

TENTATIVE AGENDA

*Schedule subject to change



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

| TIME | DESCRIPTION |
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| 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; Dr. John McLaren, Pediatric Neurology Boston Children's; Dr. Michael Behen, Detroit Children's Hospital; Dr. Brian White, Neuro-Ophthalmology, Nemours |
| 4:00 – 6:30 pm | On your own for dinner, sightseeing, swimming, etc. |
| 7:00 – 9:00 pm | Ice Cream Social, Networking, Ice Breaker Games |

Friday, June 26th

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| 7:00 – 8:00 am | Breakfast in Main Room |
| 8:00 – 8:30 am | Check in Children in KidsCamp |
| 9:00 – 9:10 am | Opening: Karen Ball, The SWF CEO and Founder |
| 9:10 – 9:30 am | Research Updates: Matt Shirley, PhD, The SWF CSO |
| 9:30 – 9:50 am | Updates: Jeff Loeb, MD, The SWF CCS |
| 9:50 – 10:30 am | Keynote Speaker (Virtual): A Big Technology Announcement with Arizona State University (ASU) |
| 10:30 – 10:40 am | Break |
| 10:40 – 11:10 am | Sponsor Keynote: UCB |
| 11:10 am – 12:00 pm | Fireside Chat with our Host Family, where they'll share inside scoop on the best things to do in San Antonio. |
| 12:00 – 1:00 pm | Lunch Break provided by The SWF |

PEDIATRIC CAREGIVER TRACK – LECTURES

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| 1:00 – 1:30 pm | Mental Health and What to Expect: Luis Sandoval, PhD, Beth Israel Deaconess |
| 1:30 – 2:00 pm | Dermatology: What you need to know, TBA |
| 2:00 – 2:50 pm | Fireside Chat with All things Neurology: John McLaren, MD Boston Children's (Diagnosis); Aimee Luat, MD, Neurology, Detroit Children's Hospital; and Moderator; Anna Pinto, MD, Emory |
| 2:50 – 3:00 pm | Break |
| 3:00 – 3:30 pm | Neuropsychology and You: Dr. Michael Behen |
| 3:30 – 4:00 pm | Neuroophthalmology and CVI: Dr. Brian White |
| 4:00 pm | Recap of the day: SWF |
| 4:05 pm | Pick up Children at KidsCamp |

SWS ADULT PATIENT TRACK – LECTURES

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| 1:00 – 1:30 pm | Dermatology: TBA |
| 1:30 – 2:50 pm | Mental Health: Luis Sandoval, PhD, Beth Israel Deaconess |
| 2:50 – 3:00 pm | Break |
| 3:00 – 3:30 pm | NeuroOphthalmology and CVI: Dr. Brian White |
| 3:30 – 4:00 pm | Adult Neurology and what to expect Roundtable: Jeff Loeb, MD |

FRIDAY EVENING ACTIVITIES

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| 4:15 pm – 9:00 pm | 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> |
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SATURDAY, JUNE 27TH

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| 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 Family, Wright Family and Covington Family |
| 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. |
| | BREAKOUTS: |
| 9:00 – 10:00 am | Building in Resilience: Luis Sandoval, PhD, Beth Israel Deaconess |
| 9:00 – 10:00 am | All About Surgery: Dr. Shahani, Cooks Children's |
| 10:00 – 11:00 am | Ophthalmology Delphi Paper: Dr. Lauren Blieden |
| 11:00 am – 12:00 pm | Breakout Rooms for fathers, mothers, grandparents, and SWS adults to connect. |
| 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 | Research Meets Lived Experience: Matt Shirley and Sana Nasim |
| 2:00 – 3:00 pm | Transition into School, Work, Living on Own: Ask our Panel of Expert Patients and Parents anything in this lively Fireside Chat. |
| 3:00 – 6:00 pm | Free time |
| 3:00 pm | Pick up Children at KidsCamp, end of meeting |
| 6:00 – 9:00 pm | Saddle up for our Dinner Party: THE SWF RODEO GALA! Dress the part in your best cowboy or cowgirl gear, boots and hats encouraged, and get ready for a night of fun. Enjoy music, snap photos with your friends, try your hand at roping a (not-so-live!) steer, 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):



Inspired by patients.
Driven by science.

SWAG BAG SPONSOR:



SILENT AUCTION | Coming Soon!