to seeing you at the conference!



*Laura and Nevaeh White, 2011 SWF Conference Orlando
P.S. Nevaeh is Heaven spelled backwards*

Be on the lookout for Hotel and Registration details in the next issue of Branching Out, at www.sturge-weber.org and in E-News. Don't get E-News? Please email swf@sturge-weber.org and join the mailing list today!

The SWF 2013 International Conference will be at the Marriott Renaissance Denver Hotel, 3801 Quebec St., Denver.

And more! Plans are in the works to have our first Miracle Miles Walk 5K walk on Friday evening of the conference followed by a pool party/picnic. First time events are always the hardest and your time and talent in organizing the event will be greatly appreciated. Are you interested in joining the walk committee? Contact Bonnie at bayers@sturge-weber.org or 800-627-5482 x 106.

You and your family will benefit by...

- ★ Learning that you are not alone
- ★ Learning from stimulating discussions, along with medical and research updates
- ★ Sharing personal connections with others who understand
- ★ Meeting others to exchange ideas, support and advice
- ★ Gaining knowledge of helpful resources
- ★ Understanding participation opportunities in research to advance our understanding Sturge-Weber syndrome and Port Wine birthmark conditions

Sturge-Weber Foundation's 25th Anniversary

Our 25th Anniversary Campaign is launching in September.....

.....and the Sturge-Weber Foundation is planning a record-breaking year long campaign to raise **\$1,250,000** for Roots to a Cure!

For our **Roots to a Cure** campaign, we're undertaking a new approach to our outreach. Here's some of what we have in the works to better serve you:

- Expanding the number of regional educational forums for your local area
- Providing better online access for educational sessions and referrals
- Engaging the services of a dedicated scientist to drive research
- Continuing our investigation into the genetics of SWS and birthmarks
- Enhancing our personal response to your inquiries

We'll be employing new technology and techniques to save money, and to learn more about you and what **YOU** want!

So Keep an eye on your mailbox for our 25th Anniversary Campaign, **Roots to a Cure**, let it begin with you.



The stronger the wind, the tougher the trees

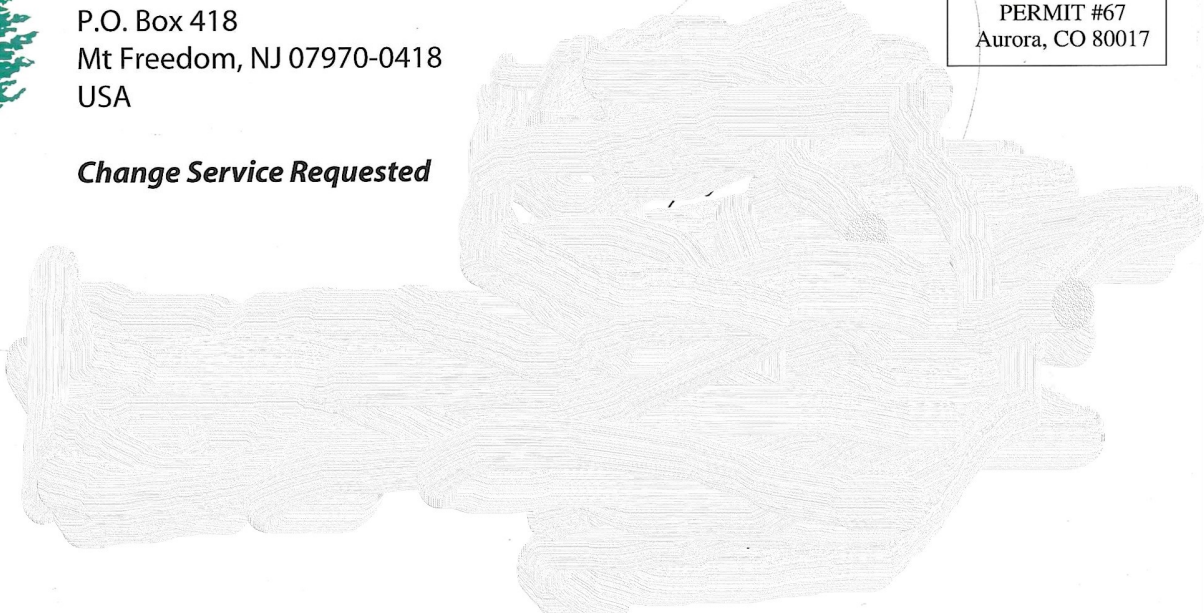


THE STURGE-WEBER FOUNDATION

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USA

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LETTERS AND CARDS FROM SOME OF OUR PARTNERS...

Port-Wine Stains (PWS) on the skin are developmental abnormalities in blood vessel formation (capillary malformations) that are more extensive and darker than the pink capillary birthmarks often seen at the nape of a baby's neck.

Sturge-Weber syndrome (SWS) is a rare congenital condition usually consisting of a facial port wine stain, glaucoma, and seizures, (although not all of these symptoms may be exhibited).

Klippel-Trenaunay syndrome, or KT, occurs as the result of a congenital vascular malformation in an extremity, such as an arm, leg, or foot.

The SWF is a clearinghouse of information for Port Wine Stains, Sturge-Weber syndrome, and Klippel-Trenaunay syndrome.

The SWF Policy Statement:

In implementing the purpose of The Sturge-Weber foundation to improve the quality of life for individuals with SWS and their families, The Foundation will act as clearinghouse of information, provide emotional support, and facilitate research on PWS, SWS and KT.

As a clearinghouse of information, The Foundation will seek information regarding management and treatment techniques and suggestions concerning education and emotional support and will facilitate the dissemination of appropriate information.

If, in facilitating research on PWS, SWS and KT. The Foundation provides financial or other support to a particular research project, The Foundation will base its decision upon need, The Foundation's financial resources, and medical advice.

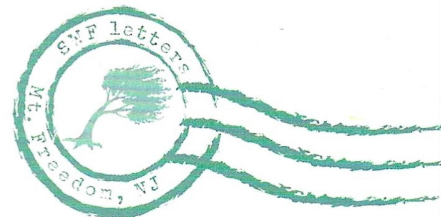
"Thanks for the packet of materials and everything that you do." -Bari, FL

"Thank you all for your endless support" -Aleksandar in Montenegro, Europe

"We never thought we would find people who knew exactly what we are dealing with, but here you are." -Sandy, MN

"My client was so thankful and impressed with what you provided. Thanks for helping me be a good advocate." -Robert, TX

THIS ISSUE IS BROUGHT TO YOU IN PART THROUGH THE GENEROUS CONTRIBUTION OF THE ALLERGAN FOUNDATION.



Save the Date:

- August 12, Falmouth MA Road Race
- September 22, Boston Education Forum
- November 18, Philadelphia Marathon
- July 25-27, 2013 International Conference Denver, CO

