

INTRODUCTION

WHO'S ATTENDING

BEFORE YOU ARRIVE

GETTING THERE

VENUE | MEALS

MEDICAL RESOURCES

DRESS CODE

GET INVOLVED

KIDS ACTIVITIES

PHOTO/VIDEO & SOCIAL MEDIA

ILLNESS
GUIDELINES

CONTACT US

Everything you need to know!



FAMILIESCN2A[®]
FOUNDATION
2026 SUMMER CONFERENCE
ORLANDO ✦ July 29-31 ✦ SCN2A.ORG



Introduction

We're so excited to welcome you to the **2026 FamilieSCN2A Family & Professional Summer Conference**—the largest SCN2A gathering in the world and a highlight of our year!

This much-anticipated, three-day event brings together more than 400 attendees, including families, professionals, researchers, and industry partners, all who are moving mountains. With sessions and activities designed across ages and interests, there's truly something for everyone.

As you prepare to join us, we're making sure every detail is covered so you can arrive feeling informed, supported, and ready to connect.

This booklet includes Everything You Need to Know (EYNTK) ahead of your travels—but if anything comes up, please let us know



Who's attending?

The FamilieSCN2A Family & Professional Conference brings together a diverse community of families, clinicians, researchers, and partners to learn from one another, connect through shared experiences, and advance the future of SCN2A-related research and care.

Guided by our core values—Urgency, Integrity, Collaboration, and Inclusion—we are committed to creating a welcoming, respectful, and compassionate space for all attendees, wherever they are on their SCN2A journey.

Our community includes families at many different stages, including those who may be attending while carrying the grief of losing a child. Our Bereavement Committee has created a brief guide with gentle suggestions to support thoughtful, respectful interaction, honoring that grief is deeply personal.

We are grateful for the care and empathy that help make this conference a space where all families feel seen and included.

Some families attending this year's conference are doing so after the death of their SCN2A Warrior. These families show incredible courage by joining us, and we are honored to hold space for them within our community.

As in past years, bereaved families may be identified by gold lanyards. These gentle identifiers are intended to support more thoughtful, compassionate interactions and help us meet one another with added care and awareness.

Tips for Interacting with Bereaved Families

- Let bereaved families lead. Each family's grief is unique. Rather than making assumptions, allow them to guide conversations and interactions based on their comfort level.
- Use their Warrior's name. Acknowledging a child by name recognizes their lasting importance and can be a deeply meaningful gesture.
- Avoid intrusive questions. Refrain from asking how a Warrior died or probing for deeply personal details. Focus instead on presence, care, and support.
- Keep conversations natural. Bereaved families want to remain part of the community. While some moments may be sad, many families welcome sharing stories, memories, and moments that bring laughter or warmth—not only grief.
- Be patient and flexible. Grief can be unpredictable. Emotions and needs may change quickly, and plans may need to shift. Your understanding and adaptability matter.
- Listen without judgment. Often, the most meaningful support is simply listening—without trying to fix, explain, or compare experiences.
- Respect cues and boundaries. Pay attention to verbal and nonverbal signals. If a family needs space, honor that. If they seek connection, meet them there. This is especially important for bereaved children and teens, who may have their own boundaries around sharing.
- Lead with compassion. Small acts of kindness—gentle words, patience, or simply being present—can make a powerful difference.

Before you arrive!



We're using **Whova** our official **conference app*** to facilitate networking, host the full event agenda, distribute documents and send announcements!

Having trouble joining? Search for our event and enter the invitation code: **agejvdssl2**

***Available to download in April**



Getting There

The Hyatt Regency Grand Cypress is located approximately 20 minutes from Orlando International Airport (MCO).

Transportation Options:

- **Rideshare (Uber/Lyft):** Widely available at MCO
Approx. \$25–\$35
- **Taxi:** Available curbside at all terminals
Approx. \$45–\$55
- **Shuttle Service** – mearstransportation.com
Shared and private shuttles available. Reserve in advance;
ADA-accessible options upon request
Approx. \$16pp | Kids Under 3 FREE
- **Rental Car*:** All major rental companies available onsite at MCO
Complimentary self-parking at the hotel

**The FamilieSCN2A Foundation has negotiated a reduced parking rate of \$15/night.*



Venue

Hyatt Regency Grand Cypress Resort

1 Grand Cypress Blvd, Orlando, FL 32836

(407) 239-1234

Room block reservations open February 24th

Hotel Check-in: 4:00 PM

Hotel Check-out: 11:00 AM

Please contact the hotel directly in advance with any special requests* (e.g., early check-in, accessible rooms, cribs, rollaway beds, etc.). Please also ensure that all members of your party are listed on your hotel reservation, as access to resort amenities is included with the room rate and requires each guest to be registered.

All conference sessions and activities will take place onsite at the hotel.



Meals

Registration includes breakfast, lunch, and dinner on both Thursday and Friday. All meals will be served on site with kid-friendly options available. If you noted any food allergies during registration, we'll do our best to accommodate them.



Dress Code:

the Most Asked Question!

Everyone gets a conference t-shirt!

Wednesday: Professional Roundtable

Researchers, clinicians, and professionals only.

Professional casual is ideal—think slacks, blouses, button-downs, or simple dresses that strike a balance between polished and comfortable.

Thursday & Friday: General Sessions

These are full days of learning, connection, and community. Conference casual is the way to go—jeans, khakis, sundresses, comfortable tops, and shoes you can walk in. Wear what helps you feel like yourself!

Thursday Evening: Remembrance & Awards Ceremony

A special and meaningful evening. While not formal, we encourage you to dress things up a bit—cocktail dresses, dress shirts, or anything a step above your daytime look.

Friday Evening: Warrior Dance Party –

Theme To Be Announced!



GET INVOLVED:

Research & Community Connections



Scan the QR codes to view and sign up for available opportunities before the conference.

Advance Research. Drive Discovery.

Your participation in research helps drive discoveries and improve care for SCN2A-related disorders.

Families are the key to unlocking answers—and your voice matters.

We're continually amazed by your eagerness to take part.

Because of you—and your amazing children—we're moving toward a cure.

Thank you!

**Check back soon for
research opportunities**

Connect with Community.

The conference is also about finding your people. Sign up for these informal gatherings. **These moments matter—don't miss them.**

**Check back soon for
gatherings you won't want to miss!**

For our Warriors

We're pleased to offer a dedicated **Sensory Room for our SCN2A Warriors**, open during general session hours on Thursday and Friday. The space will be stocked with books, toys, and floor mats, and will include an adult-sized changing table in a private corner for added comfort and accessibility. In addition, we're excited to offer some special programming, including music therapy and a visit from therapy animals to bring joy and comfort to our families.

Please note: *Child care is not provided. All children must be accompanied by an adult caregiver at all times.*



For our SuperSibs



SuperSibs Camp is designed especially for the siblings of our SCN2A Warriors, **ages 3–13**. It offers a fun, supportive space where siblings can connect, relax, and be celebrated for their unique role in the SCN2A community.

For siblings ages 14 and up, we are piloting a Counselor-in-Training (CIT) program, offering leadership opportunities and meaningful ways to support younger campers.

Limited spots available.

Check back soon for registration details.



Social Media, Photos & Videography

We encourage you to share your conference experience on social media and tag the FamilieSCN2A Foundation using the hashtags:

#SCN2A #cureSCN2A #SCN2AConference

Help us capture the magic!

If you capture any great moments, we invite you to upload photos to the Photos section of the conference app. Images may be used in future Foundation materials to help raise awareness and celebrate our community.

A professional photographer and videographer will be onsite throughout the event, and photos or video may be used to support Foundation awareness and fundraising efforts. If you prefer not to be photographed or filmed, please let our staff know at check-in.

Our videographer may also invite attendees to record brief one-on-one testimonials. We hope you'll consider sharing your story or connection to SCN2A—your voice matters.

Thank you!



Illness Guidance

While summer is not peak cold and flu season, COVID-19 and other respiratory viruses are still circulating. We ask everyone to help protect the more vulnerable members of our SCN2A community.

- If you have a fever or respiratory symptoms (like congestion, cough, or sore throat), please do not attend conference events.
- If you're recovering from a recent illness but still have mild symptoms, we kindly ask that you wear a mask during sessions.
- Please practice good hand hygiene and ensure you're up to date on vaccinations.

If you have any questions or concerns, don't hesitate to reach out to the conference team. Thank you for helping us keep our community safe.

Points of Contact

If you have any questions before, during, or after the conference, please don't hesitate to reach out:

Amanda Gale

(203) 285-4320

amanda.gale@scn2a.org

Kayla Aughe

(267) 374-5387

kayla.aughe@scn2a.org

We can't wait to welcome you to a fun, meaningful, and empowering conference.

Safe Travels!