

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
8:00 AM - 9:00 AM	Professionals Breakfast
9:00 AM - 9:15 AM	Opening Remarks & Roundtable Goals Leah Schust Myers, FamilieSCN2A & Gabi Conecker, SCN8A Alliance
9:15 AM - 9:45 AM	Topic 1: State of the Field: Non Seizure Outcomes Overview (Panel) Megan Abbott, MD & Jenny Downs, PhD
10:00 AM - 10:30 AM	Topic 2: Patient Subgroups & Phenotyping Dennis Lal, PhD & Michael Hammer, PhD
10:45 AM - 11:15 AM	Topic 3: Preclinical Models & Gaps Kathryn Salvati, PhD & Chris Makinson, PhD
11:30 AM - 11:45 AM	Topic 4: From FDA Guidance to Trial Design: <i>Developing Non-Seizure Endpoints that work</i> Ethan Hausman, MD
11:30 AM - 12:00 PM	Topic 4: Clinical Trial Readiness & Outcome Measures (Panel) Christina Theodore-Oklot, PhD (Mahzi), Olivia McManus, MD (UCSD), Steve Petrou, PhD (Praxis) and Ethan Hausman, MD . Moderator: Brian Pfister, PhD
12:15 PM - 1:00 PM	Professionals Lunch
1:00 PM - 4:00 PM	Workshop: Advancing Research to Improve Non-Seizure Outcomes Kickoff: Christina SanInocencio PhD. Moderators: Kevin Bender, PhD & Perry Spratt, PhD
2:00 PM - 5:00 PM	General Registration OPEN
4:45 PM - 5:15 PM	Roundtable Wrap up Next Steps Closing
5:30 PM - 7:00 PM	Post-Roundtable Cocktail Reception <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>UT Arlington 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 the Hospital

Recovery After Medical Crisis

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

Every child follows a different path after hospitalization. Through real-world clinical scenarios, this session will examine the spectrum of recovery following hospital and ICU admissions, including rehabilitation, functional changes, palliative care, hospice, and planning for future medical events. We'll discuss how families can partner with their care team to maximize recovery, improve quality of life, and navigate difficult conversations with confidence and compassion.

- Jordan Wyrwa, DO, *Children's Colorado*
- Megan Abbott, MD, *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

THANK YOU TO OUR GENEROUS SPONSORS:



THE JOHN AND EMILY PARK
FAMILY FOUNDATION

