



## 11<sup>th</sup> International Costello Syndrome Family Conference

### CONFERENCE PLANNING PACKET

**Delta Hotels by Marriott Baltimore Hunt Valley**  
245 Shawan Road  
Hunt Valley, Maryland 21031  
410.785.7000

We are so excited that our next family conference is almost here! It has been 20 years since that first conference in 1999 in Birmingham, Alabama, where 18 families gathered; that number grew to 65 families at our 10<sup>th</sup> conference in Orlando in 2017. New families attending the conference say it is a “life-changing experience” for them. Families returning call it their “second family” or their “family reunion”. This year will be another great conference with the theme of “TEAM COSTELLO” and we can’t wait for you to arrive.

This packet was prepared to help prepare you for the conference and 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!



*Orlando, FL 2017*

## MARK YOUR CALENDAR

April 30, 2019	•Deadline for funds to be <b>received by CSFN</b> to count toward this conference
May 2, 2019	•Deadline to submit nominations for the Costello Syndrome Ambassador Award and the Sibling Champion Award
May 20, 2019	•Deadline to submit scholarship application & attachments
May 26, 2019	•5:00pm ET Deadline for Early Bird Registration
June 10, 2019	•Deadline to order Caps, Visors and Stephanie Nimmo's books
June 22, 2019	•Deadline to send in your completed RARE Bear request
June 28, 2019	•5:00pm ET Deadline for Conference, Camp Ras and CS Lounge Registration, including full payment •Discounted hotel rates end
July 15, 2019	•Deadline to cancel registration for Conference registration 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 "Tailgate Party" with a sports theme so plan to wear those jerseys, t-shirts, cheerleader outfits, or whatever represents your favorite team in any sport. The most important thing is to dress casually and comfortably and have fun during our last evening together!



### **Transportation**

**Airport** The closest airport is Baltimore/Washington International Thurgood Marshall Airport or BWI. To take advantage of the discounted shuttle to the hotel (SuperShuttle), you will need to fly in and out of BWI.

**Transferring to and from the hotel** It is about 30-35 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 SuperShuttle.

**Car rentals** If you choose to rent a car, many companies are available at the airport. Parking at the hotel is complimentary. Bring your own car seat for Uber and Lyft for children who require one.

**Uber** The Uber rates fluctuate by the hour and demand. To give an idea of cost, a trip from the hotel to the airport on April 7, 2018 cost \$47.06 plus tip.



SuperShuttle has set up a link with discounted rates on their buses/vans/cars. Log in to see the rates and options. Discounted rates of 10% off all rides except 12% off exclusive vans are available July 28 – August 7, 2019.

- Log in: <https://group.supershuttle.com/group-page/11th-international-costello-syndrome-family-network/>
- On the first page, be sure to enter **Delta Hotels Baltimore Hunt Valley, Shawan Road, Hunt Valley, MD, USA** as your drop-off location. This hotel may not be available on the dropdown list so you would need to type it in.
- If you want to schedule your return trip, slide the No to Yes at the bottom of the page.
- Discount Code Y9VSX



## Hotel

Delta Hotels Baltimore Hunt Valley  
245 Shawan Road  
Hunt Valley, MD 21031  
410-785-7000

[www.Marriott.com/BWIDH](http://www.Marriott.com/BWIDH)

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 \$129/night plus 14% tax (\$147.06). There are Executive King rooms available for an additional \$10 but they are the same size as the King rooms; the only difference is that you have a chaise lounge instead of a chair. These rates are available July 25 through August 10, 2019. 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 28, 2019.** Please reserve your room as soon as possible by going online:

<https://www.marriott.com/event-reservations/reservation-link.mi?id=1546625831363&key=GRP&app=resvlink>

**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** Refrigerator, wireless high-speed internet, hair dryer, alarm clock, iron and ironing board, safe, coffee maker/tea service, phone, cable tv with pay-per-view.



**Hotel Amenities** include a fitness center, Sundry/convenience store, business center, indoor and outdoor pool. There is a café for coffee and morning snacks, a lounge and bar, and a full-service restaurant (with fabulous crab cakes). Room service is available.

Please visit the hotel website listed above for more information.

**Microwaves** - The hotel has a very limited number of microwaves but we are working to have one or two placed so they will be accessible to families who need to warm food for tube feedings.

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

**Laundry** There is a self-serve laundry at the hotel on the first floor behind the elevator.

**Hotel Shuttle** Complimentary hotel shuttle is available within a 3-miles radius of the hotel 6:30am – 9:00pm. Should you need a shuttle, please check with the front desk.

**Parking** Parking is complimentary at the hotel.

**What's near the hotel?** Within walking distance behind the hotel and across the parking lot is a Texas Roadhouse restaurant. Across a four-lane, divided highway and down a bit is the Hunt Valley Town Centre with many shops, restaurants, grocery store (Wegman's); it is unsafe to try to walk across the busy highway, but the hotel shuttle will take you over and pick you up during the hours it operates.



## Shipping

If you need to ship medical supplies or food to the hotel, the hotel has waived their fee specifically for these items. You should ship to arrive just a day or two before your check-in date. Packages should be addressed to:

11<sup>th</sup> International Costello Syndrome Family Conference  
Attn: [Your Name]  
Delta Marriott Hunt Valley  
245 Shawan Road  
Hunt Valley, MD 21031 USA



## CONFERENCE REGISTRATION

### Conference Registration

The link for *families* to register for the conference is: <http://www.rsvpbook.com/Costello2019Baltimore>

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 purchase TEAM COSTELLO t-shirts, caps and visors to be delivered at the conference. You may also purchase CS Parent Stephanie Nimmo's books. 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 26, 2019**

5 years and under- Free	6-12 years old - \$55
13 years & older - \$120	Person w/CS - Free

*Regular Registration* – Ends 5:00pm Eastern Time on **June 28, 2019**

5 years and under- Free	6-12 years old - \$85
13 years and older - \$180	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](mailto:sandra@costellosyndromeusa.org) or 850-832-4055 Central Time. Families with a new diagnosis of Costello syndrome after the deadline should contact Sandra Taylor to inquire about late registration.



### Conference Information

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

#### Tuesday, July 30, 2019

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

3:00pm – 6:00pm	Registration/Help Desk open to pick up your packets/drop off Silent Auction items
8:00pm – 9:00pm	Registration desk re-opens
5:30pm – 6:00pm	Non-denominational Prayer Service

#### Wednesday, July 31, 2019 – Welcome/Sharing Day

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7:00am – 8:15am	BREAKFAST BUFFET
8:00am – 2:00pm	Registration/Help Desk open
8:30am – 9:30am	New Family Orientation

5 Questions? Contact Sandra Taylor, CSFN Executive Director – [sandra@CostelloSyndromeUSA.org](mailto:sandra@CostelloSyndromeUSA.org) or 850-832-4055  
[www.CostelloSyndromeUSA.org](http://www.CostelloSyndromeUSA.org)

### **Continuation of Wednesday, July 31, 2019 – Welcome/Sharing Day**

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9:30am – 12:15pm	“Sibling Time” workshops (ages 7-17)
10:00am – 11:15am	Welcome, Announcements, Awards, Registration packets available
11:30am – 12:30pm	LUNCH BUFFET
12:30pm – 1:00pm	Drop off children at Camp Ras and CS Lounge
1:00pm – 1:15pm	Preview of Communication Skills Study – Dr. Heather Thompson
1:15pm – 1:45pm	How to Tell Others about Costello Syndrome/Advocacy – Ellyn Farrelly
1:30pm – 5:30pm	Dr. Heather Thompson’s Communication Study, by appointment
1:45pm – 2:15pm	Living on Your Own/Being an Advocate – Cherie Takemoto/Pete Scampavia
2:15pm – 3:15pm	Genetic Mutation Round Table Discussions
3:30pm – 4:00pm	“Was This in the Plan?” – Stephanie Nimmo
4:15pm – 4:45pm	Remembrance Service
5:00pm - 5:30pm	Pick up from Camp Ras and CS Lounge by 5:30pm
5:30pm – 7:00pm	DINNER BUFFET
7:00pm until...	Book signing with Stephanie Nimmo
7:30pm – 10:30pm	Moms’ Mix & Mingle (adult social time for Caregivers)

### **Thursday, August 1, 2019 – Learning Day**

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7:00am – 8:15am	BREAKFAST BUFFET
8:00am	Camp Ras & CS Lounge Open
8:00am – 2:00pm	Registration/Help Desk Open
8:00am – 12:00pm	Dr. Heather Thompson’s Communication Study, by appointment
8:30am – 11:30am	Medical Lectures
11:30am – 11:45am	Pick up from Camp Ras & CS Lounge by 11:45am
11:30am – 12:45pm	LUNCH BUFFET
12:45pm	Camp Ras & CS Lounge Open
1:00pm – 3:15pm	Medical Lectures
1:00pm – 5:00pm	Dr. Heather Thompson’s Communication Study, by appointment
3:30pm – 4:15pm	“Ask the Docs” – your chance to ask any remaining questions about CS
4:15pm – 4:30pm	Pick up from Camp Ras & CS Lounge by 4:30pm
5:00pm – 6:00pm	Work Group with Dr. Dawn Siegel (by appointment)
	DINNER ON YOUR OWN
7:30pm – 10:30pm	Dads’ Man Cave (adult social time for Caregivers)

### **Friday, August 2, 2019 – Giving Day**

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7:00am – 8:15am	BREAKFAST BUFFET
8:00am – 12:00pm	Dr. Heather Thompson’s Communication Study, by appointment
8:30am – 2:00pm	Registration/Help Desk Open
8:00am – 12:00pm	Research Stations and Appointments with the Experts
11:45am – 1:15pm	LUNCH BUFFET
1:00pm – 5:00pm	Research Stations and Appointments with the Experts
1:00pm – 5:00pm	Dr. Heather Thompson’s Communication Study, by appointment
	DINNER ON YOUR OWN

## Saturday, August 3, 2019 – Family Fun Day

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7:30am – 8:30am	BREAKFAST BUFFET
8:00am – 12:00pm	Dr. Heather Thompson’s Communication Study, by appointment
9:00am – 12:00pm	Fun Family Activities – Art & Face Painting, Create a Shaker/Games, Photo Booth, Trivia
9:30am – 9:30pm	Pool open LUNCH ON YOUR OWN
1:00pm – 3:00pm	Dr. Heather Thompson’s Communication Study, by appointment
4:30pm – 6:00pm	Silent Auction; Raffle tickets available for Coates Quilt
5:45pm – 8:45pm	TAILGATE PARTY – dinner & dancing

## Sunday, August 4, 2019 – Wrap-up

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10:30am – 11:00am	Town Hall Meeting
12:30pm – 1:30pm	Scientific Symposium Summary

**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, Awards on Wednesday morning** Registration packets will be available for anyone who has not picked theirs up the night before. We will be welcoming all our families, making announcements, recognizing fundraisers, and giving out awards.

**Siblings Only** This event is exclusively for siblings of individuals with Costello syndrome. There will be two rooms for these activities: one is for ages 7-11 and one is 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 their own private lunch. 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 you select. 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 Silent Auction***

For this event, families provide new or handmade items that represent or are unique to where they live, or perhaps something made especially for this event – a one-of-a-kind item. These items are displayed with a sheet to place your bid and bidding is open until the posted closing time. Winners will be posted during the dance time and you can claim and pay for your item then. There may also be a few instances where multiples of the same item are brought in and sold during the Silent Auction.

Items for the silent auction may be dropped off at the registration desk where you will need to complete a form that includes the starting price for the bidding sheet. Committee volunteers will handle the sale and collection of funds unless special arrangements are made in advance with Bob Hefner. Due to IRS regulations, families may not do personal fundraising at the conference. If you have questions, please contact Bob Hefner at [bob@CostelloSyndromeUSA.org](mailto:bob@CostelloSyndromeUSA.org) or Sandra Taylor at [sandra@CostelloSyndromeUSA.org](mailto:sandra@CostelloSyndromeUSA.org).

*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. This fabulous quilt will be displayed throughout the conference and raffle tickets may be purchased whenever the Registration/Help Desk is open. The winning ticket will be drawn at the Tailgate Party.

***Saturday Night Tailgate Party*** The evening starts with a meal served “tailgate style”. With the theme of “Team Costello”, wear your favorite sports attire and have fun on this last evening together. The winners of the Silent Auction will be posted, and we’ll have the drawing for the Coates Quilt, a beautiful handmade quilt sewn with love just for your conference.

Due to space limitations, we are not currently offering extra tickets for extra friends and families to attend who are not registering for the conference. If we are able to open up some seats for extra guests, you will be notified and you will be able to go back in and register your guests and pay for their tickets.

***Sunday*** There will be a Town Hall meeting at 10:30am for a brief review of the conference. You are encouraged to come and ask any questions you may have about the conference or to give comments or suggestions on how to improve the next conference. Your input is valuable for planning the next conference.

The Symposium Summary led by several of our doctors will take place around 12:30 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 child care 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 Wednesday afternoon (art-themed activities) and Thursday (sports-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 28, 2019**. The fee is \$55 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 3 conferences, is returning along with Bess Hooks and Wanda McKenzie who have 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 \$30 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. Mary Ernst will be collecting registrations and scheduling parent volunteers. The deadline to register is **June 28, 2019**.



## CONFERENCE GEAR!

**Conference T-shirts** Red Conference T-shirts designed by one of our parents, Jenny Polk, will be available for purchase when you register online for the conference. Registered conference attendees with Costello syndrome will receive a free conference t-shirt; size selection can be made in the on-line registration.



The high V-neck Youth and Adult shirts (above) come in sizes Youth S (6-8) through adult 3XL and are a 4.8 oz. poly/cotton blend. The crew neck toddler shirts (on the right) come in sizes 2T through 5/6T and are 4.5 oz. 100% combed ring-spun cotton. Printing on the back is the same as the adult. Order deadline for T-shirts: **June 28, 2019.**



**Ball caps & Visors** Royal blue TEAM COSTELLO unstructured ball caps and visors are 100% cotton twill with an adjustable Velcro back. Each will have TEAM COSTELLO embroidered on the front in white. Registered conference attendees with Costello syndrome attending the conference will receive a free cap or visor; you may make your selection on your registration. All sizes \$10 each.

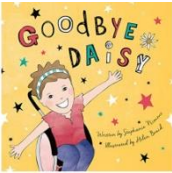
*Please note that everyone attending the conference who wants to order any of these items should purchase them through their online registration. All items will be shipped to the conference and you will pick them up in your packet at registration. There will be a separate link posted on the CSFN website for anyone who cannot attend and wants Conference Gear, and this will include a credit card/postage fee. Items will be shipped after the conference. Order deadline for ball caps and visors: **June 10, 2019.***

## **BOOKS BY STEPHANIE NIMMO**

On Wednesday afternoon, Stephanie Nimmo will be inspiring us by sharing her story about coping with the day-to-day challenges of caring for her daughter Daisy diagnosed with Costello syndrome and blending that with the needs of her other three children and husband. She has written two books which she is making available to you at a reduced rate and you can purchase them in your online registration. She will be signing books and talking with families Wednesday evening. If you have already purchased one or both books, bring them with you if you'd like Stephanie to autograph them.



Far from being a misery memoir, *Was This in the Plan?* is a frank, open and no-holds-barred account of how a family was determined not just to survive but to thrive when the odds were against them. It will make you question your own attitude to life and how you choose to respond when unexpected events throw you off course.



Stephanie's daughter Daisy was born with a rare, life-limiting, genetic disorder. Very few resources exist to help children, especially children who are non-verbal or learning-disabled, understand and communicate their feelings around death and dying. *Goodbye Daisy* is written in Daisy's honour to help others.

Stephanie will also be speaking at the Scientific Symposium on Saturday, August 3 from 12:20 to 1:20pm. RASopathiesNet invites you to register on their website if you want to attend. There is a small fee for lunch. RASopathiesNet registration page: <https://rasopathiesnet.org/2019-symposium-registration/>

## RARE BEARS



The Costello Syndrome Family Network has partnered with RARE Science to bring awareness and support to children affected by Costello syndrome and the resulting neurocognitive delays and impaired learning, through the RARE Bear Program. They will be gifting RARE Bears to families attending the conference (one per family).

RARE Bears are made from remnant fabric, making each bear one of a kind just like our one-of-a-kind rare kids! Your RARE Bear will be available at the Registration/Help Desk on Family Fun Day on Saturday morning, August 3, 2019.

To enroll in the RARE Bear Program and to request a RARE Bear for your child, you will need to complete the form through a link that will be available around **May 25, 2019** on the CSFN website conference page. The information on the form will be kept confidential and will guide them to match a handmade RARE Bear with your child. All requests must be received by **June 22, 2019**.

To read more about the RARE Science and RARE Bear Program, visit their website at <https://www.rarescience.org/rare-bear-program-faq/>



## **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. Deadline to apply is **May 20, 2019**.



## 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](mailto:award@costellosyndromeusa.org) or mail to Sandra Taylor, 1702 Tyndall Drive, Panama City, FL 32401. The deadline to submit is *May 2, 2019*. Awards will be announced at the Welcome event on Wednesday morning at the conference in Hunt Valley, Maryland.