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FAMILIESCN2A®  
FOUNDATION  
2025 SUMMER CONFERENCE

DENVER, CO • JULY 31 – AUGUST 2 • [WWW.SCN2A.ORG](http://WWW.SCN2A.ORG)

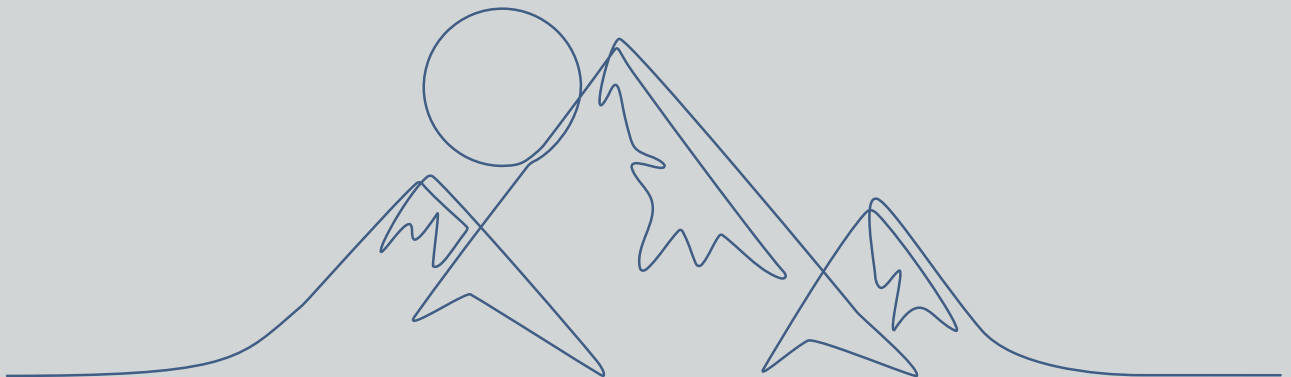
# INTRODUCTION

We're so excited to welcome you to the **2025 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, we're just a call, text, or email away.





# WHO'S ATTENDING?

The FamilieSCN2A Family & Professional Conference brings together a passionate and diverse community—including families, clinicians, researchers, drug developers, investors, and policymakers. It's a unique opportunity to learn from one another, connect through shared experiences, and contribute to the future of SCN2A-related research and care.

Guided by our core values—Urgency, Integrity, Collaboration, and Inclusion—the FamilieSCN2A Foundation is committed to creating a welcoming, respectful space for all attendees, wherever they are on their SCN2A journey.

This year, we are especially honored to welcome several families attending in remembrance of a child they've lost. Our Bereavement Committee have created a thoughtful guide on how to interact with bereaved families. These suggestions are meant to help us support one another while honoring the fact that everyone's grief is unique. We are deeply grateful for your continued efforts to include all families in the SCN2A community and at our conferences.



Some families at this year's conference are attending after the death of their SCN2A Warrior. Our bereaved families show incredible courage by joining us.

As in past years, you'll be able to identify bereaved families by their **gold lanyards**. These gentle identifiers help foster more thoughtful interactions across our community, allowing us to meet one another with extra care.

## Tips for Interacting with Bereaved Families



**Let The Bereaved Families Lead:** Acknowledge that each bereaved family has their own individual experiences and methods of coping. Instead of making assumptions about their needs or grieving process, allow them to guide the conversation and interaction at the conference according to their comfort levels and preferences.

**Use Their Warrior's Name:** Acknowledging their Warrior by name shows that you recognize their child as an important part of their lives. It's a small gesture with profound impact.

**Avoid Intrusive Questions:** Refrain from asking intrusive questions about how a Warrior died or other deeply personal details. Instead, focus on offering support and being a compassionate listener.

**Normalize Conversations:** Bereaved families want to hang out and be part of the community, just like anyone else. They want to talk about their children without it always being sad and serious. Sometimes it will be sad, but a lot of the time, they want to share stories and memories that make them laugh, smile, or feel closer to their loved ones. So, feel free to share happy and funny memories that can bring a smile to their faces. They want to talk about their children, share stories, and reminisce about happy and funny memories, not just the sad ones.

**Be Patient and Understanding:** Grief can be unpredictable. Be patient if someone needs space or if their emotions fluctuate. Reassure them that you're there whenever they're ready to connect.

**Listen Without Judgement:** Sometimes, bereaved families need someone who can simply listen. Offer your support by being a good listener without trying to solve their problems or judging their feelings.

**Respect Their Cues:** Pay attention to the verbal and non-verbal cues from bereaved families. If they need privacy, respect that. If they seek connection, be there for them.

**Honor Boundaries:** Bereaved children and teens may have different comfort levels when discussing their grief. Respect their boundaries and let them decide when and what they want to share.

**Be Flexible:** Plans and emotions can change suddenly for bereaved families. Be adaptable and ready to accommodate their needs, whether it's adjusting schedules or providing alternative options.

**Show Compassion:** Small acts of kindness and genuine empathy can make a big difference. Sometimes, just being present and offering a warm hug can provide immense comfort.





# BEFORE YOU ARRIVE!!



2025 SCN2A Family and Professional Conference, Denver CO

## Join us on our official event app

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



Having trouble joining? Search for our event and enter the invitation code: td9nrfb2qz

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



# GETTING THERE

The hotel does **not** offer an airport shuttle service. All guests are responsible for their own transportation.

A **rideshare (Taxi/Uber/Lyft)** is approximately \$25 and about a 14-minute ride from the airport.

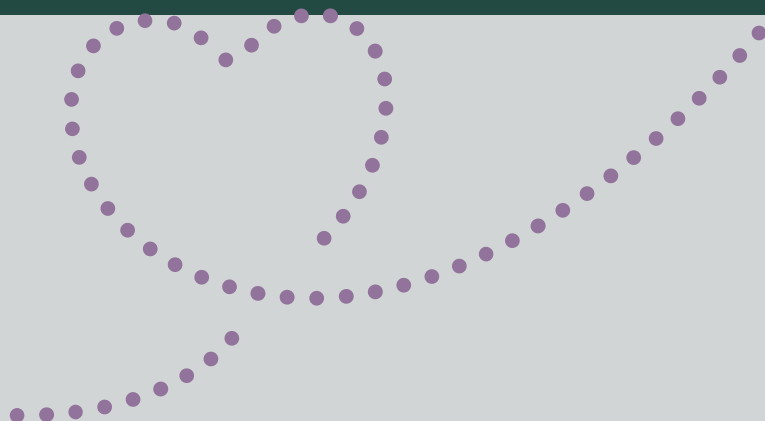
## **Public Transit Option:**

Take the A Line train from baggage claim to 61st & Peña station. From there, walk to the covered bus shelter and board the Gaylord Rockies/Blackhawk Town Center Shuttle, which runs every 30 minutes from 5:00 AM to 10:30 PM. The cost is \$10.50 per person.

For **wheelchair-accessible transport**, here are a few options to consider:

- Mobility Transportation & Services (303) 295-3900
- United Access (877) 578-1962
- RTD Access-a-Ride (303) 292-6560
- Denver Yellow Cab (303) 777-7777 (24-hour, on-demand, wheelchair-accessible service)

***Please note:** These services are not vetted or officially endorsed by the FamilieSCN2A Foundation. They are provided solely as potential options for your convenience.*



# VENUE

## The Gaylord Rockies Resort and Convention Center

6700 N Gaylord Rockies Blvd, Aurora, CO 80019

Phone: (720) 452-6900

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

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 the waterpark is included with the room rate and requires each guest to be registered.*



# MEALS

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

# MEDICAL RESOURCES

## Emergency Procedure Information

**Hotel Emergency Number:** #4444 from any guest room or office

**Public Phones:** Automatically dial the hotel operator

*For any medical emergency, guests can call 911 to contact local emergency services. The hotel will be notified by local services of an emergency call placed from the hotel. Response time is approximately 3 minutes with Fire/EMT response located 0.25 miles from hotel.*

## Medical Facilities

### Children's Hospital Colorado

13123 E 16<sup>th</sup> Ave  
Aurora, CO 80045  
720-777-1234  
24 Hours

### Concentra Urgent Care

15235 E. 37<sup>th</sup> Ave  
Aurora, CO 80011  
303-340-3053  
M-F 8AM-8PM  
SAT 8AM-4PM  
SUN Closed

## Pharmacies

### Walgreens

18550 Green Valley Ranch Blvd.  
Denver, CO 80249  
720-214-1030  
M-F 9AM-9PM  
SAT 9AM-6PM  
SUN 10AM-6PM

### CVS

2101 North Ursula St.  
Suite 35  
Aurora, CO 80045  
303-364-1139  
M-F 8AM-6PM  
SAT/SUN

### Walgreens

1205 E. Mississippi Ave.  
Aurora, CO 80012  
303-340-8860  
24 HOURS

## Local Tip

Colorado's high altitude can cause fatigue or headaches, so take it easy your first day—**stay hydrated**, rest when you can, and give your body time to adjust.





# DRESS CODE: THE MOST ASKED QUESTION!

EVERYONE GETS A CONFERENCE T-SHIRT!

PLEASE, WEAR YOUR SHIRT SATURDAY!!

## Thursday: 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.

## Friday & Saturday: Main 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!

## Friday 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.

## Saturday Evening: Colorado Western Warrior Dance Party

Time to kick up your boots! Break out your denim, flannel, fringe, or favorite western-inspired outfit. Dressing up is optional—but the fun is guaranteed.

**And don't forget your Warrior's cape!** If you haven't received one yet, we'll have one waiting for you!



# 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!



UTHouston  
Houston  
Evaluations



CVI  
Assessments



Eye  
Movements



BioGene EEG  
Study



1-1 Genetic  
Counseling



DRAGONFLY  
Study

## Connect with Community.



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



Dads Night



Moms Night



Grandparents  
Night



Family Photo  
Session

# FOR OUR WARRIORS:

We're pleased to offer a dedicated Sensory Room for our SCN2A Warriors, open during general session hours on Friday and Saturday in Cottonwood 10/11. 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



We offer a camp designed especially for the **siblings** of our SCN2A warriors, ages 3-17. SuperSibs Camp offers a fun, supportive environment where SuperSibs can relax, connect with others who truly understand, and be celebrated for their unique role in the SCN2A community. Through age-appropriate activities and meaningful connections, we honor their strength, resilience, and love—making this camp all about them. LIMITED spots available. For more information and to register, click [HERE](#)







# 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 snap any great photos, we'd love for you to upload them directly to the Photos section of the conference app. Your images may be used in future Foundation materials to raise awareness and celebrate our incredible community.

A professional photographer and videographer will also be onsite throughout the event. Photos and video may be used by the Foundation to support awareness and fundraising efforts.

If you prefer not to be photographed or filmed, just let our staff know at check-in and we'll make note of your preference.

In addition, our videographer will be inviting attendees to record short, one-on-one testimonials. We hope you'll consider sharing your story or connection to SCN2A—your voice matters!

# THANK YOU!





# ILLNESS GUIDANCE

While it's 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:

**Leah Myers**

(301) 252-8070

[leah.schust@scn2a.org](mailto:leah.schust@scn2a.org)

**Amanda Gale**

(203) 285-4320

[amanda.gale@scn2a.org](mailto:amanda.gale@scn2a.org)

**Kayla Aughe**

(267) 374-5387

[kayla.aughe@scn2a.org](mailto:kayla.aughe@scn2a.org)

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

**Safe travels!**

