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Branching Out DIGITAL

Did You Know...

FOUNDER AND CEO - KAREN BALL

Did you know the Sturge-Weber Foundation's research program began with a $2,500 stipend after Karen and Kirk Ball received the **Betty Ford Award** in 1990?

From there, the research fund grew little by little as dedicated individuals raised both vital awareness and critical funding. Their efforts helped SWF identify and support vetted clinical and basic research worthy of the community's hard work.

Over the years, the fund has supported clinicians, early-career investigators, and basic scientists exploring the unanswered questions surrounding Sturge-Weber syndrome and port-wine birthmarks.

We have been fortunate to benefit from exceptional **volunteer leadership from scientists and clinicians** who have helped shape strategic plans and research goals. Their collaboration with committed people within and beyond the SWS community contributed to the discovery of the SWS gene mutation.

Today, our network of committed researchers, and the fundraising events supporting them, continues to grow. This expanded support is accelerating discoveries and advancing projects designed to improve quality of life and care for individuals and families living with SWS.

The SWF leadership is also preparing for new directions in research, patient support, and family resources. Bringing diverse stakeholders together is essential to ensuring research efforts are connected, purposeful, and focused on shared long-term goals.

Dr. Matt Shirley has been instrumental in his role as Chief Scientific Officer, helping drive research forward and identify new frontiers for closing knowledge gaps. We are deeply grateful for his leadership and look forward to continuing our work together as his tenure concludes.

We are equally excited to welcome **Dr. Sana Nasim** as the next Chief Scientific Officer. She brings a unique and diverse background as we enter a new era of research. You will be hearing more from her very soon!

Please continue to support, participate, and donate so we can keep this momentum going. Every person has something valuable to contribute, whether on the front lines or in a behind the scenes supporting role.

Thank you for caring, sharing, and giving of yourselves. Together, we make the load lighter and move faster toward our shared goal.

With faith, hope, and love,

Karen Ball

Karen Ball and Julia Terrell attended the 14th PeDRA Annual Conference on October 15-17, 2026, in Alexandria, VA. This year's theme: *From Intention to Impact: Making Space for Research,* highlights our shared commitment to advancing meaningful research.