## The 2024 Sturge-Weber Foundation International Family Conference: It's a Wrap!

The 2024 Sturge-Weber Foundation International Family Conference was a huge success! Thank you to everyone who dedicated their time to preparing for and participating in this year's conference – we could not have done it without you!

This year's conference was held in Philadelphia, PA, from July 11-13. Fittingly, we kicked off the conference on Thursday just like Rocky Balboa did when he was preparing for his fight: by running the Philadelphia Art Museum steps with Olympic torches like warriors, somewhat of a prelude to this year's summer Olympic games being held in Paris!



Following the run, we continued with registration and clinics with specialists from four of our Clinical Care Networks (CCNs). Dr. Stephen Falchek from Nemours Children's Health took us on a tour of the old city where we they visited and toured some of Philadelphia's historic landmarks, including Ben Franklin's tomb, the Liberty Bell, and Independence Hall. The tour ended at the Arden Theater for some ice cream!

As the first night of the conference wound down, we headed back to the hotel as a group and had a wonderful reception, catching up with old friends and building new relationships. That was all on day 1!

Friday and Saturday were packed with scientific talks, presentations, and networking events. There were more than 30 talks and fireside chats, and there were seven CCNs that were represented. We're very happy with the turnout and support for the SWF community!

Thank you to our hosts Networks Nemours Hospital, Jefferson Health and Wills Eye Hospitals. We also had many sponsors including UCB, Neurelis, Jazz Pharmaceuticals, Sk Life Science, Dircks Foundation, and more. Thank you to everyone involved!

On Friday night, we were lucky to have one of our own members from the SWF community, Jordan St Cyr who is a Christian music artist and caregiver of a child living with Sturge-Weber syndrome, sing for us and take as many photos as we wanted. Jordan put on an amazing show, and he is one of the humblest individuals you can meet – it was a great experience for all!

On Saturday night, the last day of the conference, we all came together and celebrated with one last sports team party where we featured a draft, an auction, a selfie station, dancing and just plain fun!

Overall, the three-day conference was jam-packed with activities, presentations, and networking events. Some fun facts include: the oldest participant was 82, and the youngest was just 3 months! Other events included a professional dinner for the doctors, the Warrior Gala, scavenger hunts, and a children's program.

If you were not able to attend the International Conference this year, we have two more mini-summits scheduled for this fall where you will be able to interact with dermatology and ophthalmology experts and ask any questions.

- The first is a virtual event, <u>UC Irvine Mini-Summit</u>, which will be held on Saturday, Oct. 5 from 6-9pm ET
- The second is an in-person event, <u>Mini-Summit at the Children's Hospital of Michigan</u>, scheduled for Saturday, Nov. 9 from 8am-1:30pm local time in Michigan

For more information about all SWF events, visit: <a href="https://sturge-weber.org/events/">https://sturge-weber.org/events/</a>.

Our next International Conference will be in 2026 – we'll share more details when available!