



12th International Costello Syndrome Family Conference CONFERENCE PLANNING PACKET

Denver Marriott Tech Center
4900 S. Syracuse Street
Denver, CO 80237 USA

We are so excited that our next family conference is almost here! New families attending the conference say it is a “life-changing experience”. Families returning call it their “second family” or their “family reunion”. Our 2023 “CS Rare Roundup” will have a Western theme so all you buckaroos should bring your boots, denim and campfire outfits for our hoedown on Saturday night and be ready for some line dancing!

This packet will guide you through registration by providing you with information on travel, the hotel, what is close to the hotel, and the conference schedule. Please take time to read the information as many of your questions will be answered here. Looking forward to seeing you soon!



MARK YOUR CALENDAR

April 30, 2023	•Deadline for funds to be received by CSFN to count toward this conference
May 1, 2023	•Deadline to submit nominations for the Costello Syndrome Ambassador Award and the Sibling Champion Award
May 20, 2023	•Deadline to submit scholarship applications & attachments
May 25, 2023	•5:00pm ET Deadline for Early Bird Registration
June 11, 2023	•5:00pm ET Deadline for Conference, Camp Ras and CS Lounge Registration, including full payment
June 19, 2023	•Discounted hotel rates end
July 1, 2023	•Deadline to cancel Conference registration, Camp Ras or CS Lounge to receive a refund



What to Wear

Casual, comfortable attire is appropriate for the entire conference. You may want to pack a sweater or jacket for the conference rooms as they are sometimes chilly. For the pool area, pack a swimsuit, cover-up, sunscreen, sunglasses, and perhaps a hat. Swimsuits are not allowed at meals in the Maryland Ballroom. There will be designated days to wear your Costello t-shirts so bring them with you.

The Saturday night banquet will be a “Rare Roundup” with a Western theme so plan to wear your cowboy boots (or tennis shoes), cowboy hat, denim, etc. The most important thing is to dress casually and comfortably and have fun during our last evening together!



Transportation

Airport The closest airport is the Denver International Airport or DEN. Plan for plenty of time to deplane and take the train over to the main terminal.

Transferring to and from the hotel It is about 22 miles from the airport to the hotel, and there are many options to transfer between the airport and hotel: Uber, Lyft, taxi, rental car or airport shuttle services including SuperShuttle.

Car rentals If you choose to rent a car, Denver International Airport has more than 10 major car companies. Car rental agencies are located on airport property and provide courtesy shuttle service to and from Jeppesen Terminal. Shuttles pick up and drop off from Jeppesen Terminal Level 5, Island 4, outside doors 505-513 (east side) and 504-512 (west side).

Parking at the Hotel Parking at the hotel is \$15, which is 50% off the regular daily rate.



Hotel

Denver Marriott Tech Center
4900 S. Syracuse Street
Denver, CO 80237 USA

Main: 303.779.1100 **Reservations:** 888.236.2427 or 877.303.0104

Check-In: 3:00pm Check-Out: 12 Noon

Guest Room Rates CSFN has contracted with the hotel for a block of double Queen and King rooms at a discounted rate of \$159/night plus 15.75% tax (\$184.04). There are Deluxe rooms (1 King or 2 Queens) available for \$179/night plus tax and an Executive Studio Suite (sleeps 3) for \$239/night plus tax. These rates are available July 13 through July 26, 2023. All reservations must be guaranteed with a major credit card. Your card is not charged when you book but they may place a hold for the deposit amount. **The discounted rate ends June 19, 2023.** Please reserve your room as soon as possible by going online:

[12th International Costello Syndrome Family Conference - Start your reservation \(passkey.com\)](https://www.marriott.com/12thInternationalCostelloSyndromeFamilyConference)

Staying at the Conference Hotel This allows you to fully participate in all conference activities and not miss out on the informal socializing that happens at the pool, the common areas and even the hallways! Also, the convenience of having your room a few steps away from conference activities is a definite plus. CSFN contracts with the hotel well in advance and must commit to book a certain number of rooms to secure the reduced room rates, lower conference costs and free meeting spaces. We depend on our families to book at the hotel to help us reach that commitment and thus avoid a penalty for not reaching that contract commitment.



Guest Room Amenities Mini-refrigerator, complimentary internet, hair dryer, alarm clock/radio, iron and ironing board, safe, coffee maker/tea service, in-room movies.



Hotel Amenities include indoor and outdoor pools, fitness center, gift shop, convenience store, ATM. The Market is a grab-and-go for a cup of coffee, snack, or quick meal, open 6:00am – 11:00am. Pint Brothers Alehouse is a relaxed place to enjoy a meal, open 6:30am – 10:00pm daily. Room service is available.

Please visit the hotel website for more information.

Microwaves – For families who need to warm food for tube feedings, there is a microwave station in front of “the Market” at the lobby area with 24-hour access.

Rollaway Beds and Cribs Complimentary (limited supply). Only King rooms allow a rollaway or crib.

Laundry The hotel offers dry cleaning but has no laundry. The closest laundry is WaveMAX Laundry Denver Hampden Avenue, 10005 E. Hampden Avenue, Denver, CO, about 4 miles from the hotel. Phone 303-953-9823.

Hotel Shuttle There is no hotel shuttle.

What restaurants are near the hotel? According to Google Maps, Griffin Tavern, Wendy's, and Shanahan's Steakhouse are about .2 to .3 miles from the hotel.



Shipping

If you need to ship medical supplies or food to the Denver Tech Center, the fee has been waived specifically for these items. You should ship to arrive no more than 3 days before your check-in date. Packages should be addressed to:

12th International Costello Syndrome Family Conference
c/o **your name**
Denver Marriott Tech Center
4900 S. Syracuse Street
Denver, CO 80237



CONFERENCE REGISTRATION

Conference Registration

The link to register for the Denver conference is: <https://www.rsvpbook.com/Denver2023>

After reviewing all the information in this document, you'll be ready to log in and register. You will create your own password so be sure it is something you will remember as you will be able to save your progress and return to complete or make changes. You will enter information on the registrants, register for Camp Ras and the CS Lounge, and order t-shirts to be delivered at the conference. The registration is lengthy so be sure to have about 20-30 minutes to spend.

The registration fee remains the same whether you attend the conference for one day or for the entire conference. Everyone who plans to attend any sessions and/or eat any meals at the conference must register.

Early Bird – Ends after 5:00pm Eastern Time on **May 25, 2023**

5 years and under- Free	6-12 years old - \$75
13 years & older - \$150	Person w/CS - Free

Regular Registration – Ends 5:00pm Eastern Time on **June 21, 2023**

5 years and under- Free	6-12 years old - \$105
13 years and older - \$210	Person w/CS - Free

For your registration to be considered complete, all information must be entered online, and all fees paid by this date. If you have questions or need assistance with registration, please contact Sandra Taylor at sandra@costellosyndromeusa.org or 850-832-4055 Central Time. Families with a new diagnosis of Costello syndrome after the deadline should contact Sandra Taylor for late registration.

Types of Registrants

These are the four different types of registrants:

- *Families* – families with an individual diagnosed with Costello syndrome
- *CSFN Professional Advisory Board Member* – CSFN PAB members only
- *Order only* – Use if you are not attending the conference and want to order a T-shirt
- *All Other Registrants* – Attendees such as grandparents, grown siblings, friends, and others who are not the immediate family members of the individual with Costello syndrome or professionals who are not on the CSFN Professional Advisory Board but plan to eat and/or attend any of the sessions or activities.



Conference Information

Please note that all activities have not been confirmed, and there could be adjustments to times/activities.

Tuesday, July 18, 2023

Families will arrive to be ready to begin the conference early on Wednesday.

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|-----------------|--|
| 3:00pm – 6:00pm | Registration/Help Desk open to pick up your conference packets |
| 5:30pm | Brief non-denominational prayer for the conference |
| 8:00pm – 9:00pm | Registration desk re-opens |

Wednesday, July 19, 2023 – Welcoming Day

- | | |
|------------------|--|
| 8:00am – 2:00pm | Registration/Help Desk open
BREAKFAST ON YOUR OWN |
| 9:30am – 12:00pm | Family Activities <ul style="list-style-type: none">• Christmas in July• Kara's Crafts• Informal social time |
| 12:00pm – 1:30pm | LUNCH ON YOUR OWN |
| 1:00pm – 5:00pm | Dr. Heather Thompson's Communication Study, by appointment
Dr. Marni Axelrad's Research on Memory in Adults with CS, by appointment |
| 1:30pm – 4:00pm | SibShops (ages 7-17), requires pre-registration |
| 1:45pm – 2:15pm | Family Liaison Training |
| 2:15pm – 3:45pm | New Family Orientation |
| 4:00pm | Pick up from SibShops by 4:00pm |
| 4:30pm – 5:00pm | Remembrance Service |
| 6:00pm – 8:30pm | Welcome, Announcements, Awards, Registration packets available
BUFFET DINNER |
| 8:00pm – 10:30pm | Dads' Man Cave (adult social time for caregivers) |

Thursday, July 20, 2023 – Learning Day

7:00am – 8:15am	BREAKFAST BUFFET
8:30am	Camp Ras & CS Lounge Open Registration & Check-in
8:00am – 2:00pm	Registration/Help Desk Open
8:00am – 5:00pm	Dr. Heather Thompson’s Communication Study, by appointment Dr. Marni Axelrad’s Research on Memory in Adults with CS, by appointment
8:30am – 11:30am	Medical Lectures
11:30am – 12:00pm	Pick up from Camp Ras & CS Lounge by 11:45am
11:45am – 1:00pm	LUNCH BUFFET
1:00pm	Camp Ras & CS Lounge Reopen
1:15pm – 1:30pm	MyMejo.com – “Putting Me Back in Medicine” by Ryan Sheedy
1:30pm – 2:00pm	Life as an Adult with Costello Syndrome
2:00pm – 3:55pm	Medical Lectures
4:00pm – 4:30pm	“Ask the Docs” – your chance to ask any remaining questions about CS
4:30pm – 5:00pm	Pick up from Camp Ras & CS Lounge by 5:00pm
	DINNER ON YOUR OWN
7:00pm – 9:30pm	Moms Sharing Time (adult social time for Caregivers)

Friday, July 21, 2023 – Giving Day

7:00am – 8:15am	BREAKFAST BUFFET
7:45am-8:00am	Volunteer Sign-in/Training for Research & Meet the Experts
8:00am – 5:00pm	Dr. Heather Thompson’s Communication Study, by appointment Dr. Marni Axelrad’s Research on Memory in Adults with CS, by appointment
8:30am – 2:00pm	Registration/Help Desk Open
8:00am – 12:00pm	Research Stations and Appointments with the Experts
12:00am – 1:15pm	LUNCH BUFFET
1:00pm – 5:00pm	Research Stations and Appointments with the Experts DINNER ON YOUR OWN

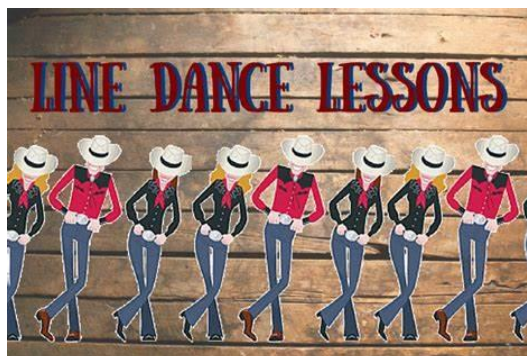
Saturday, July 22, 2023 – Sharing Day

7:00am – 8:30am	BREAKFAST BUFFET
8:00am – 5:00pm	Dr. Heather Thompson’s Communication Study, by appointment Dr. Marni Axelrad’s Research on Memory in Adults with CS, by appointment
8:20am	Group photo – location to be announced
8:00am – 1:00pm	Registration/Help Desk
8:15am	Camp Ras & CS Lounge Check-in
8:30am - 10:00pm	Roundtable Discussions by Age
10:15am – 11:15	Transitioning to Adulthood Panel
11:15am – 11:45pm	The Future of CSFN – Mary Ernst
11:45	Pick up from Camp Ras & CS Lounge by 12:00pm
12:00pm – 1:15pm	BUFFET LUNCH
1:15pm	Camp Ras & CS Lounge Check-in
1:30pm – 3:00pm	Roundtable Discussion by specialty
3:00pm – 3:15pm	Pick up from Camp Ras & CS Lounge by 3:15pm



CS Rare Roundup Western Banquet 5:45pm – 9:00pm

- Buffet Dinner
- Draw & Announce Coates' Quilt Winner
- Awards for the Costello Ambassador and the Sibling Champion
- Photos with the Grizzly Bear
- Announce location of the next conference
- Dancing with the DJ & Line Dancing Lessons



Sunday, July 23, 2023 – Wrap-up

BREAKFAST ON YOUR OWN

12:30pm – 1:30pm Scientific Symposium Summary

Descriptions of Activities

New Family Orientation All families attending the conference for the first time are strongly encouraged to attend the New Family Orientation. We will review the conference schedule, you'll get to meet other new families, and you can ask questions so that your time at the conference is productive. We want you to feel welcome from the start!

Welcome, Announcements, Registration packets will be available if you have not stopped by the Registration/Help Desk to get yours. We will be welcoming all our families, making announcements, and recognizing fundraisers followed by a Buffet Dinner.

SibShops This event is exclusively for siblings of individuals with Costello syndrome. There will be two rooms for these activities: one for ages 7-11 and one for ages 12-17. Siblings will have fun activities, get to share how it feels to be a sibling of an individual with Costello syndrome, and have refreshments. Space is limited and requires pre-registration.

Talking to Professionals at the Conference There are many opportunities to speak with the doctors and experts on Costello syndrome. There will be a Q&A session at the end of the day on Thursday. If you choose to participate in Research Day, you will be meeting one-on-one with the researchers and experts. The researchers are focusing on their approved research, but there is often time at the end of your session to ask questions. There will also be several experts available that day to discuss their area of expertise. *You are strongly encouraged to bring a list of questions to the conference and add to them as the conference proceeds so you will be prepared to get the information you need.* Remember that these are not your treating physicians so while they can answer questions specific to Costello syndrome, they cannot treat your specific child.

Research/Meet the Experts Day on Friday Detailed information will be sent to you by email after you register for the conference, including any reports the researchers request that you bring to the conference. You should bring a **copy of the report which confirms your child has Costello syndrome including the mutation**, if possible, especially if you are a new family. Typically, it takes about a half day to participate in research and talk with a team of experts.

Participation in research is important to all our families and to future families. You may choose to participate in any or all research on the schedule, and you will prioritize the experts you would like to speak with. We will do our best to accommodate your requests; however, you may not be able to meet with all the experts you select. It is important to show up on time for appointments for both Researcher and “Meet the Experts” so no one misses out on these great opportunities. It’s a hectic day and your cooperation will make the day run more smoothly.

Saturday Night – CS Rare Roundup

Saturday night is always a great time for families, and it is the last time everyone gathers for 2 years. 50/50 Raffle tickets will be sold, awards will be given, there will be line dancing and a chance to take your photo with a big ole grizzly bear. We hope to announce the location of the 2025 conference.

Quilt - For the past few years, Cathy Coates has designed and created a one-of-a-kind handmade quilt which is really a work of art and will be displayed throughout the conference. Raffle tickets may be purchased at the registration/help desk and at mealtimes. The winning ticket will be drawn at the CS Rare Roundup.

There are a few seats available for guests. If you wish to purchase tickets, contact Sandra Taylor to see if there are any seats left and instructions on how to pay.

Sunday

The RASopathies Symposium Summary led by several of our doctors will take place around 11:45am after the end of the Symposium. This informal event is presented by several of our doctors who will summarize the highlights of the Scientific Symposium.



CAMP RAS & CS LOUNGE

Camp Ras Professional childcare will be available for children affected by Costello syndrome and their siblings ages 1-17 years. Camp Ras cannot accept children under 12 months of age. Childcare is specifically provided so adults may attend the sessions on Thursday (western-themed activities) and Saturday (art-themed activities), so we expect to be able to find you in the sessions should an issue arise in Camp Ras with your child. *Please note that children are not permitted in the meeting rooms in consideration of the attendees.* Some parents bring along a relative or switch off with their spouse to care for their child if you are unable to register with Camp Ras. Parents will be responsible for administering medicines and/or tube feedings. *It is very important that you drop off and pick up your children on time each day to avoid a late fee.*



All children must be pre-registered, and payment made for childcare by **June 11, 2023**. The fee is \$70 per child for two days, which is only a small portion of the actual cost of childcare. The fee is the same whether you attend one or both days and is non-refundable. *Please note that there may not be room for last-minute on-site registration for Camp Ras.*

CS Lounge The always popular Costello Lounge will be available again this year for adults with Costello syndrome who are at least 18 years old at the time of the conference. It will be open on Wednesday afternoon and all day on Thursday. Lara Weeks, who has volunteered as the CS Lounge Director for the past 4 conferences, is returning along with Wanda McKenzie who has worked previous conferences. Parents and caregivers are asked to volunteer 2-3 hours while it is open. We cannot provide one-on-one care in the CS Lounge. The registration fee is \$50 per adult and is non-refundable. There is a CS Lounge registration form on our website that should be completed and returned as indicated on the form. Lara Weeks will be collecting registrations and scheduling parent volunteers. The deadline to register is **June 11, 2023**.



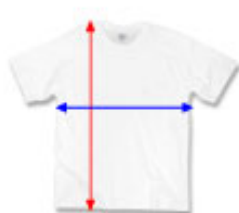
T-SHIRTS



Conference T-shirts Navy blue short-sleeved conference T-shirts have been designed by Jenny Polk; her fabulous design will be on the back of the shirt with the CSFN logo on the front. Free t-shirts (up to limit of 5) for the individual with Costello syndrome, parents/guardians and siblings may be selected at Registration. Additional shirts may be purchased in the online Registration.

The Youth and Adult shirts come in sizes Youth XS (6-8) through adult 3XL and are a 50/50 blend. The crew neck toddler shirts come in sizes 2T through 5/6T and are 4.5 oz. 100% combed ringspun cotton. See below for sizing.

garment measurements (inches)



	YXS (2-4)	YS (6-8)	YM (10-12)	YL (14-16)	S	M	L	XL	2XL	3XL	4XL	5XL
length	18	20.5	22	23.5	27.5	28.5	29.5	30.5	31.5	32.5	33.5	34.5
width	14	16	17	18	18	20	22	24	26	28	30	32

length
(shoulder seam at collar to bottom hem)

width
(side to side at 1" below the sleeves)

Order deadline for T-shirts: **June 21, 2023.**



FINANCIAL ASSISTANCE

Scholarships A limited number of scholarships are available to help with conference costs, made possible by the Nicholas Spinnell Fund, the Makenzie Belanger Scholarship Fund, and the Virginia Proud Scholarship Fund. To learn more about these opportunities, download the application form on our website or from our newsletters. Deadline to apply is **May 20, 2023.**



AWARDS

CSFN is pleased to continue with the two awards from the last conference.

The ***Sibling Champion Award*** will recognize the sibling of a person with Costello syndrome. Nominees should be siblings who show the world how wonderful their brother or sister with Costello syndrome is.

The ***Costello Syndrome Ambassador Award*** will recognize a person with Costello syndrome who raises awareness about Costello syndrome and exemplifies the possibilities.

Anyone with personal knowledge of the nominee - such as a parent, caregiver, relative, coworker or friend - can submit a nomination. There are no age limitations for the nominees. If you are interested in submitting a nomination, this is what you need to send:

- Name of nominee
- Nominee's birthdate
- Name of the award (Costello Syndrome Ambassador or Sibling Champion)
- A brief story (150-300 words) about why you are nominating this person
- Your name and contact information
- A photo of the person being nominated.

Please submit nominations to award@costellosyndromeusa.org or mail to Sandra Taylor, 159 Settings Blvd., Black Mountain, NC 28711. The deadline to submit is *May 1, 2023*. Awards will be announced at the CS Rare Roundup on Saturday night.

