



SWF NETWORK CONFERENCE

STURGE WEBER SYNDROME: MOVING
TRANSLATIONAL SCIENCE FORWARD INTO THE
CLINICAL REALM

SEPTEMBER 14-17, 2023
CHARLOTTE, NC

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SWF NETWORK CONFERENCE



Thursday, September 14th

7:00–9:00 pm Check-in and Reception Sponsored by Doug Marchuk

Friday, September 15th

JOINT MEETINGS

TIME	LOCATION	EVENT	PRESENTER
8:00–8:45 am	Queens Court	Breakfast	
8:45–9:00 am	Queens Court	Welcome: Karen Ball State of the Union	Karen Ball, SWF CEO and Founder
8:00–9:30 am	Queens Court	Sturge-Weber syndrome from a first-hand view	O'Reilly Family
9:30–10:30 am	Queens Court	UCB	Brian Moseley, MD
10:30–10:45 pm		Break	
10:45–11:15 am	Queens Court	BVMC Project and Future Uses	Jeff Loeb, MD, PhD
11:15–12:00 am	Queens Court	Example of Longitudinal Maps	Biswajit Maharathi
12:00–1:00 pm	Queens Court	Lunch	
1:00–1:30 pm	Queens Court	SWFIRN Updates	Matt Shirley, PhD
1:30–2:00 pm	Queens Court	The importance of animal models	Nathan Lawson, PhD
2:00–2:45 pm	Queens Court	Family Panel Discussion and Interview	O'Reilly and Connell Families
2:45–3:00 pm		Break	
3:00–4:30 pm	Cotillion B, C, D	Three breakout groups to answer the question - If I can fix one thing what would it be and how would you do it?	Sana Nasim, PhD; Sarah Oikemus, PhD; and Feben Messele, MS2
4:30–5:00 pm	Queens Court	Summary of next steps	Matt Shirley, PhD
7:00 pm	Queens Court	Dinner at Hotel	

Saturday, September 16th

8:00–8:40 am	Queens Court	Breakfast	
8:40–8:45 am	Queens Court	Updates from Friday	Matt Shirley, PhD
8:45am–9:45 am	Queens Court	Summaries from Round tables from day before	Sana Nasim, PhD; Sarah Oikemus, PhD; and Feben Messele, MS2
9:45–10:05 am	Queens Court	Neurology updates	Anna Pinto, MD
10:05–10:25 am	Queens Court	Longitudinal Neuroimaging in Sturge-Weber Syndrome updates	Csaba Juhasz, MD
10:25–10:35 am	Queens Court	Break and Breakouts	
12:00–1:15 pm	Queens Court	Lunch	
3:20–4:00 pm	Queens Court	Migraine Management and Updates	Kristina Juhlich, MD

Sunday, September 17th

8:00–8:40 am	Queens Court	Breakfast and Recap	Matt Shirley, PhD
9:45–10:30 am	Queens Court	Clinical Trials and goal setting and BVMC ending what next?	Matt Shirley, PhD and Jeff Loeb, MD, PhD
10:30–11:45 am	Queens Court	2024 Clinical trials and goal setting	Matt Shirley, PhD and Jeff Loeb, MD, PhD
11:45 am–12:00 pm	Queens Court	Close of Meeting with Box Lunch	Karen Ball, CEO

Saturday, September 16th

CCN MEETINGS

TIME	LOCATION	EVENT	PRESENTER
10:35-11:20 am	Cotillion B, C, D	Breakouts Dermatology, Glaucoma, Neurology, Psychiatry -- Goal 1 and 2	Task Force Leaders
11:20 am-12:05 pm	Cotillion B	Summaries	Task Force Leaders
12:00-1:15 pm	Queens Court	Lunch	
1:15-2:15 pm	Cotillion B, C, D	Breakouts Dermatology, Glaucoma, Neurology, Psychiatry Goal 3 and Transition/Warrior University	Task Force Leaders
2:15-3:00 pm	Cotillion B	Summaries	Task Force Leaders
3:00-3:20 pm		Break	
4:00-5:00 pm	Cotillion B	Mental Health and how relates to SWS.	Luis Sandoval, PhD



Saturday, September 16th

SWFIRN MEETINGS

TIME	LOCATION	EVENT	PRESENTER
10:35-10:55 am	Queens Court	Port-Wine Birthmark blood vessel characteristics measured by Optical Coherence Tomography	Feben Messele, MS2
10:55-11:05 am	Queens Court	Discussions	
11:05-11:25 am	Queens Court	Phosphoproteomic analyses of signaling networks driven by oncogenic Gq/11 in uveal melanoma	Mike Onken, PhD
1125-1135am	Queens Court	Discussion	
11:35-11:55 am	Queens Court	Recruited macrophages in GNAQ p.R183Q driven capillary malformations	Sana Nasim, PhD
11:55-12:05 pm	Queens Court	Discussion	
12:00-1:15 pm	Queens Court	Lunch	
1:15-1:35 pm	Queens Court	Effect of Conditional Expression of GNAQ p.R183Q Mutation during Development in a Mouse Model of Sturge-Weber Syndrome	Francesca Galeffi, MD
1:35-1:45 pm	Queens Court	Discussions	
1:45-2:05 pm	Queens Court	Zebrafish Talk	Sarah Oikemus, PhD
2:05-2:15 pm	Queens Court	Discussions	
2:15-2:45 pm	Queens Court	Endothelial GqPCR activity controls capillary electrical signaling and brain blood flow through PIP2depletion	Osama Harraz, PhD/Virtual
2:45-3:00 pm	Queens Court	Discussions	
4:00-4:30 pm	Queens Court	Perfusable vasculature-on-chip for modeling Sturge-Weber syndrome	Kimihiko Banno, MD, PhD / Virtual



www.Sturge-Weber.org

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