

*Dear SWS Families, Friends, and Supporters,*

I hope this finds each and every one of you healthy, hopeful, and enjoying the beauty of the season. The fall always brings a sense of nostalgia for me. It's a time to reflect, as it was when Kaelin was born and the Foundation soon followed. It's also a time to give thanks for the work we've done, the progress we've made, and the strong community that lifts this Foundation and one another, day in and day out.

As the crisp air sets in and we're surrounded by the harvest of our summer efforts, it reminds me just how much we have accomplished together. This season reminds us not only to pause and give thanks but to also recommit ourselves to the mission that connects us all. **Veterans Day** always moves me deeply. It's a time to recognize the sacrifices made for our freedom and justice, values we hold dear as an organization.

**I'm also reminded of another kind of service:** the courage and commitment of our **SWS warriors**, our veterans of a different kind. To the individuals and families affected by **Sturge-Weber syndrome**, who face each day with resilience, grace, and determination, I see you. You've forged a path forward and, in doing so, lit the way for others.

We have truly been blessed by your presence, your gifts, and your service. Your encouragement and involvement, whether through donations, volunteering, advocacy, or sharing your story, *have made an unmistakable impact on thousands of lives*. Every action, every gesture matters. No one person or act of service is greater than another. *Together, we make a difference.*

**Our mission at The Sturge-Weber Foundation has never been more urgent:**

*"To improve the quality of life and care for those with Sturge-Weber syndrome and associated Port-Wine Birthmark conditions through collaborative research, education, advocacy, and support."*

Now, as we look forward to **celebrating our 40th year**, we also take a moment to look back to where we started, how far we've come, and the many extraordinary people who've helped shape this journey. What began as a personal mission born out of necessity has grown into a global movement grounded in compassion, advocacy, and life-changing science. This milestone year is not only a time to honor our history, but also to chart a bold course forward. To plant the seeds that will grow into tomorrow's discoveries, treatments, and hope, we must continue nurturing the mission with the same passion and purpose that got us here.

**Here's how you can help today:**

Please consider making a tax-deductible donation to The Sturge-Weber Foundation. Your contribution directly supports vital research initiatives, patient resources, and important advocacy efforts for those who need it most. [Make your year-end donation now](#) and help ensure a brighter future for everyone impacted by SWS—every dollar collectively makes a difference in the lives of those affected by SWS.

From my heart to yours, I wish you and your loved ones a joyful and meaningful holiday season. May we continue to stand strong together, united by hope, compassion, and purpose.

With faith, hope, and love,

*Karen Ball*

Karen L. Ball  
CEO and Founder





# We're entering 40 years of planting acorns and watching them grow...

**2026**  
Celebrating  
40 years in July!

**2025**  
25 Clinical Care  
Networks and  
Counting!

**2025**  
Launched Blazing  
Warriors: Member  
Trailblazers for SWS  
& Events

**2025**  
BVMC Research  
Registry  
Completed

**2007**  
Guo-Yuan Yang, M.D. Ph.D.:  
University of California, San  
Francisco "Development of  
Cerebrovascular Dysplasia  
Model for SWS Study"

**2006**  
Margarita Zeichner-David, PhD:  
University of Southern California  
"A Molecular Approach to  
Understand the Oral  
Manifestations of SWS"

**Dec 2006**  
"Angiogenesis in the  
Nervous System"  
workshop held in  
Bethesda, MD  
co-sponsored by  
the SWF

**1995**  
The Second Textbook  
for Sturge-Weber  
and "Mama Warriors"  
Book Published

**Planting seeds  
for 2026...**

**Help us  
grow seeds  
of hope by  
giving  
today!**



**2025**  
Monthly Mental Health  
Virtual Meetings for  
Parents/Caregivers  
and Adult Patients

**2024**  
Family Conference in  
Philadelphia with  
guest performance  
from Jordan St. Cyr

**2024**  
UCB Family  
Epilepsy  
Scholarship  
Program

**2000**  
Webster' World:  
Sending Bears to Kids  
in the Hospital

**2008**  
Larry Scott Sherman,  
PhD, Oregon National  
Primate Research  
Center, Oregon Health  
& Science University; "Vascular  
endothelium-derived factors in  
SWS hypermyelination"

**2008**  
Teen Guide to  
SWS published

**Spring 2003**  
SWS Resource  
Guide published

**2003**  
First Reunion of  
Champions  
Awarded

**March 2000**  
Kaelin Ball testifies before the  
US House Subcommittee in  
Washington, DC in support of  
NIH budget increase

**October 1994**  
Relocation to New Jersey

**Winter, 1993-1994**  
Natural History Study begun

**Spring 1993**  
Policy is changed to include  
Klippel-Trenaunay  
syndrome

**Fall 1995**  
First Research grant of  
\$39,000 awarded to  
Dr. Bernard Maria

**2024**  
"Pass the Torch"  
on Million Miles Walk

**2024**  
Scholarships:  
Sciton Cares

**2024**  
"Ask the Experts"  
Virtual Series

**2024**  
Launched  
Legacy Leaders

**2013**  
SWF membership  
hits 5,000

**2011**  
12th International  
Conference in  
Orlando, FL

**2012**  
25th SWF  
Anniversary

**July 2007**  
11th international  
Conference: Anaheim, CA

**May 2001**  
First Day of Awareness  
proclaimed as a  
national event

**Spring 2006**  
SWS Centers of  
Excellence established

**2000**  
Herbie Russ jazz  
CD premieres "The  
Stronger the Wind"

**Spring 1999**  
Medical text: Sturge-  
Weber syndrome, edited  
by Dr. John Bodenstein  
& Dr. Steven Roach  
Published

**1998**  
First "Branching Out"  
Magazine Printed

**1998**  
SWE Website launched

**1987**  
Colorado Foundation for  
SWS Incorporated

**2024**  
Scholarships:  
Kimmi's  
Sunflower Fund

**2021**  
Inaugural  
Catalyst  
Research  
Award

**2024**  
9,000 SWS  
patients on  
record

**2024**  
Seen on the  
"Today Show"  
for Rare Day

**2012**  
Member and friend's  
fundraisers reach all  
time high - \$177,064

**2009**  
ORD/BVMC  
Grant Awarded  
Sturge-Weber  
Syndrome  
Genetics Project

**2014**  
\$88,000 in  
research  
grant awarded to  
Pevsner/Kelly:  
SWS Consensus  
Meeting

**2013**  
Launched Online  
SWS Registry

**2008**  
Wangcun Jia,  
PhD, University of  
California, Irvine:  
"Treatment of PWB  
with Multiple Laser  
Pulses Approach"

**2006**  
PD Dr. Franz Grus, PhD,  
MD; University of Mainz  
Germany "Analysis of  
Antibody Profiles in SWS  
Patients Compared to  
Glaucoma Patients"

**2006**  
Anita N. Haggstrom; University  
of Indiana "Facial PWB and  
Infantile Segmental  
Hemangiomas Associated  
with Neurocutaneous  
Disorders: Implications of  
Facial Patterns"

**June 1999**  
NIH Consensus  
Conference on SWS



**1989**  
First International  
Conference held in  
Denver

**1990**  
Two Moms of SWS boys,  
PA and TX hosted first  
fundraisers

**1990**  
Karen and Kirk Ball  
receive the first  
Betty Ford Award

**Fall 1990**  
First Endowment  
Research Fund  
Raising Campaign

**Jan 1991**  
First CCN at Children's  
Hospital, Denver

**Summer 1991**  
Patient Registry  
launched PAB  
established

**2013  
GNAQ  
Gene  
Found!**



## Why facilitate and fund our research?



“The Sturge-Weber Foundation is not only a family for patients but also a vital force for the research community. It unites purpose, fosters collaboration, and drives discoveries that bring hope to our patients.”

### Sana Nasim

MOSAIC K99 Fellow | Instructor in Surgery  
Boston Children's Hospital  
Harvard Medical School

## WAYS TO GIVE:

### SAVE THE STAMP!

Use the QR Code to the right to donate securely on-line or fill out this form and mail to:

The Sturge-Weber Foundation  
6105 S. Main Street, #200  
Aurora, CO 80016

The Sturge-Weber Foundation is a 501 (c) (3) non-profit organization.



SECURE DONATIONS

## Three ways your gift makes an impact:



### \$50 WEBSTER BEAR FOR CARE

Your donation will send a Webster Bear to two kids while in the hospital recovering from treatments.



### \$100 LASER CARE KITS

Your donation will provide a laser care kit for three children recovering from laser treatments.



### \$250, \$500, \$1000+ LEGACY LEADER

By planting seeds (acorns) for a more fruitful tomorrow, you are contributing to the growth of a robust and resilient community, where challenges only make us stronger, like trees standing tall against powerful winds.



## Your Gift Matters.



STRONGER BECAUSE WE ARE  
**UNITED**  
THE STURGE-WEBER FOUNDATION

- ☐ **YES!** I will make a tax-deductible donation of \$ \_\_\_\_\_
  - ☐ **YES!** I will make an ongoing monthly pledge of \$ \_\_\_\_\_
  - ☐ In **MEMORY** of: \_\_\_\_\_
  - ☐ In **HONOR** of: \_\_\_\_\_
  - ☐ Endowment Donation
  - ☐ Stock Donation or Real Estate Donation\*
  - ☐ I have enclosed a check # \_\_\_\_\_
  - ☐ Credit card\* (circle one) Visa MC Amex Discover
- Name on Card: \_\_\_\_\_
- Credit Card #: \_\_\_\_\_
- CSV: \_\_\_\_\_ Exp. Date: \_\_\_\_\_

*\*See "ways to give" at the left, for online donations, text-to-donate, and mailing address. You may also donate stock or real estate to The Sturge-Weber Foundation. Please contact us for more information.*

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City, State, Zip: \_\_\_\_\_

Email: \_\_\_\_\_

- ☐ **YES!** Sign me up for email newsletters.

Mobile Phone: \_\_\_\_\_

Birthmarks | Glaucoma | Seizures

[www.Sturge-Weber.org](http://www.Sturge-Weber.org)



## THE STURGE-WEBER FOUNDATION

6105 S. Main Street, #200 • Aurora, Colorado 80016



This holiday season,  
give the gift of hope.

*Let's grow the future together!*

The Sturge-Weber Foundation has been planting acorns of hope—small beginnings that, through the dedication of our researchers, doctors, donors, and supporters, have grown into a strong and thriving community for those living with SWS, KP, and PWB. Each seed was nurtured by the faith and generosity of our donors, watered by the perseverance of scientists and clinicians, and weathering the storms by our shared belief that together, we can make a difference.

Inside, we look back on four decades of growth, we are profoundly thankful for every hand and heart that helped our roots take hold and our branches reach farther than we ever imagined.

*For 40 years,*

