



# FAMILIE<sup>SCN2A</sup><sup>®</sup>

## FOUNDATION

### 2025 SUMMER CONFERENCE

## Thursday, July 31st

7:00 AM - 8:00 AM	<b>Professionals Registration OPEN &amp; Poster Set Up</b>
	Cottonwood Foyer
8:00 AM - 9:00 AM	<b>Breakfast</b>
	Adams A
9:00 AM - 12:00 AM	<b>Professionals Roundtable</b>
	Adams A
12:00 PM - 2:00 PM	<b>Professionals Lunch</b>
	Adams Prefunction A
2:00 PM - 5:00 PM	<b>Professionals Roundtable</b>
	Adams A
2:00 PM - 5:00 PM	<b>General Registration OPEN</b>
	Cottonwood Foyer
5:00 PM -6:00 PM	<b>Post-Roundtable Cocktail Reception</b>
	Adams Terrace <i>Roundtable Participants Only</i>
6:00 PM - Onward	<b>Evening at Leisure   Dinner on Your Own</b>
	Explore the resort, enjoy on-site restaurants, network, or relax at your own pace.



= COMMUNITY session



= CARE session



= RESEARCH session



= livestreamed session

AGENDA SUBJECT TO CHANGE

The mission of the FamilieSCN2A Foundation is to improve the lives of those affected by SCN2A-related disorders through accelerating research, building a supportive community, and advocating for effective treatments and cures worldwide.

## COMMUNITY

Building Community &  
Celebrating Connections



## CARE

Improving Clinical  
Care & Empowering  
Families



## RESEARCH

From Discovery to  
Impact



# Friday, August 1st

8:00 AM - 9:00 AM	<b>Breakfast</b>	
	Adams A	
8:00 AM - 8:00 PM	<b>SCN2A Sensory Room</b>	
	Cottonwood 10 & 11	
9:00 AM - 4:00 PM	<b>SuperSibs Camp</b>	
	Cottonwood 1 & 2	Please collect your camper at 12:30PM for lunch
9:00 AM - 9:30 AM	<b>Welcome &amp; Opening Remarks</b>	
	Adams A	Leah Myers, Jenny Burke & Shawn Egan
<b>Session #1: Moving Mountains Together</b>		
9:30 AM - 9:40 AM	<b>Why We are All Here - <i>Parker's Story</i></b>	
	Adams A	Jess & Lyle Williams
9:40 AM - 10:00 AM	<b>From Hope to Healing: The Promise of Gene Therapy &amp; Editing</b>	
	Adams A	Yang Yang, PhD
10:00 AM - 10:20 AM	<b>How Families Drive Change, a New SCN2A Severity Scale</b>	
	Adams A	Megan Abbott, MD
10:20 AM - 10:40 AM	<b>Session #1 Q &amp; A</b>	
	Adams A	Jess & Lyle Williams, Megan Abbott & Yang Yang
10:40 AM - 11:00 AM	<b>Break</b>	
<b>Session #2: The Dragonfly Effect - How One Tiny Gene Can Disrupt the Whole System</b>		
11:00 PM - 11:10 AM	<b>Why we are all here - <i>Volodymyr's Story</i></b>	
	Adams A	Natalia Bilokopytova
11:10 AM - 11:30 PM	<b>Improving Clinical Outcomes - Variant Informed Care</b>	
	Adams A	Dennis Lal, PhD, UTHealth Houston
11:30 AM - 11:50 AM	<b>Deep Variant Assessment &amp; Its Role in Personalized Genetic Counseling</b>	
	Adams A	Émile Moura, MS, CGC, UTHealth Houston
11:50 AM - 12:10 PM	<b>Management of Psychotropics for Individuals with SCN2A/SCN8A</b>	
	Adams A	Liz Margolis, MD, Children's Colorado
12:10 PM - 12:25 PM	<b>Session #2 Q &amp; A</b>	
	Adams A	Natalia Bilokopytova, Dennis Lal, Émile Moura, Liz Margolis
12:30 PM - 1:30 PM	<b>Book Signing with Al George - <i>Cambridge Elements</i></b>	
	Foyer	
12:30 PM - 1:30 PM	<b>Lunch</b>	
	Adams Prefunction A & Adams Terrace	
<b>Session #3: Scaling New Heights in Musculoskeletal Health</b>		
1:30 PM - 1:40 PM	<b>Why We Are All Here: <i>Josiah's Story</i></b>	
	Adams A	Rachel Dickel
1:40 PM - 1:55 PM	<b>Movement Disorders as Clinical Trial Outcome Measures in Sodium Channelopathies</b>	
	Adams A	Sunanjay Bajaj, MD, UTHealth Houston
1:55 PM - 2:10 PM	<b>The Framework Within: Caring for Bone Health in SCN2A/SCN8A</b>	
	Adams A	Shelley Brandstetter, ARNP, Children's Colorado
2:10 PM - 2:25 PM	<b>Rehab Medicine - No Stone Unturned</b>	
	Adams A	Jordan Wyrwa, MD, Children's Colorado
2:25 PM - 2:40 PM	<b>Session #3 Q &amp; A</b>	
	Adams A	Rachel Dickel, Sunanjay Bajaj, Shelly Brandsetetter, Jordan Wyrwa
2:40 PM - 3:00 PM	<b>Break</b>	

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AGENDA SUBJECT TO CHANGE

## Session #4: Industry Fireside Chat

3:00 PM - 4:00 PM

Industry Fireside Chat: Value of Patient Advocacy in Drug Development

Adams A

Moderated by Shawn Egan, PhD |  
CSO, FamilieSCN2A Foundation

4:00 PM - 4:30 PM

Group Photo - All Attendees Welcome

Front Range Lawn

4:30 PM - 6:00 PM

Break

6:00 PM - 8:30 PM

Remembrance Dinner & Awards Program

Adams A

All Are Welcome

8:00 PM - 10:00 PM

Dads Night Out!

Mountain Pass Sports Bar

8:00 PM - 10:00 PM

Grandparents Soirée

Location TBA

## Saturday, August 2nd

8:00 AM - 9:00 AM

Breakfast

Adams A

8:00 AM - 8:00 PM

SCN2A Sensory Room

Cottonwood 10 & 11

9:00 AM - 4:00 PM

SuperSibs Camp

Cottonwood 1 & 2

Please collect your camper at 12PM for lunch

### Session #1, Track 1: Seeing Through Their Eyes

#### CVI Tools, Techniques & Takeaways

9:00 AM - 10:20 AM | Cottonwood 8/9

Curious about Cerebral/Cortical Visual Impairment (CVI) and how it impacts your child's learning and interaction with the world? This hands-on, interactive session will introduce you to the basics of CVI and explore practical strategies to support your child's visual access. Through guided activities and real-life examples, you'll gain insight and build confidence—ready to support your child in new ways.

Rebecca Hommer, EdD

Elise Darrow, TVI

### Session #1, Track 2: The Next Chapter

#### Planning for Care, Legal, & Financial Considerations in Adulthood

9:00AM - 10:20 AM | Adams A

As children with special needs or complex medical conditions grow, early planning for adulthood becomes essential - and it's never too early to start. This session offers expert insights and real-life experiences to help families prepare. Discussions will focus on puberty's unique challenges from an endocrinologists POV, and the importance of coordinated, multidisciplinary care. Parents who've navigated this path will also share practical advice, including legal and financial planning tips. Whether you're just starting or already facing these decisions, you'll gain valuable tools for the road ahead.

Philip Zeitler, MD, *Children's Colorado*

Kourtney Santucci, MD, *Children's Colorado*

Jenny Burke, Renee Holmes & Anita Morris

10:20 AM - 10:40 AM

Break

### Session #2, Track 1: The Empowered Mom

#### Leading with Strength

10:40AM - 12:00 PM | Adams A

Caring for a loved one with SRD comes with unique emotional and mental challenges. This interactive workshop, designed specifically for moms and caregivers, offers a space to connect, reflect, and grow. Together, we'll explore the empowerment dynamic (TED), a transformational framework that helps us recognize and shift reactive patterns so we can lead through strength and curiosity - especially when circumstances are hard. TED unlocks our ability to be creators, challengers, and coaches, focusing on possibilities and encouraging self-discovery.

Tina Schust Robinson, MBA, *WorkJoy*



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## Session #2, Track 2: Empowered Dads

### From Reactivity to Creativity

10:40AM - 12:00 PM | Cottonwood 8/9

Caring for a child with SCN2A comes with intense challenges that can leave dads feeling isolated or overwhelmed. This session offers a space to move beyond survival mode and into a more connected, intentional way of showing up. Through honest conversation and peer support, we'll explore how to reclaim agency and rewrite your story—with strength, clarity, and purpose.

**Kent Frazier, *ParadoxEdge***

12:00 PM - 12:30 AM

**Book Signing with Kent Frazier**

Foyer

12:00 PM - 1:00 AM

**Lunch**

## Session #3, Track 1 : Beyond the Spectrum

### Understanding & Managing Autisms Many Faces

1:00 PM - 2:20 PM | Adams A

Autism is not one-size-fits-all. This session explores the diverse ways autism presents and how families, caregivers, and professionals can better support individuals by tuning into behavior patterns, tracking changes over time, and incorporating insights from BCBAs and other supports. From managing challenging moments to embracing everyday adventures, we'll look at practical, person-centered approaches for thriving across settings.

**Cora Taylor, PhD, *Simons Searchlight***

**Anna Rolston, MBA, MIT, BCBA, *Olive Behavior Care***

**Natasha Ludwig, PhD, *Kennedy Krieger Institute***

## Session #3, Track 2: Uncharted Territory

### Navigating Epilepsy's Many Roads

1:00 PM - 2:20 PM | Cottonwood 8/9

Epilepsy can take many forms and follow unpredictable paths. This session explores a range of approaches to managing seizures in SCN2A-related disorders—from medical diets like keto, to seizure detection devices, to the complexities of status epilepticus and seizure storms. With insights from neurocritical care and lived experience, attendees will gain a deeper understanding of the tools and strategies that can help families and clinicians respond to epilepsy's most challenging turns.

**Chelsey Stillman, PA-C, *Children's Colorado***

**Craig Press, MD, *Children's Hospital of Philadelphia***

**Katie Gaughan, *Danny Did Foundation***

2:20 PM - 6:00 PM

**Break**

6:00 PM - 9:00 PM

**Warrior Dance Party**

Adams A

All Are Welcome

8:30 PM - 10:00 PM

**Moms Night Out!**

Arapahoe Poolside Bar



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= CARE session



= RESEARCH session



= livestreamed session