20 KCNQ2 CURE 23 SUMMIT

7th KCNQ2 Summit
September 28–October 1, 2023

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
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**

<table>
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<tr>
<th>Time</th>
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| 10:40 - 2:00 PM | Fun Time | Doubletree by Hilton - Magnificent Mile  
Meet in Hotel lobby and walk together to Navy Pier | Doubletree by Hilton - Magnificent Mile  
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| 3:00 - 5:00 PM | Check-in | Doubletree by Hilton - Magnificent Mile  
Lasalle Ballroom 300 E. Ohio St. Chicago, IL 60611 | 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 | 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 | Preregistration required  
Timothy O’Toole’s 622 N Fairbanks Ct, Chicago, IL 60611 |
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
FRIDAY 9/29

Combined Session: All Tracks

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 KCNQ2

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
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.
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

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
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
**Parent Track**

**Saturdays, 9/30**

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

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

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**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

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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

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Break | 10:45 - 11:00 AM
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.
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.**

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**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

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**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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