



2025 Family & Professional Summit

Thursday, September 24, 2025

3 PM-5 PM Registration

Overature
3rd Level

Friday, September 26, 2025

8:00 AM KCNQ2 Sensory Room

Overature

10:00 AM SuperSib Camp

8:00 AM Breakfast

8:30 AM *Welcome and Opening Remarks*
Sara James, KCNQ2 Cure Alliance

Symphony
Ballroom

8:50 AM Session 1

8:50 AM *Through Our Eyes: Harper's Story*
Scotty Sims, ED KCNQ2 Cure Alliance

9:00 AM *Therapeutic overview - Small molecules to gene editing*
Brooke Babineau, PhD, KCNQ2 Cure Alliance

9:20 AM *Science is Better Together: Insights from the Research Roundtable*
Al George, MD, Northwestern University

9:40 AM *Session #1 Q&A*
Sara James, KCNQ2 Cure Board Member

10:00 AM Break

10:15 AM Session 2

10:15 AM *Through Our Eyes: Nolan's Story*
Kara Boulter, KCNQ2 Parent

10:20 AM *Finding Guidance: NeuroJourney*
Chrissy Salley, Ph.D., Courageous Parents Network

11:05 AM NeuroJourney Q&A

11:15 AM *Emerald Study - Praxis*
Elisa Evans, Praxis

11:25 AM *Promise and progress of ASOs for DEEs – experience from Dravet syndrome*



Andreas Brunklaus, PhD, University of Glasgow

11:45 AM ***Gene Therapy and KCNQ2***
Acacia Mayfield, MD, PhD, Asymptote

12:05 PM **Session #2 Q&A**

12:25 PM Lunch

1:30 PM **Session 3**

1:30 PM ***Through Our Eyes: Mae's Story***
Colin Sanford, KCNQ2 Parent

1:35 PM ***Mapping the Patient and Family Journey: The KCNQ2 Disease Concept Model***
Michele Potashman, M.S., PhD, Biohaven

1:55 PM ***Inchstones, why do we need more information?***
Natasha Ludwig, PhD, Inchstones

2:15 PM ***Clinical Trial Readiness Initiatives: How pediatric NDD patients are evaluated***
Derek Ansel, MS LCGC, World Wide Clinical Trials

2:35 PM **Session #3 Q&A**
Sara James, KCNQ2 Cure Alliance

2:55 PM Break

3:10 PM ***Coping with the Diagnosis: Anticipatory Grief***
Chrissy Salley, PhD, Courageous Parents Network

4:00 PM **Group Photo**

5:00 PM Dinner



Saturday, September 26, 2025		
8:00 AM	Breakfast	
9:00 AM	SuperSib Camp	Concerto B
9:00 AM	Session 1	
9:00 AM	Our First Chapter: A 10-Year Round-Up Sara James, KCNQ2 Cure Board	
9:10 AM	Through Our Eyes: Ivanna’s Story Neysha Miranda, KCNQ2 Parent	
9:20 AM	KCNQ2: What you need to know Ann Poduri, MD, Boston Children’s	
9:50 AM	Decoding KCNQ2 Together Dennis Lal, PhD, UT Health Houston	
10:10 AM	Session #1 Q&A Sara James, KCNQ2 Cure Board Member	
10:30 AM	Break	
10:45 AM	From Here to Hope	
10:45 AM	Through Our Eyes: Ariella’s Story Rebecca Gutman, KCNQ2 Parent	
10:50 AM	Parent Panel Caroline Loewy, Kara Boulter, Anja Zimmerman, Danuta Gill	
11:20 AM	KCNQ2 Can: Strategic Planning Discussion KCNQ2 Community	
12:00 PM	Lunch	
1:00 PM	Take a Break	
2:00 PM	Walk and Roll Tour of Philly	Front of Hotel
5:00 PM	Dinner	Overture
6:00 PM	Warrior Dance Party	Symphony