



Rooms Key:

- Estancia BC
- Estancia A
- Las Brisas/Los Portales
- Art Gallery/Las Ventanas

AGENDA

Thursday, June 25th • 1:00 pm Check-in

*Schedule subject to change

TIME	DESCRIPTION	ROOM
2:00-4:00 pm	Clinic Appointments (Link Through Sign-up Genie to Come): Anna Pinto, MD , Neurology Emory; Luis Sandoval, PhD, Mental Health Beth Israel Deaconess; John McLaren, MD, Pediatric Neurology Boston Children's; Michael Behen, PhD, Detroit Children's Hospital	■
4:00-6:30 pm	Dinner on your own, swimming, the Alamo, etc. Be sure to enjoy the Scavenger Hunt!	
7:00-9:00 pm	Ice Cream Social, Networking, Ice Breaker Games	■
7:00-8:00 pm	Check-in in Children at KidsCamp	■

Friday, June 26th

7:00-8:00 am	Breakfast in Main Room	■
8:00-8:30 am	Check-in Children in KidsCamp	■
8:30-8:50 am	The Future of Care: Technology, Research, and Community at SWF Karen Ball, The SWF CEO & Founder	■
8:50-9:10 am	Improving Patient Care Through Collaboration, Updates and Future Goals: Jeff Loeb, MD, PhD, CCS - University of Illinois Chicago	■
9:10-9:30 am	Translating Research Into Better Care: Basic Science Updates: Sana Nasim, PhD - Boston Children's Hospital	■
9:30-9:50 am	The Gift of Research: Why Tissue Donation Matters: Thuy Phung, MD, PhD - UT Health San Antonio	■
9:50-10:00 am	Break	
10:00-10:40 am	A New Digital Resource for the SWF Community: ASU - Anannya Reddy Gade, Jared Chiew, Pranav Manikanta Inturi, Yuecong	■
10:40-11:10 am	Keynote Speaker: Raj Sandhar, PharmD, MRPharmS - UCB	■
11:10 am-Noon	Fireside Chat - Stories That Connect Us: Voices From the SWF Community: Young and Wright Families	■
12:00-1:00 pm	Lunch	■

PEDIATRIC CAREGIVER TRACK - GROWING UP WITH SWS

1:00-1:30 pm	When Symptoms Change. Understanding Migraines and Stroke-Like Episodes: Kristina Julich, MD, Dells Children's	■
1:30-2:00 pm	Tools for Learning, Behavior, and Daily Life: Michael Behen, PhD - Wayne State	■

PEDIATRIC CAREGIVER TRACK - CONTINUED...

2:00-2:30 pm	Understanding Skin Health in SWS: Marilyn Liang, MD, Boston Children's Hospital - Virtual	■
2:30-2:40 pm	Break	
2:40-3:30 pm	What Families Want to Know About Neurology and Surgery in SWS: John McLaren, MD, Boston Children's Hospital; Shivani Rangwala, MD Neuro Surgery, Boston Children's Hospital; Moderator: Anna Pinto, MD, Emory University	■
3:30-4:00 pm	Preparing for Independence and Adult Healthcare: Aimee Luat, MD, Pediatric Neurology, Detroit Children's	■
4:00 pm	Recap of the day: SWF	■
4:05 pm	Pick up Children at KidsCamp	■

SWS ADULT TRACK - LIVING WELL WITH SWS

1:00-1:30 pm	Whole-Person Health: Integrative Approaches for Living Well with SWS: Jennifer Abraczinskas, MD, Spring and Spruce, Virtual	■
1:30-2:00 pm	Skin Health in Adulthood: What Every Person with SWS Should Know: Taryn Murray, MD, Cleveland Clinic	■
2:00-2:50 pm	Building Resilience: Mental Health for Teens and Adults: Luis Sandoval, PhD Beth Israel Deaconess	■
2:50-3:00 pm	Break	
3:00-3:30 pm	Neuropsychology in Action: Tools for Success at Home, Work, and School: Michael Behen, PhD, Wayne State	■
3:30-4:00 pm	Roundtable Discussion: Adult Neurological Care and Future Planning: Jeff Loeb, MD, PhD, Univ. of Illinois Chicago	■

FRIDAY NIGHT CONTINUED ON NEXT PAGE>>>

FRIDAY NIGHT: RIVER WALK AND BOAT RIDE

4:15-9:00 pm	Wear your Conference T-shirt! Enjoy a River Walk boat ride followed by dinner on your own. The first bus departs promptly at 4:15 PM, and the second leaves at 5:00 PM sharp. Round-trip shuttles will run approximately every 30 minutes, with the final return to the hotel at 9:00 PM. <i>This event is graciously paid for by an anonymous donor.</i> DON'T FORGET YOUR SCAVENGER HUNT SHEETS!
7:30-9:30 pm	Reception Sponsored by UCB (by Invitation only)

SATURDAY, JUNE 27TH

7:00-8:00 am	Breakfast in Main Room	■
8:00-8:30 am	Check-in Children in KidsCamp	■
8:30-9:00 am	Host Families Fireside Chat: Marlow and Walsh Families	■
9:00 am-12:00 pm	NEW THIS YEAR: The SWF Community Resource Exchange: This event is designed to bring together businesses that support the Sturge-Weber Syndrome (SWS) community, fostering connections and offering invaluable resources to families. Plus, special Fireside Chats.	■
9:00-9:30 am	SWF Through the Years: Building a Future Together: E. Steve Roach, MD	■
9:30-10:00 am	The Future of SWS Care, Research, and Support: Jeffrey Loeb, MD, PhD, University of Illinois Chicago	■
10:00-10:30 am	Glaucoma Care in SWS: Current Guidelines and Best Practices: Lauren Blieden, MD, Texas Children's, Glaucoma Specialist	■
10:30-11:00 am	Fireside Chat: Keys to Independence: a Conversation on Adaptive Driving with Chad Strowmatt	■
11:00 am-Noon	Living Beyond Seizures: Finding Your New Normal: Anna Pinto, MD; Jeff Loeb, MD; Dave Shahani, MD; Aimee Luat, MD; and Lauren Blieden, MD	■
12:00-1:00 pm	Lunch Break. Fathers, mothers, grandparents, and SWS adults are welcome to take lunch back to the breakout rooms to continue connecting.	■
1:00-2:00 pm	Building Resilience and Emotional Well-Being: Luis Sandoval, PhD, Beth Israel Deaconess	■
2:00-3:00 pm	Navigating Life Transitions with SWS: Patient Perspectives: Patients Fireside Chat with Sydney, Aden, Bruce and Bryan	■
3:00 pm	Pick up Children at KidsCamp, end of meeting	■
4:00 pm	SWF Board Meeting (Board Members Only)	■
3:00-6:00 pm	Free time	
6:00 - 9:00 pm	Saddle up for our Texas-style BBQ Dinner Party: THE SWF RODEO GALA! Dressing the part in your best cowboy or cowgirl gear, boots, and hats are encouraged, and get ready for a night of fun. Enjoy music, snap photos with your friends, and join in the excitement with our silent auction and raffle. It's a rootin'-tootin' good time you won't want to miss!	■

THANK YOU TO OUR SPONSOR(S):



SWAG BAG MADE POSSIBLE BY ONE BY ONE GRANT:



SHARE YOUR PHOTOS WITH US

And the best part, you can see what everyone is posting at this event!

TAG US ON SOCIAL MEDIA!



Free things to do in San Antonio:

- The Alamo
- San Antonio Missions National Historical Park
- San Fernando Cathedral
- The San Antonio River Walk
- The Japanese Tea Garden
- San Pedro Creek Culture Park
- The Historic Market Square
- The Pearl District
- Brackenridge Park Museum and Gardens