

# CONFERENCE GUIDE

2026



# FAMILIESCN2A<sup>®</sup>

FOUNDATION

2026 SUMMER CONFERENCE

ORLANDO ♦ July 29-31 ♦ SCN2A.ORG

*a Wish in Motion*

Leah Myers, *Executive Director*

Amanda Gale, *Director of Programs & Operations*

Angie Weaver, *Director of Philanthropy & Development*

Melody Kisor, *Director of Advocacy & Education*

Jeff Cotrell, PhD, *Interim Chief Scientific Officer*



COMMUNITY



CARE



RESEARCH

*Families is in our name for a reason!*

# RESEARCH ROUNDTABLE

Wednesday, July 29, 2026

7:30 AM - 8:00 AM	<b>Professionals Registration OPEN</b> Grand Cypress Prefunction
8:00 AM - 9:00 AM	<b>Professionals Breakfast</b> Grand Cypress Ballroom
9:00 AM - 9:15 AM	<b>Opening Remarks &amp; Roundtable Goals</b> Grand Cypress Ballroom
9:15 AM - 9:45 AM	<b>Topic 1: State of the Field: Non Seizure Outcomes Overview (Panel)</b> Grand Cypress Ballroom
10:00 AM - 10:30 AM	<b>Topic 2: Patient Subgroups &amp; Phenotyping</b> Grand Cypress Ballroom
10:45 AM - 11:15 AM	<b>Topic 3: Preclinical Models &amp; Gaps</b> Grand Cypress Ballroom
11:30 AM - 12:00 PM	<b>Topic 4: Clinical Trial Readiness &amp; Outcome Measures (Panel)</b> Grand Cypress Ballroom
12:15 PM - 1:00 PM	<b>Professionals Lunch</b> Portico West
1:00 PM - 4:00 PM	<b>Workshop: Advancing Research to Improve Non-Seizure Outcomes</b> Grand Cypress Ballroom
2:00 PM - 5:00 PM	<b>General Registration OPEN</b> Grand Cypress Prefunction
4:45 PM - 5:15 PM	<b>Roundtable Wrap up   Next Steps   Closing</b> Grand Cypress Ballroom
5:30 PM - 7:00 PM	<b>Post-Roundtable Cocktail Reception</b> Portico East <i>Roundtable Participants Only</i>
7:00 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.

Download the App for  
 detailed agenda  
 and speakers



AGENDA SUBJECT TO CHANGE

# Thursday, July 30th

8:00 AM - 9:00 AM	<b>Breakfast</b>	
	Portico	
8:00 AM - 8:00 PM	<b>SCN2A Sensory Room</b>	
	Grand Cypress A	
9:00 AM - 3:30 PM	<b>SuperSibs Camp</b>	
	Regency 1	Please collect your camper at 12:30PM for lunch
<b>Session #1: A Wish in Motion - 9:00 AM</b>		
9:00 AM - 9:20 AM	<b>Welcome &amp; Opening Remarks</b>	◆
	Grand Cypress DEF Leah Myers	
9:20 AM - 9:30 AM	<b>Why We are All Here - Family Story</b>	◆
	Grand Cypress DEF Amanda Gale	
9:30 AM - 9:50 AM	<b>Turning Momentum into Medicine</b>	◆
	Grand Cypress DEF Kevin Bender, PhD, USCF	
9:50 AM - 10:10 AM	<b>Different SCN2A Variants, Different Gene Therapies: How Close are We?</b>	◆
	Grand Cypress DEF Yang Yang, PhD, Purdue University	
10:10 AM - 10:40 PM	<b>Session #1 Q &amp; A</b>	◆
	Grand Cypress DEF Kevin Bender, Yang Yang	
10:40 AM - 11:00 AM	<b>Break</b>	
<b>Session #2: Navigating a Complex Path - 11:00AM</b>		
11:00 AM - 11:10 AM	<b>Why we are all here - Family Story</b>	◆
	Grand Cypress DEF Sarah Haas	
11:10 AM - 11:25 PM	<b>Time is Brain: Infantile Spasms in SCN2A</b>	◆
	Grand Cypress DEF Kimberly Wilttrout, MD, Boston Children's	
11:25 AM - 11:40 AM	<b>Beyond the Variant: When function changes everything</b>	◆
	Grand Cypress DEF Dennis Lal, PhD, UT Arlington   Cook Children's	
11:40 AM - 11:55 PM	<b>The Right Drug for the Right Function: Variant Informed ASM Use</b>	◆
	Grand Cypress DEF Laura McGarry, MD, PhD, CHOP	
11:55 PM - 12:10 PM	<b>Defining Severity in a Variable Disorder</b>	◆
	Grand Cypress DEF Megan Abbott, MD, Children's Colorado	
12:10 PM - 12:30PM	<b>Session #3 Q &amp; A</b>	
	Grand Cypress DEF Kimberly Wilttrout, Yang Yang, Keith Coffman	
12:30 PM - 1:30 PM	<b>Research Poster Session &amp; Family Voting</b>	
	Foyer	
12:30 PM - 1:30 PM	<b>Lunch</b>	
	Portico	

AGENDA SUBJECT TO CHANGE

= COMMUNITY session
  = CARE session
  = RESEARCH session
  = livestreamed session

Download the App for detailed agenda and speakers



### Session #3: Moving Care Forward - 1:30 PM

1:30 PM - 1:40 PM

**Why We Are All Here: Family Story**

Grand Cypress DEF

Will Hutson

1:40 PM - 2:25 PM

**Comprehensive Care in Action: The SCN2A MDC Model**

Grand Cypress DEF

UTH, CC, BCH, MDC Family

2:25 PM - 2:35 PM

**The Evolving Therapeutic Landscape in SCN2A**

Grand Cypress DEF

Morgan Weberg, *FamilieSCN2A TASCO*

### Industry Fireside: From Discovery to Delivery - 2:45 PM

2:45 PM - 3:30 PM

**How Rare Disease Therapies Move from the Lab to Patients**

Grand Cypress DEF

Industry

4:00 PM

**Group Photo - All Attendees Welcome**

Grand Cypress Lobby

4:30 PM - 6:00 PM

**Break**

4:30 PM - 5:30 PM

**Grandparents Social**

Location TBD

6:00 PM - 8:00 PM

**Remembrance Dinner & Awards Program**

Grand Cypress DEF

All Are Welcome

8:00 PM - 10:00 PM

**Dads Night Out!**

Lobby Bar Patio

## Friday, July 31st

8:00 AM - 9:00 AM

**Breakfast**

Portico

8:00 AM - 2:30 PM

**SCN2A Sensory Room**

Grand Cypress A

9:00 AM - 2:30 PM

**SuperSibs Camp**

Regency 1

Please collect your camper at 12PM for lunch

### Thinking Outside the Box

9:00 AM - 9:10 AM

**Morning Welcome & Recap**

Grand Cypress DEF

Amanda Gale

9:10 AM - 9:40 AM

**Are you smarter than a SuperSib?**

Grand Cypress DEF

SuperSibs vs Researchers, *hosted by Stephan Sanders*

9:40 AM - 9:55 AM

**Downregulating the DysFUNCTION: An Intro to Functional Medicine**

Grand Cypress DEF

Julie Buckley, MD, IFMCP

### Session #1, Communication in All Its Forms

#### Behavior and AAC

10:00 AM - 10:55 AM | Grand Cypress DEF

Communication comes in many forms, including behavior, regulation, and AAC use for non-speaking individuals. Understanding communication beyond spoken words can strengthen connection and better support individuals with SCN2A-related disorders.

- **Joan Winter, MD, Children's Colorado**
- **Daniel Dardiz, M.A., CCC-SLP, PRC-Saltito**

### Session #1, Track 2: Beyond Seizures

#### Caring for the Whole Child

10:00 AM - 10:55 AM | Grand Cypress BC

Children with SCN2A-related disorders often have needs that extend far beyond seizures. Coordinated, whole-child care can support each child's medical, behavioral, communication, mobility, and quality-of-life needs, while also caring for the family as a whole.

- **Jordan Wyrwa, DO, Children's Colorado**
- **Heather Olson, MD, Boston Children's Hospital**

10:55 AM - 11:15 AM

Break

Session #2, Track 1: Moving through SCN2A

11:15AM - 12:10 PM | Grand Cypress DEF

Movement disorders are a common part of SCN2A-related disorders but can look very different from person to person. This session will explore movement symptoms across the spectrum, current treatment approaches, and practical insights for families and clinicians.

- Keith Coffman, MD, Mayo Clinic
- Thakur Nivedita, MD, UTHealth
- Sunanjay Bajaj, MD, UTHealth

Session #2, Track 2: Autism in SCN2A – Lets talk about it!

11:15AM - 12:10 AM | Grand Cypress BC

Autism presents differently across the SCN2A spectrum and often raises important questions for families and clinicians. This interactive ask-me-anything session will explore communication, behavior, sensory differences, daily life, and supportive strategies through open discussion with experts and lived experience voices.

- Anna Rolston, BCBA
- Catherine Hallam, PhD, LPC

12:15 AM - 12:45 PM

Book Signing

Foyer

12:30 PM - 1:30 PM

Lunch

Session #3, Track 1 : The Impact of Rare Disease on Relationships and Well-Being

1:30 PM - 2:25 PM | Grand Cypress BC

This discussion will explore the emotional and relational impact of raising and caring for a child with a rare disease, including caregiver burden, chronic stress, medical trauma, and the often-invisible weight carried by families. Together, participants will discuss how rare disease affects parents, siblings, extended family, friendships, and community connections, while sharing experiences and strategies to support emotional well-being and relationships.

- Sarah Stoney, MSW, LCSW, CHOP

2:30 PM - 6:00 PM

Break

6:00 PM - 9:00 PM

Warrior Dance Party

Grand Cypress DEF

All Are Welcome

8:00 PM - 10:00 PM

Moms Night Out!

Location TBD

AGENDA SUBJECT TO CHANGE

THANK YOU TO OUR GENEROUS SPONSORS:



THE JOHN AND EMILY PARK FAMILY FOUNDATION

