

Drury Plaza Hotel - Disney Springs, 2000 Hotel Plaza Blvd, Lake Buena Vista, FL 32830
July 23-26, 2026 <https://coffinsiris.org/conference/>

Thursday July 23

10:00 a.m.	 Registration  Simons Searchlight Info Table (ARID1B, SMARCC2, SMARCA4)  Apricity Hope Project	Pre-function Space Pre-function Space Pre-function Space
11:00 a.m. - noon	 Meet & Greet, CSS Foundation Board of Directors	Coral Ballroom
11:00 a.m.- 1:00 p.m.	Teens and Adults with CSS: Lunch & Bingo!	City Beautiful Terrace
Noon - 2:00 p.m.	Break for Lunch (On Your Own)	
Noon - 2:00 p.m.	 Pool Party with the Apricity Hope Project	Saltwater Pool
1:00 - 2:00 p.m.	 New Diagnosis & First Timers to Conference Meet Up	Coral Ballroom
2:30 - 3:00 p.m.	 Welcome from the CSS Foundation	Coral Ballroom
3:00 - 4:00 p.m.	 Registry & Research Updates with Dr. Vergano	Coral Ballroom
4:00 - 4:30 p.m.	 Simons Searchlight Research Updates: ARID1B, SMARCC2, SMARCA4 with Dr. Rasmussen	Coral Ballroom
4:30 - 5:30 p.m.	 Dr. Vergano Q&A - bring your popcorn or drink	City Beautiful Terrace
5:30 - 7:00 p.m.	Kickback Food and Drinks at the Drury	2nd Floor Commons
5:45 - 6:45 p.m.	 Dad's Social Hour	City Beautiful Terrace
7:30 - 9:30 p.m.	Dads' Night: Splitsville Bowling (Finger Foods)	1494 E. Buena Vista Dr.
7:00 - 9:30 p.m.	 Movie Night Hang and Connect on the Terrace	Coral Ballroom City Beautiful Terrace

Friday July 24

All Day:	Positive Exposure Photo Portraits Coral Ballroom Sessions Streaming	Prefunction Space Scarlett Ballroom A+B
All Day:	 Fun Activities for Kids, Teens and Family (No Childcare: Kids must be supervised by family/caregivers)	Scarlett Ballroom C+D
8:00 - 9:00 a.m.	Mad Science: Superhero Science	
9:00 -10:00 a.m.	Mad Science: Fire and Ice	
10:30 - noon	Reptile Show	
2:00 - 4:00 p.m.	CSS Got Talent Show	
2:45-5:45pm	Kona Ice Truck	
All Day:	 Simons Searchlight Enrollment and Blood Draws  Miller Lab Epigenetics Research Enrollment and Blood Draws (All CSS Genes)  Epilepsy Foundation Florida - Florida Epilepsy Services  Apricity Hope Project, CARER	Prefunction Space Prefunction Space Prefunction Space Prefunction Space



Community & Support



Research



Social Connections



Kids & Family

Featured sessions  will be repeated. Please only attend one so others can do the same.

**Agenda: 2026 Coffin-Siris
Syndrome Foundation
Conference | Orlando, FL**

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Friday July 24

6:00 - 9:30 a.m.	Breakfast at the Drury	2nd Floor Commons
8:00 - 9:00 a.m.	Welcome from the CSS Foundation ★	Coral Ballroom
9:00 - 10:00 a.m.	Registry & Research Updates with Dr. Vergano ★	Coral Ballroom
9:00 -10:00 a.m.	Parents of Teens & Adults with CSS Meet Up 🎉	City Beautiful Terrace
10:00 - 11:00 a.m.	Epilepsy Foundation Florida - Florida Epilepsy Services Epilepsy awareness and SUDEP	Coral Ballroom
10:00 -11:00 a.m.	Dr. Vergano Q&A ★	City Beautiful Terrace
11:00 a.m. - noon	Dr. Miller, Epigenetics Research 🧬	Coral Ballroom
11:00 a.m. - noon	Single Parenthood Meet Up ❤️	City Beautiful Terrace
Noon - 2:00 p.m.	Break for Lunch on Your Own	
Noon - 1:00 p.m.	Florida Families Unite (Bring Your Lunch) 🎉	City Beautiful Terrace
1:00 - 2:00 p.m.	Meet Medical Advisor Genetic Counselor Emily Place 🧬	City Beautiful Terrace
2:00 - 3:00 p.m.	Dr. Bancroft, Autism and CSS (R) 🎥	Coral Ballroom
2:00 -3:00 p.m.	Angela Tyszka, IEP Advocacy ❤️	City Beautiful Terrace
3:00 - 4:30 p.m.	Epilepsy Foundation Florida - Florida Epilepsy Services (Seizure First Aid course for ages 13+) ★	Coral Ballroom
3:00 - 4:00p.m.	Outgrowing Cute with Becky Dubay ❤️	City Beautiful Terrace
4:00 - 4:30p.m.	Siblings Speak Out with Ellie and Juliette ❤️	City Beautiful Terrace
4:30 - 5:00p.m.	Group Photo	Location TBD
5:30 - 7:00p.m.	Kickback Food and Drinks at the Drury	2nd Floor Commons
6:00 - 7:00p.m.	Moms' Social Hour - Bring Your Drinks 🎉	City Beautiful Terrace
7:00 p.m.	Moms' Night: Paint the Town (Finger Foods)	Scarlett Ballroom
7:00 p.m.	Movie Night 🎬	Coral Ballroom

Saturday July 25

7:00 - 9:30a.m.	Breakfast at the Drury	2nd Floor Commons
8:00 - 9:00a.m.	Joy & Acceptance amid Grief & Trauma with Becky ❤️	City Beautiful Terrace
8:00 - 9:30a.m.	Epilepsy Foundation Florida - Florida Epilepsy Services (Seizure First Aid course for ages 13+) ★	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
9:00 - 10:00 a.m.	Dr. Feyma, Neurology	Coral Ballroom
9:00- 10:00 a.m.	Dr. Vergano Q&A ★	City Beautiful Terrace
10:00-11:00a.m.	Self Advocate Panel	Coral Ballroom
10:00-11:00a.m.	Dr. Chen, CSS Sleep Research (Virtual) 🧬	Scarlett Ballroom
11:00 a.m.	Closing Remarks	Coral Ballroom



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Sessions with 🎥 will be streamed into the Scarlett Ballroom and recorded.