



Branching Out

DIGITAL



FOUNDER AND CEO - KAREN BALL

Here's what has happened this fall and what we are looking forward to!

Welcome to The Sturge-Weber Foundation's first digital mini-newsletter! We are thrilled to share with you the latest developments in our mission to make a positive impact in our SWS, KT, and PWB communities.

Firstly, we would like to express our gratitude to all of our donors and volunteers who have continued to support us during these last 37 years. Your generosity and dedication have allowed us to keep our programs running and research moving forward.

Speaking of research, we are happy to report that the **BVMC project now has 120 patients enrolled!** Have you signed up yet? There is space for about 50 more participants. Now is your chance to make a difference by getting involved with SWS research. Email Julia for more information at jterrell@sturge-weber.org.

It's time to update your contact information. We recently changed to a new management system. Go to www.Sturge-Weber.org, click the "Contact" tab to update your address, phone number, email, or any other information, like birthdays. This will help us keep you in the loop in the new year.

We are also excited to announce that our newly designed **Spanish brochure** is now available. You can download and print any of our resources to help spread awareness for free! If you can't find something just let us know, we will find it for you.

The staff has been busy developing a new virtual chat series entitled, "**Inside SWS: The Warrior's Perspective**" with the first chat scheduled for October 29 (see page 3) and our calendars are filling up fast! Looking forward to 2025, we are planning even more virtual and in-person mini-summits, too.

Finally, we want to remind everyone that our Foundation relies on the kindness and support of our community. If you are able to donate your time or resources, please do not hesitate to reach out to us.

Together, we can make a real difference in the lives of those who need it most. Thank you again for your continued support!

With faith, hope, and love,

Karen Ball



Newly Diagnosed

Newly diagnosed Callie Bellflower was born in July. Mama Warrior, Kristin reports she could use our prayers right now as the family navigates Sturge-Weber medical issues.



Life is a *huaka'i*

Skyler and his siblings, who live in Hawai'i, have tirelessly campaigned to support his Sturge-Weber syndrome (SWS) medical expenses. They kindly shared Skyler's story with us in the hopes of spreading awareness of his rare case while highlighting Skyler's individual experience and *huaka'i* (journey).

Skyler's story is one of hope, bravery, perseverance, enlightenment, and grit!

[READ THE STORY ON OUR WEBSITE...](#)



Reunion of Champions



ICEBAR • ORLANDO

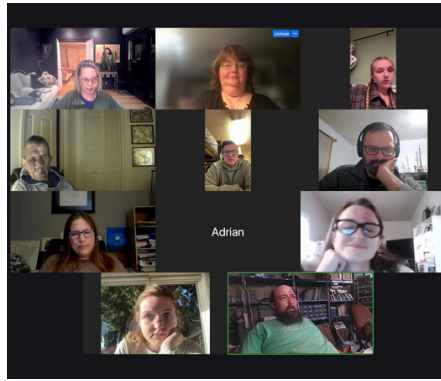
ROC Announced

We chose "Fire and Ice" as our theme to vividly represent the dual nature of the laser treatments and the cooling ice packs during aftercare. The "fire" symbolizes the intense heat generated by the laser, which targets and treats birthmarks. In contrast, "ice" represents the soothing cooling therapy that follows, helping to alleviate discomfort and protect the skin. This theme encapsulates the balance between power and comfort, highlighting our commitment to delivering effective yet gentle care.

Corporate Sponsorships Available. Honoree to be announced soon. Contact Julia Terrell at jterrell@sturge-weber.org for more information.

GIVING TUESDAY

Mark your calendar for Giving Tuesday on **December 3rd.**



Mental Health Matters

Our Mental Health Chats are baaaaack!

Join us for SWS Caregiver and Parent Chat:

- Thursday, November 14
- 7:30 pm - 8:30 pm EST

Join us for a Holiday SWS Adult Patient Chat (21+):

- Wednesday, December 18
- 7:30 pm - 8:30 pm EST
- Wear your most festive holiday sweater!

[Events Page](#)

UCI University of California, Irvine

Mini-Summit at UC Irvine

The Mini-Summit with UC Irvine was a great success. We had over 20 people present from doctors, students and families. We learned so much about latest studies in dermatology, the latest in glaucoma and many questions from neurology too! We had more adults than we ever had too!

Thank you **Dr. Kristen Kelly** and her team from our CCN UC Irvine for always being supportive to The SWF.



Inside SWS: The Warrior's Perspective



"Inside SWS: A Warrior's Perspective" promises to be inspiring virtual event series where you will hear stories and experiences to uplift your soul. You will hear from a diverse range of voices, including community members, researchers, doctors, and parents. Here are The SWF, we believe in sharing stories that fosters a sense of connection and support for all our members. Have a story idea? Contact us and let us know.

Join us for a virtual book signing with Sturge-Weber syndrome warrior and author, Chelsey Peat as she discusses her new book, "In Two Sides to a Face" on Oct. 29 @ 7pm EST.

What to expect:

- Chelsey will read an excerpt from her book.
- Q&A at the end of the event.
- One person will win a signed copy of the book.*

[REGISTER HERE](#)



Call for Laser Treatment Study Participants

Study Leader: Dr. Yakir Levin, MD, PhD, MassGeneral Hospital for Children

Study: Tolerability of 532 nm laser treatment of port-wine birthmarks

Ages: Adults over 18 years old with port-wine birthmarks

Purpose: The purpose of the study is to compare standard single-pulse purpuric laser pulsing with multipulse sub-purpuric pulsing in terms of efficacy and pain. The thinking is that if sub-purpuric multipulsing can achieve similar results with less pain and/or less purpura, there may be advantages in treating children this way.

It is your decision whether or not to join the study. We are asking you to be in this study because you have a port wine stain. We are researching to see whether laser treatment of port wine stains can be improved. If you agree, you will undergo three laser treatment sessions at approximately one-month intervals, as well as a final visit one month after your third laser treatment. You will be in the study for 3 months if you decide to stay for the whole study.

The main risks of being in the study are that you may experience some pain with the laser treatment, and you may experience some redness, swelling, bruising, or (very unlikely) blistering of the skin, infection, or scar.

You will be paid \$250 for taking part in this research study. There is additional compensation for optional biopsies. You may participate in the study even if you do not agree to biopsy.

For more information please email the foundation at jterrell@sturge-weber.org.

Thank you for reading!



THE STURGE-WEBER FOUNDATION

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