



Branching Out **DIGITAL**

ISSUE #03, VOLUME 4

May 2026



Spring into Action with MOA

FOUNDER AND CEO - KAREN BALL

Dear SWF Family,

As we step into this vibrant new season, I can't help but feel energized by all that's unfolding within our community. We are truly off to the races at SWF, and what a beautiful way to begin.

Our recent **Reunion of Champions** was a heartfelt and uplifting evening that reminded me, once again, of the extraordinary strength and love that defines this community. Seeing our loyal dermatologist and ROC honoree **Paul M. Friedman, MD** and Legacy Leader honoree **Brian Biesman, MD, FACS** gathered together filled the room with hope and purpose. Moments like these remind us why we continue to push forward, together. I am deeply grateful to everyone who made it so meaningful.

Now, we turn our eyes toward the **Month of Awareness**, a time when our collective voice spread awareness of SWS, PWB, and KT around the world. I invite you to join us in our **Pass the Torch Challenge**. One meaningful act like sharing your story will start a conversation, and encourage others to learn more. This is enough to ignite something powerful during May.

This is also the moment to strengthen our Foundation for the road ahead. Building a strong "war chest" of support ensures that we can remain on the front lines, advocating fiercely, funding research, and providing critical resources for our SWS Warriors and their families. Your generosity fuels hope. Your support drives action. Together, we can make sure no one fights alone.

There are so many opportunities in the weeks ahead to connect and engage. We'll be gathering in Boston

at Boston Children's Hospital for our in-person Mini-Summit. Just check our Events Page on the website.

We've also prepared new **2026 MOA awareness resources** (available for free) to help you share your story and amplify our mission.

Behind the scenes, our staff and Board of Directors have been hard at work conducting interviews, listening closely, and gathering essential feedback to help guide our next strategic chapter. We are building toward new initiatives in research and engagement, and even a few special surprises. I truly look forward to hearing your thoughts when they make their way to your corner of the world.

We say goodbye to **Crystal Elliers**, who has stepped down from the Board of Directors and welcome in **Shad Elliers** and **Annette Coutu** on board.

As we head toward summer, I can't wait to see you at the **SWF Family Reunion** in San Antonio, Tx! This event, hosted every other year, is a great way to stay connected, meet new families and reconnect with old ones, and continue lifting one another up.

Spring into action with us. Join the Month of Awareness challenge. Let's all commit to show up and give what we can. Invite someone new into our family.

The future we are creating starts today, and it starts with you and me!

With faith, hope, and love,

Karen Ball



Join us all month long, we're coming together as a community to share our stories, spread awareness, and shine a light on Sturge-Weber syndrome with our **3-Day Pass the Torch Challenge**.

How It Works:

May 6 Day 1: Share your story, include a photo or video.

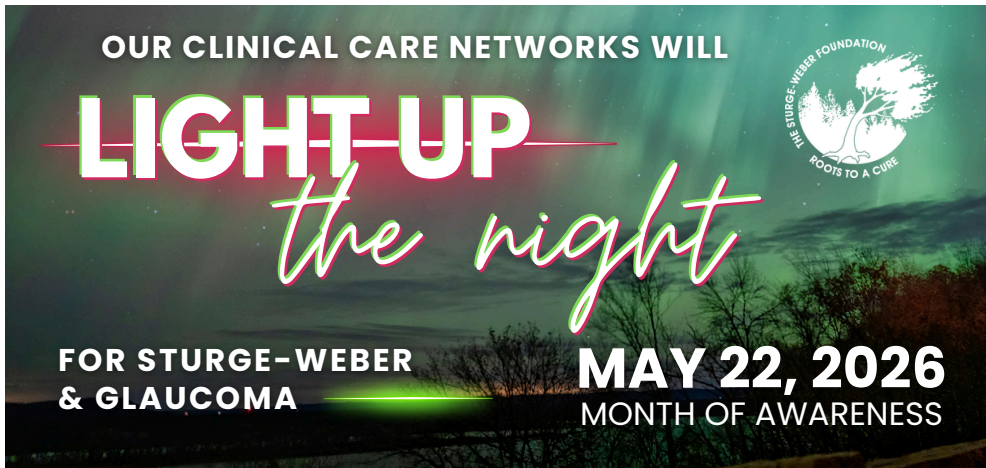
May 7 Day 2: Share what you want the world to know about Sturge-Weber syndrome.

May 8 Day 3: Share something you love about The Sturge-Weber Foundation or how it has made a difference in your life.

- Post each day
- Tag The SWF
- Pass the torch by nominating one person each day to participate ("I am passing the torch to @___")

Together, we can raise awareness for SWS, PWB, and KTS while uplifting one another for a cause!

Use the Hashtags: #PassTheTorchChallenge #SturgeWeber #SWFStrong #SWSMonthofAwareness #ShowYourStripes



May 28 SWF DAY OF GIVING

SUPPORT OUR MISSION TODAY!



THE STURGE-WEBER FOUNDATION

6105 S. Main Street, #200 • Aurora, Colorado 80016
973-895-4445 • contact@Sturge-Weber.org
Sturge-Weber.org



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

Mark YOUR Calendar

Register for all events at Sturge-Weber.org

May 6: Mental Health Chat for Patients 21+

@7:30 PM EST

Our Mental Health virtual chats allow one to meet other adults (21+) with SWS, KTS, and PWB. Register below, and we will send you the Zoom link on the day of the event. Moderated by Luis Sandoval, PhD, SWF Task Force Leader for Mental Health.

May 14: Mental Health Chat for Caregivers and Parents

@7:30 PM EST

These virtual chats are an opportunity to meet other caregivers and parents of SWS, KTS, and PWB children and adults. Moderated by Luis Sandoval, PhD, SWF Task Force Leader for Mental H

May 18: Be the Torch, Be the Light @7:30 PM EST

Join us for a virtual chat, Be the Torch. Be the Light, with Ansley and Donald—a night of hope and inspiring conversations about faith.

May 26: Gaming Lounge @7:30 PM EST

Participants are invited to bring their favorite game, whether it's a video game, mobile game, tabletop game, or online activity, and spend time playing, chatting, and hanging out with peers who truly understand their journey.

Download SWS Month of Awareness Resources:



COLORING SHEETS

ENGLISH, SPANISH, AND FRENCH. Let's spread awareness with these adorable Webster Bear coloring sheets! Perfect for engaging young minds in meaningful conversations of acceptance. Teachers, let's empower our students to share stories of facial differences.

MONTH OF AWARENESS POSTER

Download from the website (or see next page) and post at schools, doctor offices, rec centers, at the office, and more to spread awareness.



Social Media Profile Photo

Social Media Graphics



THE STURGE-WEBER FOUNDATION

Shop for a Cause

THE OFFICIAL SHOP OF THE SWF





MAY IS STURGE-WEBER MONTH OF AWARENESS

STURGE-WEBER SYNDROME FACTS:

- 300 million people worldwide live with a rare disease.
- That's 5% of the world population.
- There are 6,000+ identified rare diseases.
- 72% of rare diseases are genetic.
- Equity means we fight for access to diagnosis, treatment, and care opportunities.



A legacy that began in 1986

STURGE-WEBER SYNDROME
PORT-WINE BIRTHMARKS
KLIPPEL-TRENAUNAY SYNDROME

Birthmarks | Glaucoma | Seizures



SECURE DONATIONS

BE A LIGHT FOR RARE DISEASE...DONATE TODAY!



Where SWS Families Connect, Rest, and Celebrate: The SWF Reunion 2026

Get ready because we are Kickin' it with My Family at the SWF Family Reunion & Conference in San Antonio this June 2026! We invite you to join us for a memorable gathering designed to bring families together through rest, connection, and shared experiences.

Enjoy thoughtfully planned respite time, exciting sightseeing events, meaningful fireside chats, and so much more. And of course, your favorite doctors will be on hand for informative seminars and personalized appointments—making this reunion both enriching and restorative.

Y'all don't want to miss this celebration of SWS family with us in the heart of San Antonio!



What to Expect:

- KidsCamp for your children during the Conference
- Breakout Sessions you may choose to attend
- Clinic appointments with CCN specialists (limited appointments available)
- Respite for Caregivers
- Adult-Only Events
- **NEW:** Community Resource Exchange

Planned activities for the entire family, including:

- Swimming at the hotel pool
- Bus Trip to the San Antonio River Walk
- Time to do your own thing, like visit the Alamo
- Rodeo theme dinner with dancing
- Learn what researchers are up to
- Meet new friends, hang out with old ones
- SWF Swag Bag and Commemorative T-Shirt for Each Attendee
- New Seminars and Workshops
- Ice Cream Social
- Sightseeing in San Antonio
- **And so many more surprises are still in the works!**

Our Speakers and Doctors:

The doctors, clinicians, and researchers who speak at the SWF Int'l Family Conference generously volunteer their time. The Foundation doesn't pay for their presentations; they cover their hotel and travel expenses.

[Read the Tentative Schedule now!](#)

Register Now

REGISTER TO JOIN US TODAY
SAVE \$30 ON EACH REGISTRATION UNTIL APRIL 15TH.

CONNECT, REST, AND CELEBRATE

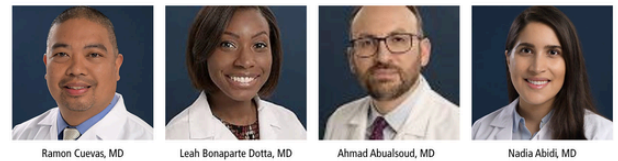
THERE'S A NEW CCN IN TOWN!

Welcome Kaskey Birthmark Center of Excellence at St. Luke's

St. Luke's University Health Network (SLUHN) is proud to announce its formal induction into the Sturge-Weber Foundation (SWF) Clinical Care Network. St. Luke's becomes the 27th institution globally to receive this prestigious designation and stands as the first and only healthcare provider in the Lehigh Valley – and only the second in Pennsylvania – to be recognized for this level of specialized clinical excellence. The addition of St. Luke's to the Clinical Care Network further strengthens the Sturge-Weber Foundation's global mission to improve the quality of life and care for people with Sturge-Weber syndrome and associated port wine capillary malformations through ongoing collaboration with clinical partners and pioneers, education, advocacy, research, and patient/family support.



Meet the Doctors:



Port wine capillary malformations are a specific type of birthmark – now known to be caused by genetic mutations within the skin itself – that are present at birth, can be located anywhere on the body, and that will thicken in texture and darken in color over time. Rarely, a port wine birthmark on the face may be associated with glaucoma – abnormally high pressures in the eye – and seizures, constituting what is known as Sturge-Weber syndrome. Due to its multi-system nature, patients with Sturge-Weber syndrome often require a highly coordinated "medical home" to manage complex cutaneous, ocular, and neurological symptoms. Until recently, these highly specialized services were largely unavailable in the Lehigh Valley.

"As a parent of a child with Sturge-Weber syndrome, having a Clinical Care Network in my hometown is truly incredible," says Julia Terrell, Director of Community Relations for the Sturge-Weber Foundation.

"For years, families in the Lehigh Valley have had to travel long distances for specialized care—trips that are costly, time-consuming, and hard on patients.

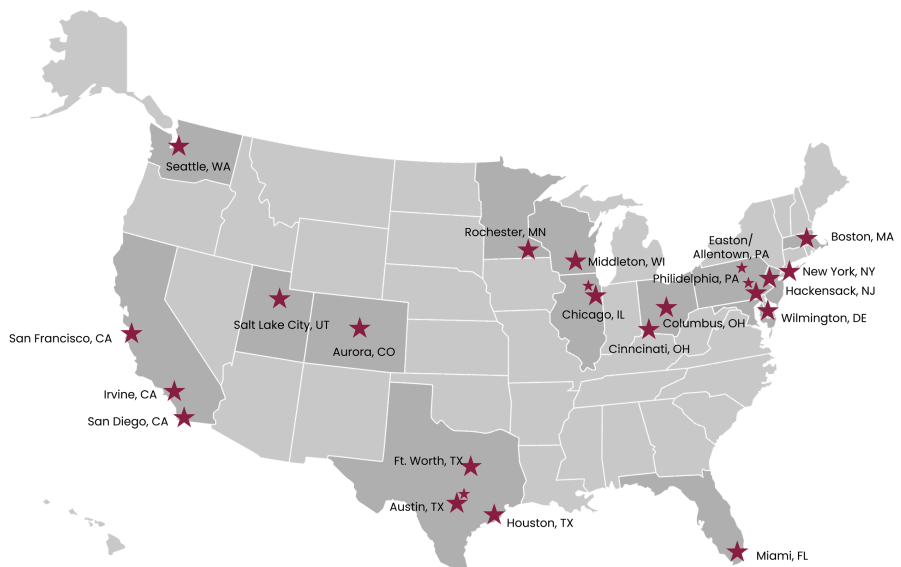
The expertise may have always existed, but families didn't always know where to go or who to trust. Now, having a dedicated team close to home means families have clear direction, trusted care, and no longer feel alone in their journey. That truly warms my heart."

FIND YOUR CCN

The SWF Clinical Care Network is known nationally and internationally.

The Network has over 26+ centers that provide the comprehensive care necessary for treating adults and children who have a port wine (PW) birthmark, Sturge-Weber syndrome (SWS), or Klippel-Trenaunay (KT).

Each center is staffed by a team of specialists who collaborate in the evaluation and management of each patient. This team approach ensures the individual's treatment plan is carefully developed and coordinated.



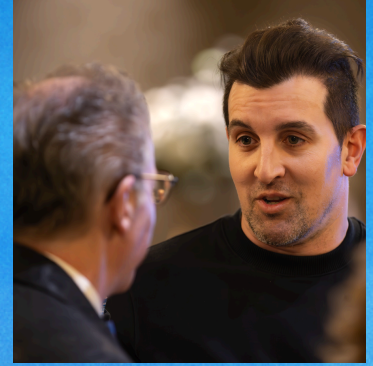
[Find a CCN \(Clinical Care Network\) near you.](#)

GEMS *of* HOPE & STRENGTH

CELEBRATING RARE
BRILLIANCE
& THE POWER OF RESILIENCE

Downtown Aquarium • Denver
March 27, 2026





[VIEW ALL THE PHOTOS ON OUR WEBSITE](#)

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