

# 20 KCNQ2 CURE 23 SUMMIT

**7th KCNQ2 Summit**  
**September 28–October 1, 2023**  
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**Doubletree by Hilton - Magnificent Mile and  
Northwestern University, Feinberg School of Medicine | Chicago, IL**



**THURSDAY–SUNDAY, SEPTEMBER 28 – OCTOBER 1, 2023**  
**303 E. SUPERIOR ST. CHICAGO, IL 60611**



## WELCOME

# 2023 KCNQ2 CURE SUMMIT

The objective of the KCNQ2 Cure Summit is to combine patient-centered science and real-world strategies for patients and families living with KCNQ2-related disorders.

We planned sessions aimed at professionals, families, and all audiences to achieve this goal. The pages in the program are colored based on the intended audience. Attendance for each session will be based on the capacity for each room.

### Parent Track

### Professional Track

### Combined Session

THURSDAY 9/28

Everyone welcome

#### Conference Opening – family activity

10:40 - 2:00 PM

#### **Fun Time | Doubletree by Hilton - Magnificent Mile**

Meet in Hotel lobby and walk together to Navy Pier

3:00 - 5:00 PM

#### **Check-in | Doubletree by Hilton - Magnificent Mile**

Lasalle Ballroom 300 E. Ohio St. Chicago, IL 60611

5:40 PM

#### **Group walk to dinner**

Doubletree by Hilton - Magnificent Mile Lobby

6:00 - 9:00 PM

#### **Dinner | Preregistration required**

Timothy O'Toole's 622 N Fairbanks Ct, Chicago, IL 60611

FRIDAY 9/29

## Parent Track

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Parent track conference opening & Session 0 will take place at the hotel:  
Doubletree by Hilton – Magnificent Mile | 300 E. Ohio St. Chicago, IL 60611

Parent Track – Conference Opening & Plenary Session | 7:30 AM – 8:30am

7:30 – 8:30 AM

### Breakfast and late check-in

Doubletree by Hilton – Lasalle Ballroom

8:30 – 5:00 PM

### Moving KCNQ2 Forward by Participating in Research

Doubletree by Hilton – State Room

8:30 – 9:00 AM



### Sara James

Vice President, KCNQ2 Cure Alliance

**Welcome Remarks and  
Research Challenge – Make a Difference**

9:00 – 9:40 AM



### Sarah Weckhuysen

University of Antwerp

**KCNQ2 Unraveled: A Journey into the Essentials**

9:40 – 10:00 AM



### John Millichap

Northwestern University

**Tele-Rare: Bridging Hope in Rare Epilepsies Through  
Telemedicine!**

Break | 10:00 – 10:30 AM

10:30 – 11:15 AM



### KCNQ2 Parent Panel

Moderated by Sara James

**KCNQ2 Journeys: Uniting Parents for Life's Unexpected  
Ride!**

11:15 – 12:00 PM



### Sarah Weckhuysen, Ingrid Scheffer, and John Millichap – Clinical Panel

Moderated by Sara James

**KCNQ2 Unlocked: Minds, Molecules, and Mysteries**

Lunch | Lasalle Ballroom at the DoubleTree 12:00 – 1:00 PM

Check-in continued | 3:30 – 4:00 PM

*Conference check-in will continue at Northwestern for the professionals and anyone else who missed check-in at the DoubleTree. Refreshments will be served.*

***Meet in DoubleTree lobby at 3:15 PM for group walk to Lurie***

3:30 – 4:00 PM

**Check-in continued | Lurie Medical Research Center**  
Ryan Family Atrium 303 E. Superior St. Chicago, IL 60611

All tracks – Session I. New age therapeutics

4:00 – 6:35 PM | Baldwin Auditorium

Chair: Sarah Wechkuysen, University of Antwerp

*This session will be a combined session intended for families and scientists to come together. We invite all attendees to join us in Hughes Auditorium in the Lurie Medical Research Center.*

4:00 – 4:15 PM

**Welcome remarks from Alfred George Jr.**

4:15 – 4:40 PM

**Rohan Seth**

Lydia Accelerator

**One parent's mission to find a cure**

4:40 – 5:05 PM

**Tim Yu**

Boston Children's Hospital

**Development of antisense oligonucleotides for KCNQ"**

5:05 – 5:30 PM

**Evangelos Kiskinis**

Northwestern University

**Delivery of ASO to iPSC-neurons using spherical nucleic acids**

Break | 5:30 – 5:45 PM

FRIDAY 9/29

Combined Session: Both tracks

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5:30 - 6:10 PM



**Robin Sherrington**

Xenon Pharmaceuticals

**The Therapeutic Potential of XEN1101: A Novel Potassium Channel Opener**

6:10 - 6:35 PM



**Steven Dworesky**

Biohaven Pharmaceuticals

**BVH-7000 for KCNQ2-DEE**

Dinner | Northwestern - Ryan Family Atrium 6:35 PM

Everyone welcome:

Mingle and unwind at the HotHouse at the DoubleTree Magnificent Mile

*Let's mingle and unwind back at "home" after an informative, fun day by hanging out at the DoubleTree Magnificent Mile's bar and restaurant called the HotHouse. Located on the main lobby level, there are plenty of tables and seating for us to hang out, grab a snack, or get a drink. It closes at 12 am. If we get lucky with warm weather, we can hang at the rooftop pool deck, with plenty of tables, seating, and games. It is open seasonally, and they are unsure when they will close for the season this year. Both the indoor and outdoor areas are accessible and near restrooms.*

Continental breakfast | Ryan Family Atrium 7:15 – 8:00 AM

**Session II. Pathophysiological Mechanisms  
8:00 – 10:45 AM | Chair: Edward Cooper, Baylor College of Medicine**

**8:00 – 8:25 AM**



**Steven Petrou**

Praxis Precision Medicines

**New mouse model of KCNQ2-DEE**

**8:25 – 8:50 AM**



**Hee Jung Chung**

University of Illinois Urbana-Champaign

**Behavioral effects of heterozygous Kcnq2 mutation in mice**

**8:50 – 9:15 AM**



**Anastasios Tzingounis**

University of Connecticut

**Mouse model of KCNQ2 gain-of-function**

**BREAK | 9:15 – 9:30 AM**

**9:30 – 9:55 AM**



**Tristan Sands**

Columbia University

**Mouse model of KCNQ3 gain-of-function**

**9:55 – 10:20 AM**



**Dina Simkin**

Northwestern University

**Maladaptive compensation in human neuronal models of KCNQ2-DEE**

**10:20 – 10:45 AM**



**Mark Estacion**

Yale University

**Regulation of pain by KCNQ2/3 channels**



**SATURDAY, 9/30**

**Professional Track**

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Break | 10:45 – 11:00 AM

Scientific Track – Session III. Pharmacology of KCNQ2/3 channels  
11:00 – 12:55 AM | Chair: Anastasios Tzingounis, University of Connecticut

**11:00 – 11:25 AM**



**Harley Kurata**

University of Alberta

**Biophysical mechanism of action of retigabine**

**11:25 – 11:50 AM**



**Sarah Weckhusen**

University of Antwerp

**Using iPSC-neurons for testing novel Kv7 activators**

Break | 11:50 – 12:05 PM

**12:05 – 12:30 AM**



**Bruce Bean**

Harvard University

**Activation of neuronal Kv7 channels by cannabidiol**

**12:30 – 12:55 PM**



**Geoffrey Abbott**

University of California, Irvine

**Modulation of neuronal Kv7 channels by natural products**

Lunch & Poster Session | Ryan family Atrium 12:55 – 3:15 PM

***Meet in DoubleTree lobby at 7:10 AM for group walk to Lurie***

Continental breakfast | Ryan Family Atrium 7:15 – 8:00 AM

Session II. Caregiver Connection: Navigating the Journey Together  
8:00 – 11:00 AM

8:00 – 8:05 AM



**Sara James**

Vice President KCNQ2 Cure  
**Welcome**

8:05 – 8:35 AM



**Jelena Ivanisevic, MS, CGC**

Lurie Children's

**Decoding KCNQ2: Unraveling the Genetic Tapestry**

8:35 – 9:15 AM



**Erica Filipovits, MS and Lindsey Moss, PT**

NAPA Center of Chicago

**Intensive Therapy Programs Tailored to Your  
Child's Unique Needs**

Break | 9:15 – 9:30 AM

9:30 – 10:15 AM



**Jeremy S. Joseph, CFP, ChSNC**

Savant Wealth Management

**Managing Finances for Those with Special Needs**

10:15 – 10:45 AM



**Erin Hickey, MD**

University of Illinois, College of Medicine

**Parents Guide to the Transition to Adulthood**

Break | 10:45 – 11:00 AM



## Session II. Caregiver Connection: Navigating the Journey Together

11:00 – 12:55 PM

11:00 – 11:30 AM

**Abby Turnwald MS CGC**

Cincinnati Children's Hospital

**The Rare Sibling Experience: Supporting Siblings of Individuals with KCNQ2**

To allow families to get the most out of Dr. Goldberg's presentation, we ask families NOT to have children present during her talk. While we understand this might not be optimal, we are offering a concurrent **SibShop** for siblings ages 6 – 10 years old to help out.

SibShop will be run by Abby Turnwald and held in the State Room.

11:30 – 12:15 PM

**Corrie A. Goldberg, PhD**

Shore Therapy Center for Wellness

**Caring for the Caregiver: How to Recognize and Address Parent and Caregiver Burnout**

11:30 – 12:15 PM

**Abby Turnwald MS CGC**

Cincinnati Children's Hospital

**SibShop**

12:15 – 12:55 PM

**Free Time**

Return to the hotel if needed

Lunch &amp; Poster Session | Ryan family Atrium 12:55 – 3:15 PM

**SATURDAY, 9/30**

**Combined Session: Both tracks**

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Session IV: KCNQ2 beyond the brain

3:15 – 5:10 PM | Chair: Sara James, KCNQ2 Cure Alliance

**3:15 – 3:30 PM**



**Danuta Gill, PhD**

Unique U Psychology, Melbourne, Australia

**A Parents Perspective**

**3:30 – 3:55 PM**



**Ingrid Scheffer**

University of Melbourne

**Overview of co-morbidities in KCNQ2-DEE**

**3:55 – 4:20 PM**



**Veronica Beck**

University of Michigan

**Gastrointestinal symptoms in KCNQ2-DEE**

**4:20 – 4:45 PM**



**Madusha Peiris**

University of London

**Neuronal Kv7 channels in visceral sensory function**

**4:45 – 5:10 PM**



**Thanos Tzounopoulos**

University of Pittsburgh

**The role of Kv7 channels in tinnitus and hearing loss**

**5:10 – 5:15 PM**

**Closing remarks from Alfred George Jr.**

Dinner | Lasalle Ballroom, DoubleTree Hotel 5:30 – 6:30PM

6:30 – 7:30 PM Join us in the hotel bar while they set up the Ballroom up for our event

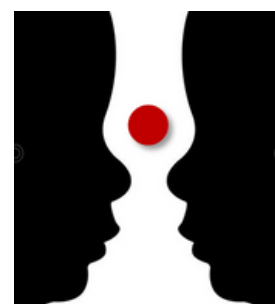
**7:30 PM** We are excited to have you join us for our Improv event. **The Second City** is a world-renowned improv and sketch comedy theater and training center operating in Chicago for over 60 years! Their Alumni include folks like Gilda Radner, Amy Poehler, Tina Fey, Bill Murray, Keegan-Michael Key... and many other Saturday Night Live alumni!

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