



10th International Costello Syndrome Family Conference
July 25-30, 2017
Renaissance Orlando at SeaWorld
6677 Sea Harbor Drive, Orlando, FL 32821 USA

Attending the Conference – What You Need to Know

Thank you for your interest in attending the 10th International Costello Syndrome Family Conference at the Renaissance Orlando at SeaWorld from July 25-30, 2017. This information is provided to assist you in planning your trip. Contact information for the people mentioned in this document are available at the end.



DEADLINES

May 2, 2017	<ul style="list-style-type: none">•Cutoff for donations to apply to incentives (postmarked mail or posted in FirstGiving)•Deadline to submit nominations for the Costello Syndrome Ambassador and the Sibling Champion Award
May 28, 2017 (5pm ET)	<ul style="list-style-type: none">•Early Bird Registration ends•Deadline to submit scholarship application & attachments
June 25, 2017 (5pm ET)	<ul style="list-style-type: none">•Registration (conference, Camp Ras and CS Lounge) must be completed by this date, including payment
June 30, 2017	<ul style="list-style-type: none">•Discounted hotel rates end
July 10, 2017 (5pm ET)	<ul style="list-style-type: none">•Deadline to cancel conference registration for refund•Deadline to register for SeaWorld Family Trip or cancel for refund



WHAT TO PACK

Orlando Weather July is hot and humid with rain showers often occurring in the afternoon. The average high temperature is 92°F (29°C) and the average low temperature is 72°F (17°C).

Proper Attire for the Conference 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 areas, pack a swimsuit, cover-up, sunscreen, sunglasses, and perhaps a hat!

The Saturday night banquet will have a luau theme and casual Hawaiian dress will be appropriate. A Hawaiian or colorful shirt with khaki pants or nice jeans are a good choice for men, and women may want to wear a colorful or floral sundress (long or short), muumuu's or top with slacks. Children may dress similarly, and flip-flops or sandals are fine, if they like. We plan to have grass skirts for the children to wear over their clothes, leis for everyone, and flowers to

accessorize your outfit. Shell jewelry is very acceptable! The most important thing is to dress casually and comfortably and have fun during our last evening together!



TRANSPORTATION

Airport It is recommended that guests fly into Orlando International Airport (MCO), which is 13 miles from the Renaissance Hotel.

Traveling between the Orlando airport and the Renaissance Hotel The hotel does not provide a shuttle to and from the airport; however, there are other options.

Taxi According to the hotel, a one-way taxi ride will cost approximately \$37-40. Uber is available but may not be as reliable.

Bus This option is low cost, but you'll have a bit of a walk with your luggage from the bus stop at Sea World to the hotel. The Lynx Bus No. 111 is about a 40 to 50-minute ride from the airport to SeaWorld and stops very close to our hotel.

Link to Schedule: http://www.golynx.com/maps-schedules/routes-detail.html?portalProcess_dd_0_1_1=showPublicPosting&calendar_entry_id=3392

Link to map: (The hotel is the pushpin right above time stop #1)
<http://www.golynx.com/lynxmap/PublishedMaps/AerialAndMap/Route%20111.pdf>

Fixed Route Single Ride Standard Pass is \$2/person. <http://www.golynx.com/buy-tickets/>

SuperShuttle: A discounted fare is available with SuperShuttle for a shared-ride van. Sample round trip fares: 1 passenger \$36; 3 passengers \$108. You must **book online in advance** using the link below. They can accommodate wheelchairs, but tell them in advance. Here are their instructions to take advantage of the discount. Just keep going through the screens to complete the round trip.

Link: <http://www.supershuttle.com/default.aspx?GC=85U86>

GROUP: Costello Syndrome Family Conference

HOTEL: Renaissance – Orlando Resort (Renaissance Sea World, 6677 Sea Harbor Dr., Orlando)

DISCOUNT CODE: 85U86

DISCOUNT VALID DATES: July 20 through August 4, 2017

ARRIVAL PROCEDURES: SuperShuttle Shared Ride – Reservations must have been made in advance. After collecting your luggage, you must call 1 (407) 513-0230 to notify local dispatch of your arrival and coordinate pick-up.

RESERVATIONS: For special reservation *questions* call 1-800 BLUE VAN (800-258-3826) or customer service, available 24/7. Please note that if you call in your reservation instead of booking and paying online with your discount code, then your discount is not valid and a \$3 call center fee applies.

DISCOUNT: Your discount gives you 10% off one-way and round-trip shared ride reservations made online. Discount does not apply to private ExecuCar vehicles, or exclusive vans (which are already discounted).

Rental Cars Rental cars are available at the airport. They are also available at the Renaissance through Hertz, phone +1-407-351-4900. There is a Budget car rental nearby at 8978 International Drive, Orlando, FL, phone +1-407-363-9890.

Parking at the Hotel The self-parking rate is \$10 (includes tax) per day per vehicle (reduced from \$22 per day) if you are staying at the hotel for our event. If you are not staying at the hotel, the rate is \$11 (includes tax) per day per vehicle and you will pay at the parking lot. If you prefer, daily valet parking is available for \$32 overnight or \$27 per daytime hours. All guests driving hybrid cars receive complimentary valet parking.

Local public transportation near the Hotel The I-RIDE Trolley information, including maps and fares, is available online at <http://www.iritrolley.com/maps.asp> Red Line Stop 32 is near the Renaissance Hotel—ask the desk for directions. If you take the trolley, be aware that it has many, many stops along the way and it will take some time to get to your destination.



HOTEL

Check-in Time: 4:00pm
Check-out Time: 11:00am



Website <http://www.marriott.com/hotels/travel/mcosr-renaissance-orlando-at-seaworld/>

Guest Room Rates CSFN has contracted with the Renaissance for a block of double Queen rooms and King rooms at the rate of \$125/night plus 12.5% tax (\$140.63 total per night). These discounted rates are available from 7/22/17 through 7/31/17, and there are plenty of rooms in our block! All reservations must be accompanied by a first night room deposit or 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 30, 2017.** Please reserve your room as soon as possible by going online:

<https://resweb.passkey.com/go/CostelloSyndromeFamilyForum>

Should you wish to make a phone reservation, please call the Group Reservations phone number, 1-407-351-5555 or 1-800-266-9432, and refer to 10th International Costello Syndrome Family Conference.

Optional Daily Resort Fee The negotiated room rate does not include the hotel daily Resort Fee of \$25 per room per night, plus 6.5% tax. This is offered to you as an optional upgrade upon check-in and not associated with the CSFN contract with the hotel. Please refer to the Renaissance website for details on what the Resort Fee covers.

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 the busy schedule is a definite plus. The schedule is packed and you will find it is much more convenient. 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 lower our overall costs.

Guest Rooms Refer to the Renaissance website for details. Rooms come with a flat screen TV, alarm clock, safe, iron, ironing board, a coffeemaker with coffee and tea, hair dryer, telephone with voicemail, and a mini-refrigerator.

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 feedings.

Rollaway Beds and Cribs Complimentary (limited supply). Double Queen rooms and King rooms both allow 1 rollaway and 1 crib and a total of 5 guests per room.

Gathering Areas The atrium is newly updated, and there are many seating areas to gather and visit.

Internet Service Complimentary Wi-Fi is available in the public areas of the hotel, poolside and in your room. Be sure to review your statement on checkout to confirm that you have not been charged for service in your room.

Coin Laundry Self-service coin-operated washers and dryers are located on the Atrium Level. Laundry detergent is available in coin operated vending machines.



Pools There is a large outdoor pool with chairs, umbrellas, and hot tub. There are also two water play areas for the children complete with waterslide and water jets.

Pools are open from dawn to dusk. If there is rain, the pool often must be closed for a short period to check and adjust the chemicals.



On-Site Recreation Electronic games are available in Shamu's Game Room, and there is foosball and table tennis near the pool area.



The **Fitness Center** has cardiovascular equipment, free weights and state-of-the-art life fitness machines with televisions. It is located on the main level.

The **Neu Lotus Spa** offers manicures, pedicures and massages.



Activities Close to the Renaissance Before or After the Conference The Renaissance is right across the parking lot from SeaWorld. Orlando has many amusement and water parks including nearby Discovery Cove, Disney World and Universal. You can ride the I-Trolley up and down International Drive where there are many shops, restaurants and a discount mall. And of course, there are several golf courses.



DINING

Meals Included in Your Conference Registration

Tuesday – Breakfast

Wednesday – Picnic Dinner in the Atrium

Thursday – Breakfast & Lunch

Friday – Breakfast, Lunch & Desserts at the evening poster session

Saturday -Breakfast, Lunch & Luau Banquet

The new “Siblings Only! Pizza Party” starts at 10:45am and is for siblings of individuals affected by Costello syndrome. There will be two age groups, tentatively Group 1- Ages 7-11 and Group 2-Ages 12-17. Space may be limited. There will be fun activities, a pizza party for lunch and maybe a surprise or two. Attendees should wear shorts/pants (no dresses).

All families who are attending the conference for the first time should attend the New Family Orientation in early afternoon. The Registration/Welcome Reception begins in the Discovery Ballroom at 4:00pm followed by a “picnic in the Atrium” (near the exit to the pool area). You may dine in the atrium or take your plate to the pool area to relax and mingle with the other families.

Research/Meet the Experts Day on Friday Detailed information will be sent to you by email after you register for the conference. There may be certain items the researchers request that you bring with you. One of those items is copies of the report which confirms your child has Costello syndrome and the mutation, if possible. A few changes have been made to make the day run more smoothly. This is a busy, hectic day so please be patient as we try to fit in the appointments each family has requested. More to come on this!

Craft Fair, Silent Auction and Raffles It is fun to see what our families bring from all over the world for these events! All monies raised from these on-site fundraisers will go to CSFN to help defray the Conference expenses.

The craft fair on Friday night from 7:30pm-8:30pm is a wonderful shopping experience created by the items you bring. This is usually a selection of multiple items of the same type; some are handmade, some are personally designed, and some are purchased.

On Saturday night, families provide 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 placed on tables, tickets are sold and families drop the stubs in the bags stationed by the items they hope to win. Winners will be posted on a big screen during the dance portion of the evening.

Cathy Coates is putting together another fabulous 2017 Conference Handmade Quilt as a raffle fundraiser. It will be difficult to surpass the design and creativity of Cathy’s last two quilts, but it will undoubtedly be spectacular. Tickets will be sold at the Craft Fair and at the Luau Banquet.

Items for the craft fair, raffle or silent auction may be dropped off with a completed form at the registration table or taken to the CS Lounge Parlor suite (TBD). If you do not indicate a price on the form, we will price it for you. Committee volunteers will handle the sale and collection of funds unless special arrangements are made in advance with Raileen Eaton. Due to IRS regulations, families may not do personal fundraising at the conference. If you have questions about any of these events, please contact Raileen or Sandra.

Saturday Night Family Luau Banquet The evening starts with a delicious luau buffet dinner followed by ticket sales for the raffle, silent auction and quilt. The winner of the Coates handmade Costello quilt will be announced. There will be a DJ for dancing and who knows--we may even wear grass skirts, leis and do the hula! Pack your colorful Hawaiian attire for this event. (See “What to Wear at the Conference” on page one for more details.)



A limited number of extra tickets for this single event are available for purchase when you register for the conference online. The cost for extra tickets will be \$40 for adults and \$20 for children under 13 years of age. This is included on the registration form.

Sunday There will be a Town Hall meeting at 10:30am for a brief overview of conference events and costs. You are encouraged to come and ask any questions you may have about the conference including the budget or to give comments or suggestions on how to improve the next conference. The Symposium Summary by Drs. Gripp, Kerr and Stevenson will take place at 12:40 after the end of the Symposium.



CAMP RAS & CS LOUNGE

Camp Ras Professional child care will be available for toddlers through age 17 for children affected by Costello syndrome and their siblings. Camp Ras cannot accept children under 12 months of age. This childcare is available while adults attend the sessions on Thursday and Saturday. Parents must be attending the CS sessions on Thursday and Saturday to utilize child care services—we will know where to find you in case we need you in 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.* Please note that children are not permitted in the meeting rooms in consideration of the attendees. Many 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.



All children must be pre-registered and payment made for childcare by June 25, 2017. 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 will be no last minute on-site registration for Camp RAS.*

CS Lounge The ever-popular Costello Lounge will be available again this year for those who are at least 18 years of age at the time of the conference and have been diagnosed with Costello syndrome. Lara Weeks, a schoolteacher who has volunteered as the CS Lounge Manager for the past 2 conferences, is returning! She will plan activities and attendees can bring movies and games. 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 25, 2017.



CONFERENCE REGISTRATION

Conference Registration

The registration form will be available through a link on the CSFN website sometime in March. You will register and pay fees online, though separate registrations will be required for Camp Ras and the CS Lounge. These will be provided to you after you register. CSFN makes every effort to make it economically feasible for our families to attend the conference, and the registration fee covers only a very small portion of the costs.

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 – Registration and payment must be submitted online **by 5:00pm Eastern Time on May 28, 2017**

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

Regular Registration – Registration and payment submitted online **after 5:00pm Eastern Time on May 28, 2017**

5 years and under	Free
6-12 years old	\$85
13 years and older	\$180
Person w/CS	Free

The deadline to Register is June 25, 2017. 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.



FINANCIAL ASSISTANCE

FirstGiving Many families are successful in fundraising for CSFN by setting up a FirstGiving page and sharing it with friends, family and co-workers. Directions on how to create your own FirstGiving page are posted on our website under the tab, Support CSFN:

http://costellosyndromeusa.com/wpmain/wp-content/uploads/2014/02/FirstGiving_Page_Directions_Feb_2017.pdf

If you need assistance or have questions, contact Angel Thomas.

If you want to know your CSFN fundraising total since the last conference that will apply toward incentives, contact Sandra Taylor.

Scholarships A limited number of scholarships are available to help with conference costs and airfare. Please go to <http://costellosyndromeusa.com/conferences/> to download the application form which contains information about the different kinds of scholarships we have available. Deadline to apply is May 28, 2017.



NEW AWARDS

CSFN is pleased to announce two new awards. The Sibling Champion Award will recognize the sibling of a person with Costello syndrome.

The Costello Syndrome Ambassador Award This award will recognize a person with Costello syndrome. Nominees should be individuals with Costello syndrome who raise awareness about Costello syndrome and exemplify the possibilities.

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.

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 raileen@costellosyndromeusa.org. The deadline to submit is **May 2, 2017**. Awards will be announced at the conference in Orlando, Florida



T-SHIRTS

Awareness T-shirt: This should be available soon. The design is complete and we are working on having them made available for you to purchase.

Conference T-shirt We have a concept and are working to have it finalized. We will let you know as soon as they are available. All individuals diagnosed with Costello syndrome will receive a free conference t-shirt at the conference.



SCIENTIFIC SYMPOSIUM

5th International RASopathies Symposium: When Development and Cancer Intersect The scientific symposium overlaps the CS conference and is hosted by RASopathiesNet. This is a scientific meeting about all the RASopathies, including Costello syndrome. Sessions are presented by professionals to professionals. Except for the session with family presenters Saturday morning and the break-out session for the families Sunday, the language will be highly technical and may be difficult for non-scientifically-educated people to understand. Please read the following information carefully to understand about registration and attending sessions.

Symposium Registration Link: <https://rasopathiesnet.org/2017-symposium-registration/>

Childcare The Poster Session welcomes all family members. However, the Symposium does not offer child care during the scientific sessions.

Friday From 8pm to 10pm, you are invited to an informal Dessert and Scientific Poster Session open to all family members. Families, two from each of the four RASopathy syndrome groups, will present posters depicting the life of an individual with a RASopathy. Enjoy the desserts. Stop by the Costello syndrome posters to show your support and chat with our families. You will broaden your knowledge about Costello syndrome and our cousin syndromes by visiting all the poster presentations.

Saturday RASopathiesNet invites you to join the Symposium attendees from 12:00 to 1:00pm for Rick Guidotti's Symposium presentation, *Positive Exposure*. CSFN will have their usual lunch so you may choose which lunch you would like to attend. Please register for only one. There will be limited scholarships available to adults in all the syndromes attending the conference; there is no charge for children ages 12 and under. If you do not receive a scholarship, you will pay \$28 per adult to attend. **To attend this event, Costello families must complete the registration on the RASopathiesNet website at the above link under Symposium registration; you must select the Saturday "Lunch and Learn" event and can apply for the scholarship there.** If you have questions, please contact Lisa Schoyer at lschoyer@rasopathiesnet.org. Rick will also be taking photos of our children and families after the sessions end on Saturday around 4:30pm and at the Luau Banquet.

Sunday From 12:40 to 1:30pm, Dr. Gripp, Dr. Stevenson and Dr. Kerr will present a summary of the Scientific Symposium sessions in language we can understand. This is an informal session that is always very informative and interesting.



NEED TO CANCEL?

Cancellation Policies We hope you do not have to cancel but if you do, here are the policies.

- **Hotel Room** – Please cancel your room reservation directly with the hotel per their policy, at least 72 hours prior to arrival date.
- **Conference** - To receive a refund of your registration fee, less a \$25 processing fee, you must cancel no later than July 10, 2017 by notifying Sandra Taylor. It may take up to 60 days to receive your refund check but it will be issued as soon after the conference as possible.
- **Camp RAS and CS Lounge** – There is no refund for child care at Camp RAS or for the CS Lounge. Please notify Sandra Taylor if you need to cancel to assist in planning.
- **SeaWorld Family Trip** – SeaWorld will be paid in advance and we cannot offer refunds unless you cancel by July 10, 2017.



CONTACT INFORMATION

We are happy to provide information or assistance. The quickest way to receive a response is to email the contact person. We might miss your text or Facebook post.

Setting up FirstGiving Account for fundraising; information on family SeaWorld trip	Angel Thomas	Angel@CostelloSyndromeUSA.org
Flight Assistance	Tammy Moore	Tammy@CostelloSyndromeUSA.org
Craft Fair, Raffles, Silent Auction	Raileen Eaton	Raileen@CostelloSyndromeUSA.org
General Questions/information	Cherie Takemoto	Cherie@CostelloSyndromeUSA.org
Any conference or hotel questions, child care, CS Lounge, cancellations, fundraising totals	Sandra Taylor	Sandra@CostelloSyndromeUSA.org

