

CONFERENCE GUIDE

2026



FAMILIESCN2A®

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	Professionals Registration OPEN	Grand Cypress Prefunction
8:00 AM - 9:00 AM	Professionals Breakfast	Grand Cypress Ballroom
9:00 AM - 9:15 AM	Opening Remarks & Roundtable Goals	Grand Cypress Ballroom
9:15 AM - 9:45 AM	Topic 1: State of the Field: Non Seizure Outcomes Overview (Panel)	Grand Cypress Ballroom
10:00 AM - 10:30 AM	Topic 2: Patient Subgroups & Phenotyping	Grand Cypress Ballroom
10:45 AM - 11:15 AM	Topic 3: Preclinical Models & Gaps	Grand Cypress Ballroom
11:30 AM - 12:00 PM	Topic 4: Clinical Trial Readiness & Outcome Measures (Panel)	Grand Cypress Ballroom
12:15 PM - 1:00 PM	Professionals Lunch	Portico West
1:00 PM - 4:00 PM	Workshop: Advancing Research to Improve Non-Seizure Outcomes	Grand Cypress Ballroom
2:00 PM - 5:00 PM	General Registration OPEN	Grand Cypress Prefunction
4:45 PM - 5:15 PM	Roundtable Wrap up Next Steps Closing	Grand Cypress Ballroom
5:30 PM - 7:00 PM	Post-Roundtable Cocktail Reception	Portico East <i>Roundtable Participants Only</i>
7:00 PM - Onward	Evening at Leisure Dinner on Your Own	Explore the resort, enjoy on-site restaurants, network, or relax at your own pace.

AGENDA SUBJECT TO CHANGE

Download the App for
 detailed agenda
 and speakers



Thursday, July 30th

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

Grace Cauzo

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

5:00 PM - 6:00 PM

Research Poster Session & Family Voting

Portico

4:30 PM - 5:30 PM

Grandparents Social

Location TBD

6:00 PM - 8:00 PM

Remembrance Dinner & Awards Program

Grand Cypress DEF

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-Salttillo**

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**

AGENDA SUBJECT TO CHANGE

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!

Oak Terrace

AGENDA SUBJECT TO CHANGE

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THE JOHN AND EMILY PARK
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