

# **COFFIN–SIRIS SYNDROME FOUNDATION CONFERENCE**

**JULY 23–26,  
2026**

**Orlando, FL**

**avg. July  
temp: 92°**



**RARE COMMUNITY.  
REAL MAGIC.**

Coffin-Siris Syndrome Foundation Conference

ORLANDO, FL ✦ 2026

## **why all the zebras?!**

In medical school, physicians are taught, “when you hear hoofbeats, think horses, not zebras,” which tells doctors to consider the most likely possibility first when thinking of a diagnosis. With CSS, however, we proudly live in the world of “rare disease.” Welcome to Zebra land! We are better together!



**Fun Fact:** Did you know that a group of zebras can be called a “dazzle”? Some zoologists think zebras use their stripes as camouflage when they’re together to confuse predators, making it harder to pick out individual zebras!

Aren’t we a **DAZZLING** crew!  
**Thanks for joining us in Orlando!**

# Drury Plaza Hotel Disney Springs

2000 Hotel Plaza Blvd, Lake  
Buena Vista, FL 32830  
(map link)

407-560-6111

Free Transportation to Disney  
Parks/Monorail  
(Link)



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## Hotel Booking (link)

Book your room by June 23, 2026  
to receive our room block rate

|          |         |
|----------|---------|
| Check-in | 4:00 PM |
|----------|---------|

|           |          |
|-----------|----------|
| Check-out | 11:00 AM |
|-----------|----------|

*\*Parking fees are discounted to  
\$15/day for our group*

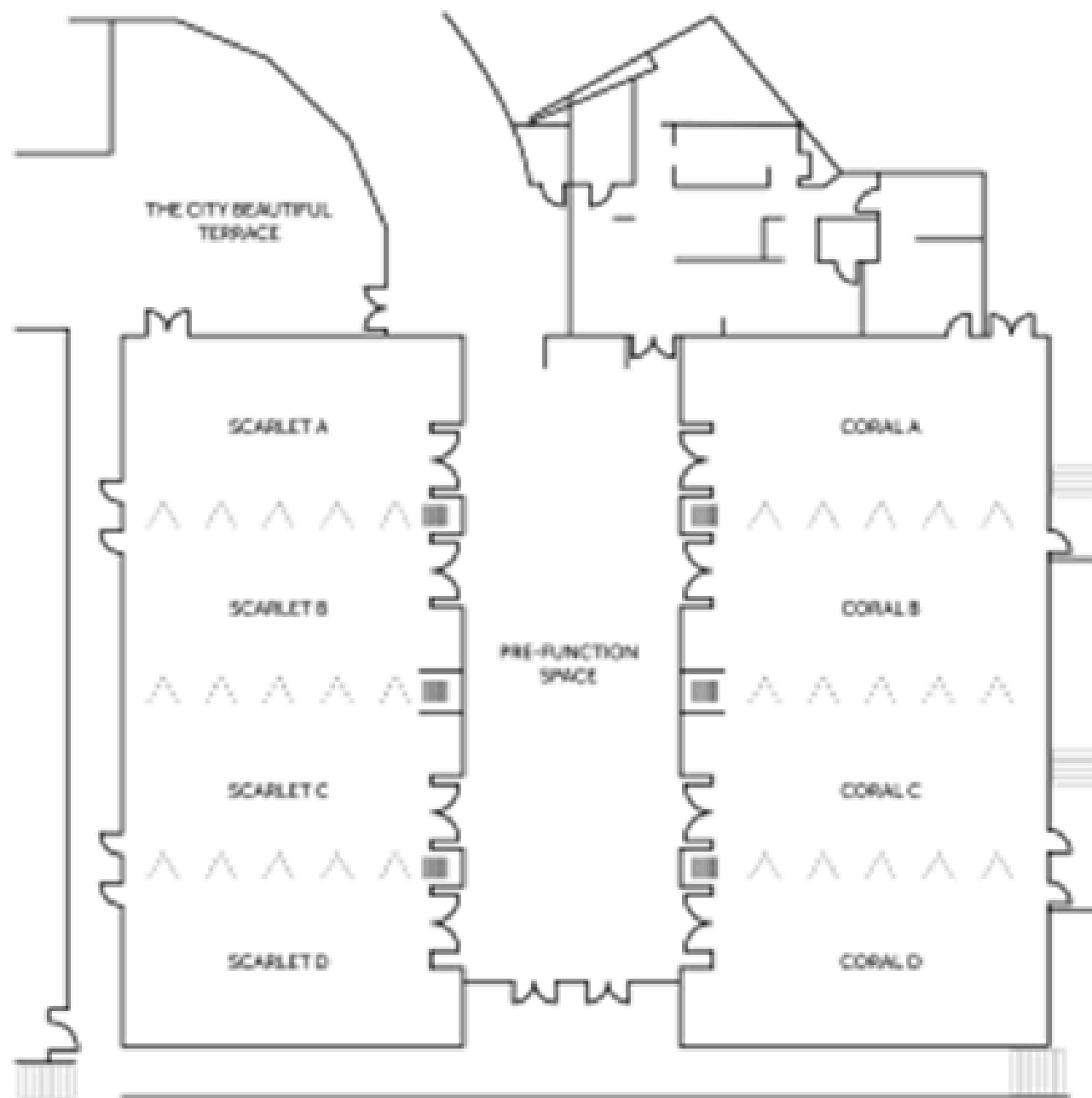
## Getting There

Orlando International Airport (MCO)

Transportation Considerations (link)

Airport Map (link)

Mears Shuttle Info (link)



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## Hotel Takeover: Ballrooms At A Glance



**Check out our Conference  
Accessibility  
Guide (Link)**

If you have any needs you did not indicate on your registration form please reach out to us at:  
**conference@coffinsiris.org**

**Join our WhatsApp Group  
for updates during the conference**



**2026 CSS Foundation Conference Orlando**

WhatsApp group



**We seek to create an  
inclusive community at the  
conference.**

**All are welcome to be  
themselves.**

**Come as you are.**

**Conference  
Social Story (Link)**



## **ON-SITE BABYSITTING**

- **Storybook Nannies** (Link)
- **Twinkle Toes Nanny Agency** (Link)
- **Once Upon A Nanny** (Link)
- **The Magical Nanny** (Link)
- **Kid's Nite Out** (Link)
- **NannyLand** (Link)

## **STROLLER RENTALS**

- **Kingdom Strollers\*** (Link)
- **Strollerfy** (Link)
- **Orlando Stroller Rentals\*** (Link)
- **Orlando Medical Rental\*** (Link)

**\*has special needs strollers available**



# **Nearby Hospitals and Urgent Care**

- **AdventHealth Centra Care Lake Buena Vista - 0.6 miles from hotel, 7AM-12AM daily**
- **Buena Vista Urgent Care - 2.4 miles, 8AM-6PM daily**
- **Orlando Health Dr. P. Phillips Hospital - 5.1 miles, comprehensive emergency services 24/7**
- **AdventHealth Celebration - 7.7 miles, comprehensive emergency services 24/7**
- **Orlando Health Arnold Palmer Hospital for Children Emergency Room - 14.8 miles, 24/7**
- **AdventHealth for Children - 18.9 miles, dedicated pediatric ER**
- **Nemours Children's Hospital, Florida - 18 miles**

**Local tip: July in Orlando is hot and humid. Stay hydrated, plan indoor breaks, and dress for the heat. Cooling towels and water bottles are encouraged—especially for our medically fragile Zebras.**







MESSAGES

now

**ATTN: SERVICE DOG AT CONFERENCE**

Ruff! Service dogs incoming... I am here to work, not play. Please try not to talk to me, feed me, or touch me without permission.



MESSAGES

3m ago

**I LOVE PEOPLE**

But please talk to my handler, not me.



MESSAGES

10m ago

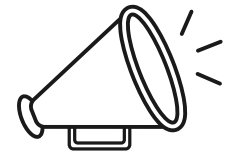
**WORK HARD, PLAY HARDER**

When I am helping my handler, I am not a pet. Please respect that.



# ALLERGY ALERTS

**NUTS (PEANUTS, TREE NUTS)**



Please be aware that all communal conference spaces and meals will be NUT FREE to protect the most vulnerable in our community. Please keep all peanut and tree nut foods away from community spaces for the inclusion and safety of all.



# HYDRATION AND HEAT

You need MORE water at high heat.

- Proper hydration is vital in high heat to support the body's cooling system, which relies on sweating.
- Drink water consistently, even before feeling thirsty.
- Severe dehydration can lead to heat exhaustion or heat stroke, showing symptoms like dizziness, nausea, and confusion.

How much extra?

- 1 to 1.5 liters of water daily.
- This means you should aim for a total of 3 to 4 liters of fluids per day (101 to 135 oz.)

**AVG. JULY TEMP: 92°**  
**Refill Often. Enjoy.**





**Party Zebras! Here's your reminder to sunscreen kids  
(and yourself) this weekend.**



**The Florida  means business!**

# CSS CONFERENCE SCHEDULE OVERVIEW

## THURS, JULY 23

Check In

Registration and  
Board Meet and  
Greet

Teen/Adult w CSS  
Lunch and Bingo

New Diagnosis/First  
Timers Connect

Welcome & Sessions

Hang w/ Dr. V

Pool Party

Dad's Night

Terrace Karaoke

## FRI, JULY 24

Conference Sessions  
(Coral Ballroom)

Kids Activities  
(Scarlett)

Conference Sessions  
Streaming (Scarlett)

Connect Conversations  
(Terrace)

Research Engagement  
& Enrollment, Vendors  
(Hallway)

Pool Party

Mom's Night

Movie Night (Ballroom)

## SAT, JULY 25

Conference Sessions  
(Both Ballrooms  
Different)

Self-Advocate Panel

Connection  
Conversations  
(Terrace)

Character Brunch  
(Pre-Registration  
Required)

Explore parks, swim,  
Disney Springs... so  
many options!

Terrace: Karaoke and  
Connect

## SUN, JULY 26

Disney Parks  
Meetups

Pool Party

Teen/Adult Casual  
Meet Up @ Drury

Character Dinner  
(Pre-Registration  
Required)



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# CSS POOL PARTY

JOIN US AT THE WATERING HOLE!

Drury Plaza Hotel Disney Springs

Thursday, July 23

12PM - 2PM

sponsored by





# **NEW DIAGNOSIS/FIRST CONFERENCE CONNECT**

**Thursday, July 23 @ 1pm  
Coral Ballroom**

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**Are you new to the CSS world and overwhelmed by all  
these new faces? Is this your first conference?  
SO. MANY. ZEBRAS.**

**You're not alone. Come find your footing among the herd.**



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**Bring a bracelet**  
to trade, gift, or share!



**Use** names, favorite things,  
diagnoses, AAC phrases,  
zebra themes, Disney themes,  
colors, or encouraging words.



**No pressure. No rules.**

*Just connection.*



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# THURSDAY JULY 23

| Time                     | Activity                                                                | Location                   |
|--------------------------|-------------------------------------------------------------------------|----------------------------|
| 10:00 a.m.–<br>5:00 p.m. | Registration, Raffles and Swag                                          | Prefunction Space          |
| 10:00 a.m.–<br>5:00 p.m. | Simons Searchlight (ARID1B, SMARCC2, SMARCA4) and Apricity Hope Project | Prefunction Space          |
| 11:00 a.m.–noon          | Meet and Greet the CSS Foundation Board                                 | Coral Ballroom             |
| 11:00 a.m.–<br>1:00 p.m. | Teens and Adults with CSS Lunch and Bingo!                              | City Beautiful Terrace     |
| Noon–2:00 p.m.           | Lunch on Your Own<br>Pool Party with the Apricity Hope Project          | Outdoor Pool and Splashpad |
| 1:00–2:00 p.m.           | New Diagnosis & First Time to Conference Connect                        | Coral Ballroom             |

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# Show Your Badge

**You can use your badge for discounts at Disney Springs.  
[Check out the full list of discounts! \(Link\)](#)**



**We have over 500 attendees at conference this year!  
Please wear your conference nametag at all times  
during the conference sessions.**



# THURSDAY JULY 23

*\*Sessions with an asterisk will be held twice.  
Please only attend one so others can do the same.*

| Time           | Activity                                                                  | Location                      |
|----------------|---------------------------------------------------------------------------|-------------------------------|
| 2:30–3:00 p.m. | Welcome from the CSS Foundation*                                          | Coral Ballroom                |
| 3:00–4:00 p.m. | Research and Registry Update<br>with Dr. Vergano *                        | Coral Ballroom                |
| 4:00–4:30 p.m. | Simons Searchlight: ARID1B, SMARCC2,<br>SMARCA4 with Dr. Astrid Rasmussen | Coral Ballroom                |
| 4:30–5:30 p.m. | Q&A with Dr. Vergano *                                                    | City Beautiful<br>Terrace     |
| 5:30–7:00 p.m. | Kickback Dinner and Drinks                                                | 2 <sup>nd</sup> Floor Commons |

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# DAD'S NIGHT OUT

**THURSDAY, JULY 23**

**SPLITTSVILLE DISNEY SPRINGS  
PREGAME AT DRURY, TERRACE 5:30-6:45  
WALK TO SPLITTSVILLE 6:45PM  
LAUGH. CONNECT. BOWL. WIN.**



THURSDAY JULY 23

| Time           | Activity                                                                   | Location                   |
|----------------|----------------------------------------------------------------------------|----------------------------|
| 5:45–6:45 p.m. | Dads’ Night PreGame<br>Walk to Splitsville at 6:45                         | City Beautiful<br>Terrace  |
| 7:30–9:30 p.m. | Dads’ Night: Splitsville Bowling<br>Light Bites, Lanes and Shoes Included! | 1494 E. Buena Vista<br>Dr. |
| 7:00 p.m.      | Connect and Hang                                                           | City Beautiful<br>Terrace  |
| 7:00 p.m.      | Movie Night                                                                | Coral Ballroom             |



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## **FOOD AND DRINK (onsite)**

**Coffee & Tea:** Hotel Lobby, free

**Free Daily Breakfast:** Floor 2 of Drury, 6–9:30 a.m. weekdays  
7–10 a.m. weekends

**Popcorn & Soda:** Floor 2 of Drury, 4–8 p.m.

Free **5:30 Kickback (dinner):** Floor 2 of Drury, 5:30–7:00 p.m. daily

**The Kitchen + Bar:** casual meal, quick bite, on-site cocktails,  
Mon–Sat 5 p.m.–12 a.m., Sun 5 p.m.–11 p.m.

**Lakeside Bar & Grill:** poolside restaurant and full-service bar,  
11 a.m.–10 p.m. daily – you can order ahead if you like!

## **Nearby Restaurants and Shopping**

### **Disney Springs**

<https://www.disneysprings.com/dining/>

1486 Buena Vista Dr, Lake Buena Vista, FL 32830 (.6 mile walk)

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**FRIDAY JULY 24**

## Research Engagement, Vendors and Photos

| Time    | Activity                                                                                | Location          |
|---------|-----------------------------------------------------------------------------------------|-------------------|
| All Day | <u>Positive Exposure</u> Photo Portraits                                                | Prefunction Space |
| All Day | <u>Apricity Hope Project</u>                                                            | Prefunction Space |
| All Day | <u>Simons Searchlight</u> Research Enrollment and Blood Draws: ARID1B, SMARCC2, SMARCA4 | Prefunction Space |
| All Day | <u>Dr. Miller</u> Epigenetic Research Enrollment: All CSS Variants                      | Prefunction Space |

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**FRIDAY JULY 24**

## **Kids Activities**

**No childcare: kids must be supervised by a caregiver**

| <b>Time</b>     | <b>Activity</b>                          | <b>Location</b>       |
|-----------------|------------------------------------------|-----------------------|
| 8:00–9:00 a.m.  | <u>Mad Science</u> : Superhero Science   | Scarlett Ballroom C/D |
| 9:00–10:00 a.m. | <u>Mad Science</u> : Fire and Ice        | Scarlett Ballroom C/D |
| 10:30–noon      | Reptile Show                             | Scarlett Ballroom C/D |
| 2:00–4:00 p.m.  | <u>CSS Got Talent Show: Sign up here</u> | Scarlett Ballroom C/D |
| 2:45–5:45 p.m.  | <u>Kona Ice</u>                          | Patio                 |

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# CSS GOT TALENT

An afternoon to shine!

**JULY 24 | 2:00 PM**

Submit your act today! Acts must be under 2 mins.  
<https://forms.gle/ws2143BwUsxhdLJg9>

**ALL TALENTS  
WELCOME!**



# FRIDAY JULY 24

**\*Sessions with an asterisk will be held twice. Please only attend one so others can do the same.**  
**Sessions marked (R) will be recorded and streamed live into the Scarlett Ballroom C/D.**

| Time             | Activity                                                                                         | Location                      |
|------------------|--------------------------------------------------------------------------------------------------|-------------------------------|
| 6:30–9:00 a.m.   | Breakfast at the Drury                                                                           | 2 <sup>nd</sup> Floor Commons |
| 8:00–9:00 a.m.   | Welcome from the CSS Foundation* <b>(R)</b>                                                      | Coral Ballroom                |
| 9:00–10:00 a.m.  | Research and Registry Update with Dr. Vergano* <b>(R)</b>                                        | Coral Ballroom                |
| 9:00–10:00 a.m.  | Parents and Caregivers of Teens & Adults Meet Up                                                 | City Beautiful Terrace        |
| 10:00–11:00 a.m. | Epilepsy Foundation Florida – Florida Epilepsy Services: Epilepsy Awareness and SUDEP <b>(R)</b> | Coral Ballroom                |
| 10:00–11:00 a.m. | Q&A with Dr. Vergano *                                                                           | City Beautiful Terrace        |

# FRIDAY JULY 24

**\*Sessions with an asterisk will be held twice. Please only attend one so others can do the same.**  
**Sessions marked (R) will be recorded and streamed live into the Scarlett Ballroom C/D.**

| Time            | Activity                                                     | Location               |
|-----------------|--------------------------------------------------------------|------------------------|
| 11:00 a.m.–noon | Dr. Miller, Epigenetics Research (R)                         | Coral Ballroom         |
| 11:00 a.m.–noon | Single Parenthood Meet Up                                    | City Beautiful Terrace |
| Noon–2:00 p.m.  | Lunch on Your Own                                            |                        |
| Noon–1:00pm     | Florida Families Unite (Bring Your Lunch)                    | City Beautiful Terrace |
| 1:00–2:00 p.m.  | Meet our Medical Advisor,<br>Genetic Counselor – Emily Place | City Beautiful Terrace |



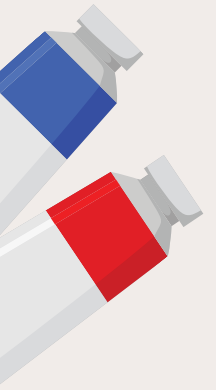
# FRIDAY JULY 24

**\*Sessions with an asterisk will be held twice. Please only attend one so others can do the same.**  
**Sessions marked (R) will be recorded and streamed live into the Scarlett Ballroom A/B.**

| Time           | Activity                                                                                                                                     | Location               |
|----------------|----------------------------------------------------------------------------------------------------------------------------------------------|------------------------|
| 2:00–3:00 p.m. | Angela Tyska, IEP Advocacy                                                                                                                   | City Beautiful Terrace |
| 2:00–3:00 p.m. | Dr. Bancroft, Autism and CSS <b>(R)</b>                                                                                                      | Coral Ballroom         |
| 3:00–4:30 p.m. | Epilepsy Foundation Florida– Florida Epilepsy Services * (Seizure First Aid course suitable for ages 13 and up – will receive certification) | Coral Ballroom         |
| 3:00–4:00 p.m. | Outgrowing Cute with Becky Dubay                                                                                                             | City Beautiful Terrace |
| 4:00–4:30 p.m. | Siblings Speak Out                                                                                                                           | City Beautiful Terrace |
| 4:30–5:00 p.m. | Group Photo                                                                                                                                  | Location TBD           |

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# MOMS NIGHT OUT *PAIN*T AND *SIP*

**FRIDAY, JULY 24**

**6PM: SOCIAL HOUR ON THE  
TERRACE... BRING YOUR  
DRINK!**

**7-9PM: PAINT, LAUGH, AND  
MAKE A NEW BEST FRIEND.  
LIGHT BITES AND DESSERT,  
SCARLETT BALLROOM**



FRIDAY JULY 24

| Time           | Activity                              | Location                      |
|----------------|---------------------------------------|-------------------------------|
| 5:30–7:00 p.m. | Kickback Dinner and Drinks            | 2 <sup>nd</sup> Floor Commons |
| 6:00–7:00 p.m. | Moms’ Social Hour – Bring Your Drinks | City Beautiful Terrace        |
| 7:00–9:00 p.m. | Moms’ Night: Paint and Sip            | Scarlett Ballroom             |
| 7:00 p.m.      | Movie Night                           | Coral Ballroom                |



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# SATURDAY JULY 25

| Time            | Activity                                                                                                                                     | Location                      |
|-----------------|----------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------|
| 7:00–9:30 a.m.  | Breakfast at the Drury                                                                                                                       | 2 <sup>nd</sup> Floor Commons |
| 8:00–9:00 a.m.  | Joy & Acceptance amid Grief & Trauma with Becky Dubai                                                                                        | City Beautiful Terrace        |
| 8:00–9:30 a.m.  | Epilepsy Foundation Florida– Florida Epilepsy Services * (Seizure First Aid course suitable for ages 13 and up – will receive certification) | Scarlett Ballroom             |
| 8:00–8:30 a.m.  | Dr. Santen Research Update (Virtual)                                                                                                         | Coral Ballroom                |
| 8:30– 9:00 a.m. | Dr. Kim Research Update (Virtual)                                                                                                            | Coral Ballroom                |

# SATURDAY JULY 25

| Time             | Activity                               | Location               |
|------------------|----------------------------------------|------------------------|
| 9:00–10:00 a.m.  | Dr. Feyma: Neurology                   | Coral Ballroom         |
| 9:00–10:00 a.m.  | Q&A with Dr. Vergano*                  | City Beautiful Terrace |
| 10:00–11:00 a.m. | Self Advocate Panel                    | Coral Ballroom         |
| 10:00–11:00 a.m. | Dr. Chen, CSS Sleep Research (Virtual) | Scarlett Ballroom      |
| 11:00 a.m.       | Closing Remarks                        | Coral Ballroom         |

# DR. VERGANO

**Dr. Vergano is the Associate Medical Director for Outpatient Services for Genetic Medicine at Seattle Children's Hospital in Seattle, WA. She established the natural history registry for Coffin-Siris Syndrome and related disorders in 2015, which has enrolled over 500 individuals. She enjoys teaching medical students and residents, as well as participating in scholarly activities and patient advocacy. CSS is her passion and area of expertise, and she's thrilled to join us again in Orlando!**



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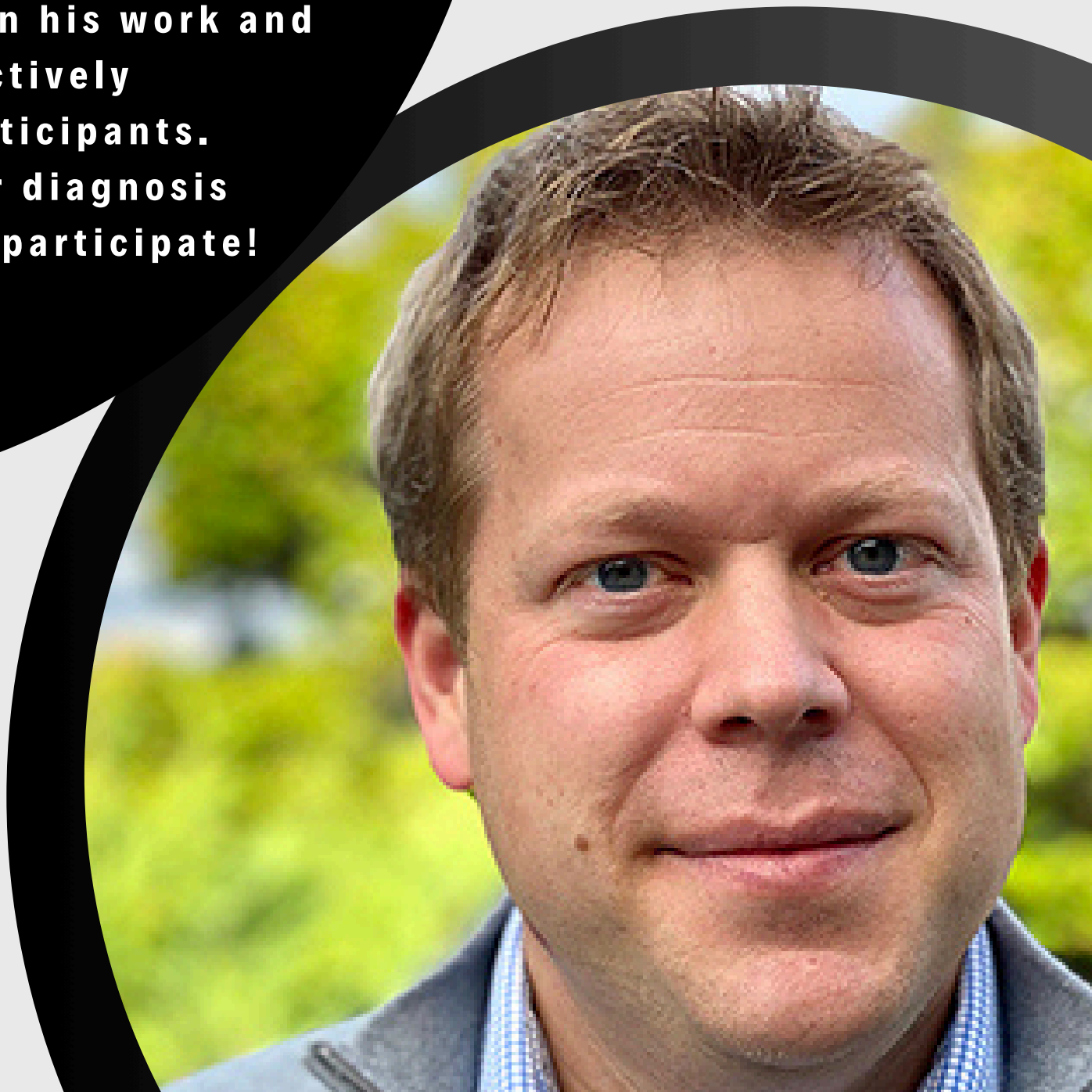
# DR. MILLER

**Dr. Miller will be joining us again from Seattle, Washington where he runs a lab out of UW and is working on a CSS Epigenetics Study. He is also a clinical geneticist at Seattle Children's Hospital, and a medical advisor to the Foundation. He'll explain his work and his study, and will be actively enrolling interested participants. Anyone with a molecular diagnosis of CSS is encouraged to participate!**



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# DR. FEYMA

**Dr. Feyma is a board certified pediatric neurologist. He contracts time at Gillette Children's Hospital in St. Paul, MN, and has recently started full time at a new practice in the Twin Cities. He specializes in epilepsy, developmental delay, and genetic syndromes as well as other neurologic conditions. He has a sweet spot for our community, and we are thrilled he's joining us again in Orlando!**



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# DR. SANTEN

**Dr. Santen will be joining us (virtually) from the Netherlands to share his research updates and insights. He has recently published a natural history study on adults with CSS. Dr. Santen is a medical advisor to the CSS Foundation, and is a clinical geneticist at Leiden University Medical Center in Leiden, Netherlands.**



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# DR. CHEN

**Dr. Chen will be joining us virtually from Seattle Children's Hospital, where she is the Director of Pediatric Sleep Disorders. Her clinical and research interests are in sleep disorders – both respiratory and non-respiratory – in clinical populations with medical complexity. She has been working on CSS sleep research this past year and is eager to share updates!**



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# DR. KIM

**Dr. Kim will be joining us (virtually) from Kent State in Ohio. He last joined us in 2018, and will be sharing updates to his research and work, specifically related to ARID1B, Autism, and Intellectual Disability.**

**Dr. Kim is a professor of Biological Science and Chairs the Neuroscience Graduate program, both at Kent State.**



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# SIMONS SEARCHLIGHT

**This year we will have Dr. Astrid Rasmussen, Kaitlyn Singer, Sanjana Kadirvel, and Aidan Sandhoefner with us from Simons Searchlight. Simons Searchlight is a trusted research partner that is studying the CSS genes ARID1B, SMARCA4, and SMARCC2 (among many other autism related genes). They will be presenting on their organization and work, as well as enrolling interested participants and offering on-site blood draws for willing individuals.**



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The Simons Searchlight logo is displayed on a laptop screen. The logo consists of the word "SIMONS" in a sans-serif font above the word "SEARCHLIGHT". The "O" in "SEARCHLIGHT" is replaced by a stylized orange and yellow flame or DNA helix icon.

SIMONS  
SEARCHLIGHT

# BECKY DUBAY

Becky Dubay, MSW, is our resident social worker. She serves on our Board of Directors, is mama to 3, lives in Canada, and has become the hero of Zoom events for our self-advocates and parents alike. Becky will be leading a few conversations over the weekend. She is brilliant at navigating grief, expectations, and processing the journey around disability. Take a deep breath, and get ready to dive in.





# CSS SELF- ADVOCATES

Our Self-Advocate Board Members: Eddie, Matthew, Marky, Mollie-Aidan, and Victoria will share their experiences with us, along with several of their friends with CSS. This event is a highlight every year!



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# EMILY PLACE

**Emily is a Senior Genetic Counselor and Manager of Genetics and Genetic Counseling at the Ocular Genomics Institutes at Mass Eye and Ear. She serves as a Medical Advisor to the CSS Foundation, and most importantly, she is mom to Jonah, who has CSS.**

**Emily will be leading a casual conversation and/or Q&A Friday for anyone interested.**



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# **EPILEPSY FOUNDATION FLORIDA**

## **FLORIDA EPILEPSY SERVICES**

**All things seizures... big and small.**

**We are thrilled to have the Epilepsy Foundation Florida – Florida Epilepsy Services with us in Orlando. They will be presenting on the hard but real truths around seizures, epilepsy, and SUDEP, as well as leading two (separate offerings, same training) seizure first aid certification classes (available for ages 13+).**

**Joining us from the Epilepsy Foundation are:**

- Johnny Douglas (Intake and Outreach Specialist)**
- Camille Washington (Operations Manager)**
- Lenore A. Brinson (Executive Director)**



# DR. ALEXIS BANCROFT

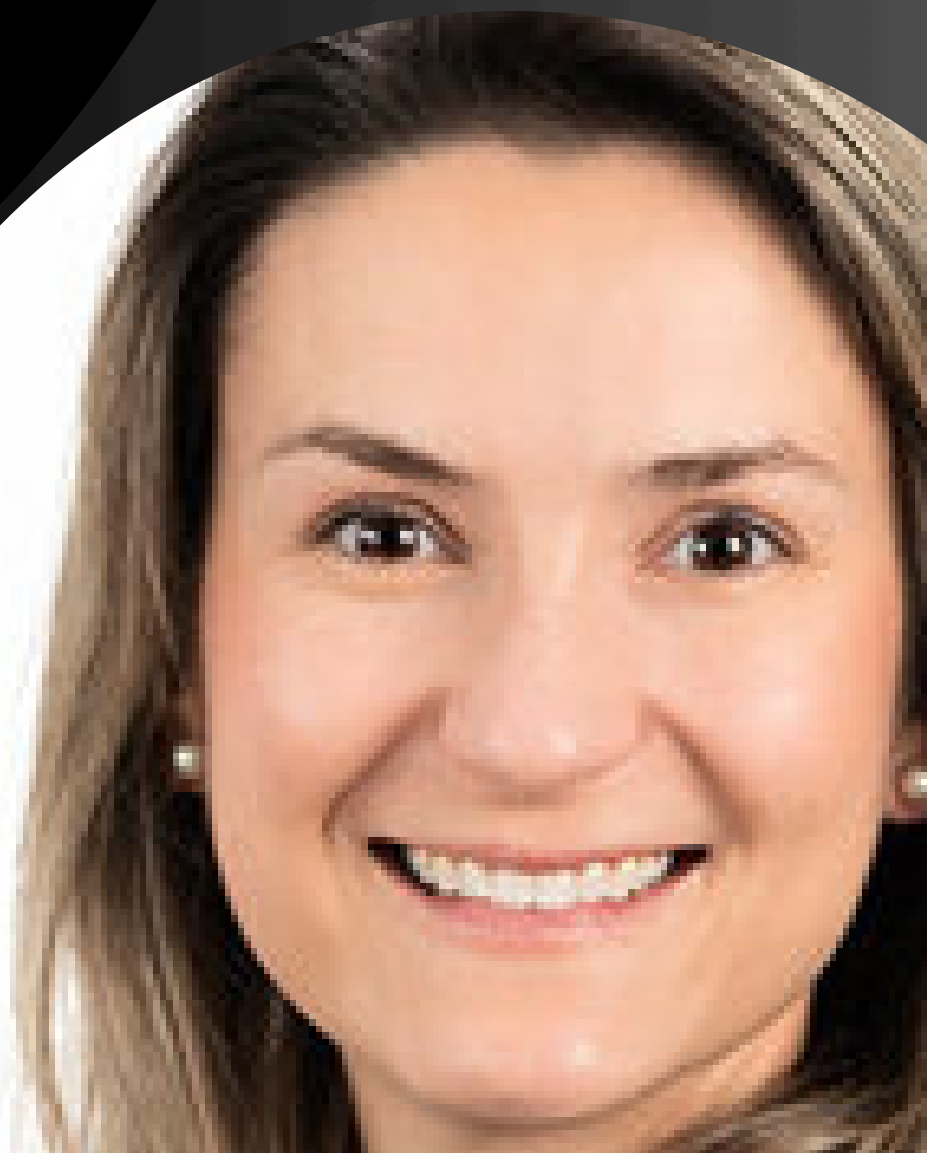
Alexis is a PhD Neuropsychologist in private practice and at Learning Spring School in NYC. She specializes in the psychological and neuropsychological evaluations of individuals with autism and co-occurring neurodevelopmental disorders. Additionally, and most importantly, she is a mom to an amazing kid with both CSS (ARID1B) and Autism.

She is so excited to connect with this community... make sure to grab her say hi!



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# ANGELA TYSZKA

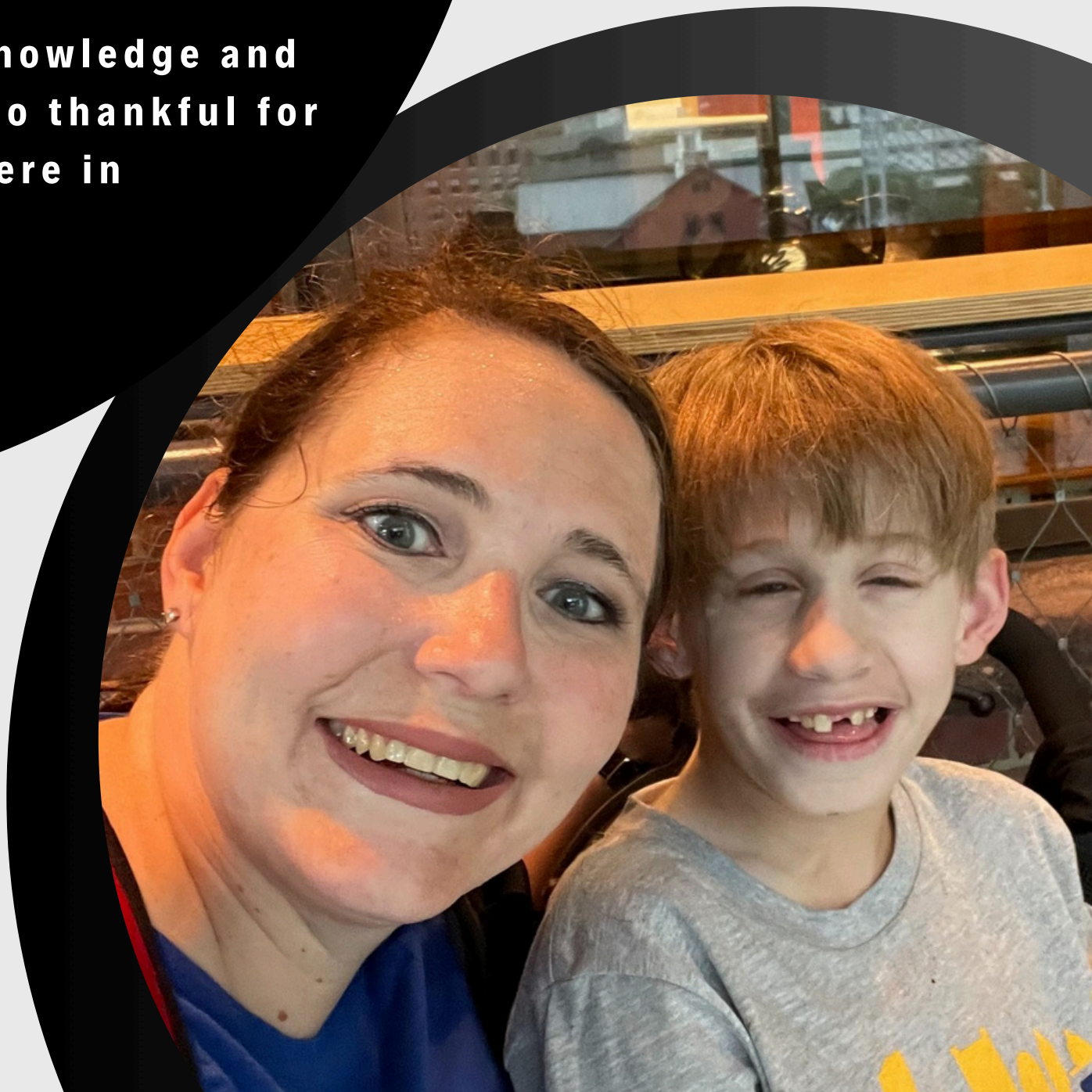
Angela joins us from Michigan Student Advocacy Services to lead a conversation about school advocacy, IEPs, and all the related things. Most importantly, she is mom to two incredible kids, one of whom has CSS.

Angela is a wealth of knowledge and resources, and we are so thankful for her willingness to be here in Orlando!



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# ALISON GRAHAM

Alison is a photographer with Positive Exposure. She will be capturing all of the amazing memories and portraits! Positive Exposure partners with hundreds of nonprofits, hospital systems, advocacy groups, and educational institutions, creating educational resources and programming to reconstruct societal attitudes towards individuals living with genetic, physical, behavioral, or intellectual difference.

This will be our 5<sup>th</sup> year working with Positive Exposure and our 2<sup>nd</sup> year having Alison taking pictures.



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# Vendors And Tables Not To Miss



Take advantage of time to talk with CSSF Research table, Dr. Miller, and the Simon's Searchlight team while you are here! Dr. Miller will be enrolling and taking blood samples for his CSS Epigenetics study; Simon's Searchlight will be doing the same for their work around ARID1B, SMARCA4, and SMARCC2.

Apricity Hope Project: The Apricity Hope Project provides mental, physical and emotional health support to primary caregivers of medically complex children with disabilities.

CarerSPK: Toilet training, incontinence, and night time enuresis... please take and try kids and adult sizes of incontinence underwear and period wear.

Functional Formularies & Kate Farms: whether it's tube feeding or oral supplementation, please take and try samples!

# DISNEY TICKETS

**You can purchase your tickets to Disney with our group discount via our micro site. There are options for single day, multi-day, and partial day tickets.**

**Tickets can be purchased in advance or day of. If you intent to apply for a DAS pass, this can be initiated 2–60 days prior to and ticket of person with disability needs to be pre-purchased (only 1, if planning multiple days/parks).**

**Check out the Accessibility Guide for more details on DAS.**

**CSS DISNEY MICRO SITE (LINK)**

**Special tickets deals for  
attendees good 7 days prior,  
during, and 7 days after event!**



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# UNIVERSAL TICKETS

**You can purchase your tickets to Universal with our group discount via our micro site. There are options for single day, multi-day, and partial day tickets.**

**Tickets can be purchased in advance or day of.**

**CSS UNIVERSAL MICRO SITE (LINK).**

**All tickets purchased from this link are valid for use from July 16, 2026 through August 12, 2026.**

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# Looking for non-Disney activities in and around Orlando? We've got you!

(for weekly events, check out [Orlando on the Cheap](#))

DISNEY SPRINGS

Sea World

Universal Studios

Millie Moo's (owned by CSS mom Kelly Wells)

SeaLife Orlando Aquarium

Green Meadows Petting Farm

Gatorland

Museum of Illusions

Discovery Cove

WonderWorks

Dreamplex

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**ROADiD is partnering with the CSS Foundation to give us 20% off their products. Visit [www.roadid.com](http://www.roadid.com) to see their selection of wrist id's, shoe id's, watch id's, etc. for kids and adults!**

## **CSS Foundation ROADiD 20% off**



*It's who I am.*



**ROAD iD**



**COFFIN-SIRIS  
SYNDROME  
FOUNDATION**

# THE CSS REGISTRY IS BACK!

The IRB approved international registry for CSS and related disorders is again active and seeking enrollments of patients diagnosed with all genes associated with (and related to) CSS:

- ARID1A
- ARID1B
- ARID2
- BICRA
- DPF2
- SMARCA4
- SMARCB1
- SMARCC2
- SMARCD1
- SMARCE1
- SOX4
- SOX11

To register: [cssregistry@seattlechildrens.org](mailto:cssregistry@seattlechildrens.org)



# THANK YOU

Apricity Hope Project  
Kate Farms/Functional  
Formularies  
Anonymous  
Heather Britt  
Coco Chen  
Andrea Chess  
Mihaela Chiderov  
Amanda Cole  
Dominique Fields  
Michelle Gabriel  
Suzanne Gale  
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Ana Valle  
Dr. Vergano  
Kelly Wells  
Jean Wojcik



Logo Design: Alexa Croft

*Thank you to all of our donors and  
sponsors over the years.*

*Thanks to your generosity, this year  
we are proud to provide scholarships  
to every family who has requested  
one (29%).*

*Your belief in this work and this  
community keeps us going.*

# THANK YOU!!

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# THANK YOU

## 2026 WISH LIST DONATIONS:

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**Our mantra:**

**“Aim for perfection, go with the flow.”**

Thank you for your patience and kindness throughout this event. This is a big, messy, fun weekend and nothing ever goes perfectly.

Thank you all so much for trusting us, for joining us, and for doing the daring work of being in community together.





The legalese: By attending and participating in the Coffin–Siris Syndrome Foundation (CSSF) Conference, you acknowledge that you are responsible for your own well–being and that of any children or dependents attending with you.

While the CSSF works hard to provide a safe and welcoming environment, participation in conference activities is voluntary and involves inherent risks. By attending, you voluntarily assume responsibility for any illness, injury, loss, or damage that you or your dependents may experience during or as a result of participating in conference activities.

