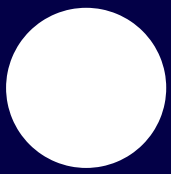




# FAMILY REGISTRATION GUIDEBOOK





# Are you ready for the time of your life?

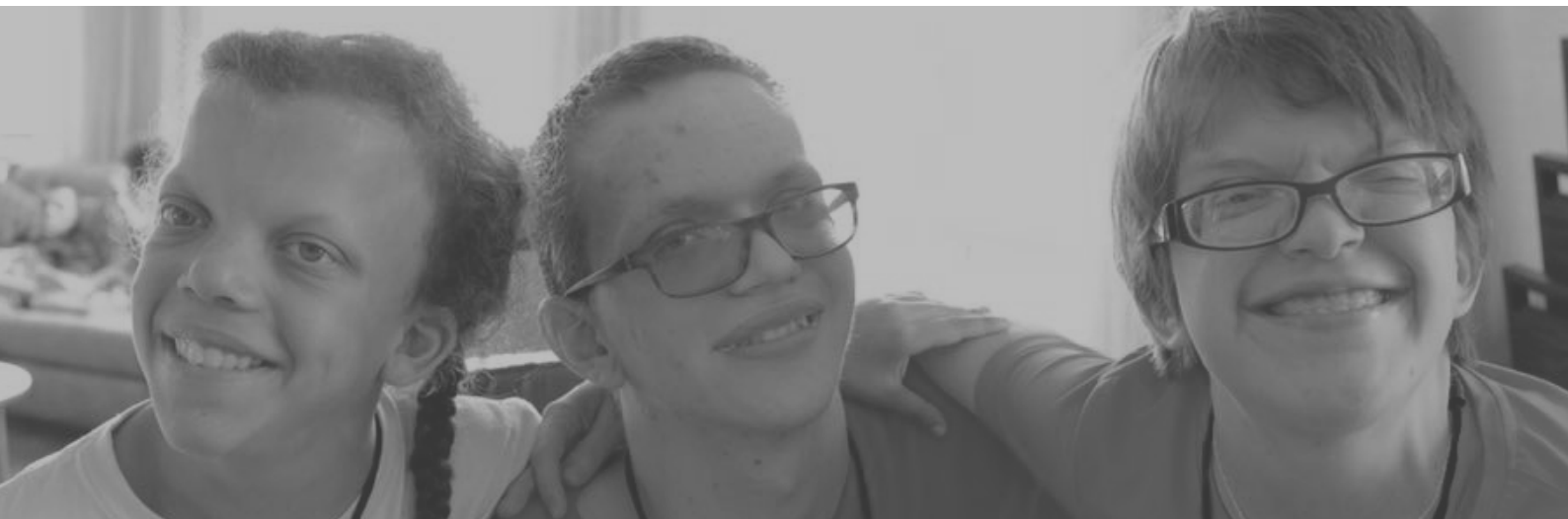
We're so excited to see you in July!

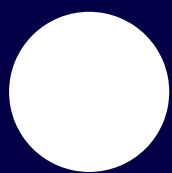
**This year's Family Medical Conference will kick off on July 10th and close with our Family Celebration on the evening of July 13th.**

In it's 10th year, the CFC Family Medical Conference is truly one of the most memorable events for our families. We are excited that you'll be experiencing the conference... whether it's your first time, or 10th time! This year is also the 20th Anniversary of CFC International, and we have so much in store for you, including our Family Celebration on Saturday, July 13th that we're sure will be magical.

The following booklet will help you prepare for a truly wonderful experience this year! Please take the time to read through this booklet, as many of your questions will be answered here. If you have questions beyond what's in this booklet, you may contact CFC International at [info@cfcsyndrome.org](mailto:info@cfcsyndrome.org).

We can't wait to see you in sunny Florida!





# CONFERENCE REGISTRATION INFO

This year, CFC International's families have worked hard to raise money that insures families and caregivers of individuals diagnosed with CFC Syndrome can attend the conference free of registration fees. We are expecting an increased number of registrations this year, so we are asking that you **register once you've confirmed your ability to travel to Tampa, Florida** and attend the conference. **If you register and do not attend, you may be taking an opportunity to attend away from another family. Registration cancellations must be received by May 31, 2019.** We understand that by the very nature of caring for someone with CFC Syndrome, last minute emergencies could occur, but please notify CFC International immediately.

**The following registrations for attendees are free:**

**-Adult/Child with CFC Syndrome**

**-Up to 2 Adult Caregivers**

**-Up to 3 Siblings in the Family**

This incentive applies ONLY to the immediate family or caregiver family of a child - living or deceased - diagnosed with CFC Syndrome. The adult registrations may apply to an immediate family member, caregiver, or other designated family member assisting with travel and care at the conference. For example, adult registrations may be used for a mom and her sister attending the conference with a child diagnosed with CFC Syndrome.

**Additional conference registrations or Family Celebration ticket may be purchased upon registration, at the following rates:**

Adult Registration Ages 13 and up: \$180/person

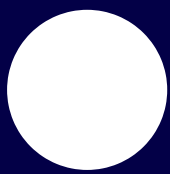
Children Ages 7 - 12: \$85/child

Children 6 and under, free (Please still include their information at registration.)

Adult Family Celebration Ticket (Ages 13 and up): \$50/person

Child Family Celebration Ticket: \$25/child

**DEADLINE FOR CONFERENCE REGISTRATION - MAY 31, 2019**



# CONFERENCE REGISTRATION INFO

## **ATTENDEE DIRECTORY RELEASE**

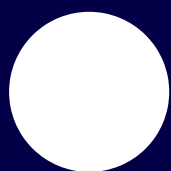
At each conference we compile a list of contact information for the families in attendance. All registrants will be included on the list unless they request removal before June 15, 2019. After this deadline, the contact list will be sent to print and no changes can be made.

## **RELEASE OF LIABILITY/USE OF PHOTOGRAPHS**

By registering for the conference, attendees waive, release and discharge all rights, actions, and claims which they or their heirs, executors, or assigns may have against CFC International or its officers, directors, staff, volunteers, representatives, successors, and assigns for death, injury, loss or any and all damages which the attendee or attendee's child sustains and/or suffers in connection with participation in this event. By registering for this conference, attendees grant permission to CFC International to use their or their child's photograph in legitimate accounts and promotional and educational materials. Attendees receive no compensation for the use of their or their child's photograph.







# CONFERENCE INFO

## LOCATION

The conference is located at the Grand Hyatt Tampa Bay, which is very conveniently located only 5 minutes from Tampa International Airport, International Plaza, Bay Street Dining and Entertainment area, and Westshore Mall. The hotel sits on 35 acres of tropical, waterfront property and includes 2 pools, jogging trails, a nature estuary, and a fitness center. A complimentary shuttle provides transportation to Bay Street, International Plaza, and Westshore mall.

All rooms contain one mini-refrigerator. Please contact CFC International if you require additional appliances to accommodate your child with CFC Syndrome's medical or nutritional needs. We will do the best that we can, but cannot guarantee all requests.

### **Hotel and Conference location address:**

**Grand Hyatt Tampa Bay**

**2900 Bayport Drive**

**Tampa, Florida 33607**

### **To book your reservation:**

**<https://www.hyatt.com/en-US/group-booking/TPARW/G-CFCI>**

**For assistance by phone, call 877-803-7534**

**CFC International Group Rate: \$139/night**

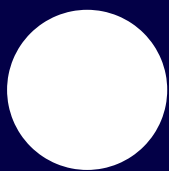
**Deadline to reserve hotel room at the group rate: June 10, 2019.**

Guest rooms must be guaranteed with a major credit card at the time of booking.

**The Tampa Bay area is full of exciting activities, from sports and beaches, to theme parks and museums. For more information about the area:**

[www.visittampabay.com](http://www.visittampabay.com)

[www.visitstpeteclearwater.com](http://www.visitstpeteclearwater.com)



# CONFERENCE INFO

## TRANSPORTATION

### **Tampa International Airport (TPA)**

A complimentary shuttle is available to and from Tampa International Airport (5 minutes away) departing the hotel every half hour or upon request for pick up. To request airport pick up, claim your checked bags and call the hotel at 813.874.1234. Exit the side doors for Ground Transportation closest to baggage belt Blue #7 or Red #9. Hours of transportation: 5:00 AM – 1:00 AM daily

Tampa Bay provides additional airports, such as St. Petersburg - Clearwater (PIE) Airport. Transportation from PIE is available by cab or ride sharing for \$15 - \$40.

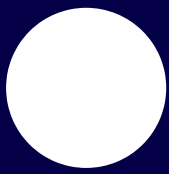
### **Driving**

Complimentary self-parking is available on-site at the Grand Hyatt Tampa Bay. Open surface lot parking is available for oversized vehicles. Please contact the hotel for requests for oversize parking. Valet parking is available at \$15 per day.

### **Amtrak Train**

The Amtrak bus station is located in downtown Tampa and connects Tampa Bay to Orlando. Taxi service to the Tampa station is \$26 each way.





# Schedule of Events

Wednesday, July 10, 2019\*

## **12 p.m. - 7:00 p.m. Registration Open**

Visit the registration desk to receive your name badges, t-shirts, goodie bags, and program.

## **5:30 p.m. - 6:30 p.m. Family Liaison Meeting** (For registered Liaisons only)

## **6:30 p.m. - 7 p.m. New Family Orientation**

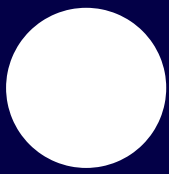
If this is your first time attending the Family Medical Conference, the New Family Orientation will give you an opportunity to meet other new families, talk with our family liaisons, meet with CFC International's Board Members and Staff, and gain information to get the most out of your first conference experience.

## **7:00 p.m. - 8 p.m. Welcome Reception (Desserts Only)**

After you get settled in and enjoy dinner on your own, join us as we kick-off the conference with fun, desserts, and refreshments. Everyone is welcome!

\*All meals on this day are on your own. We encourage families to enjoy dinner on their own prior to the Welcome Reception.





# Schedule of Events

## Thursday, July 11, 2019\*

### 8 a.m. - 7 p.m. Registration Open

### 8 a.m. - 4 p.m. Meet the Experts

We are fortunate to have clinicians and CFC Syndrome experts available at our conference. They will be sharing their knowledge on the topics you wish to discuss, so come prepared with your most important questions related to CFC Syndrome. Please bring medical records (not mandatory) in case you wish to share specific information about your child. Your Genetic Diagnostic report may be helpful as well. **All meetings are by pre-scheduled appointment only.**

#### Experts in the following specializations will be available:

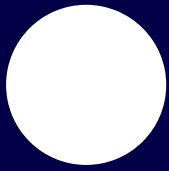
Genetics .	Gastroenterology .	Ophthalmology
Cardiology .	Dermatology	Neurology
Neuropsychology	Physical & Rehabilitative .	Immunology
	Medicine	

You will be able to schedule **three** sessions with experts. Availability may change. We will make every accommodation possible to meet your appointment time requests, but please be aware that some times slots could change. Please be sure to check your times when you receive your packet at onsite registration.

### 8 a.m. - 4 p.m. Research Stations

You will have the opportunity to participate in research that could transform the life of your child, as well as other children with CFC Syndrome. Research stations are not mandatory, but each research team will require that you review and sign a consent form before any research is conducted. Registered families will be notified of research opportunities at the end of June, prior to the conference.





# Schedule of Events

## Thursday, July 11, 2019\*

**Continued...**

### **8 a.m. - 4 p.m. Enroll in the CFC Registry**

Trained CFC International volunteers will be available to assist and answer questions from families interested in joining the CFC Registry, powered by Invitae. The CFC Registry is our best resource to advance research, treatment and diagnosis for individuals with CFC Syndrome.

### **3 p.m. - 4 p.m. CFC Volunteer Committee Meetings: Research, Technology, Fundraising**

### **4 p.m. - 6 p.m. Family Pool Party**

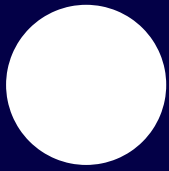
Join us at the Bayside Pool for a family fun afternoon.

### **7 p.m. - 10 p.m. Dad's Night Out**

Dad's plan for an offsite experience that's relaxing and fun, while you get to know fellow dads of children with CFC Syndrome.

\*All meals on this day are on your own. Refreshments and light fare will be served at Dad's Night Out.





# Schedule of Events

Friday, July 12, 2019\*

**7:00 a.m. - 5 p.m. Childcare Open**

**8 a.m. - 5 p.m. Registration Open**

**7 a.m. - 8:30 a.m. Breakfast (Please bring children for breakfast before they go to childcare, Sibshop, or Teen Lounge).**

**8:30 a.m. - 12 p.m. Sibshop**

**8:30 a.m. - 9:30 am. Keynote Speaker: Rachel Callander**

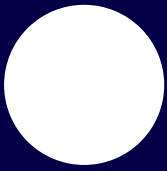
**9:45 a.m. - 10:45 a.m. - General Session: CFC Research, What's on the Horizon**

**11 a.m. - 12 p.m. - Expert Panel, Treatment of CFC Syndrome**

**12 p.m. - 1 p.m. Lunch** (Please retrieve children from childcare for lunch)

After lunch, please assist children in returning to childcare or the Teen Lounge. Sibshop will no longer be open.





# Schedule of Events

## Friday, July 12, 2019\*

Continued...

### **1 p.m. - 5 p.m. BREAKOUT SESSIONS**

**1 p.m. - 1:50 p.m. Breakout 1**

**2 p.m. - 2:50 p.m. Breakout 2**

**3 p.m. - 3:50 p.m. Breakout 3**

**4 p.m. - 4:50 p.m. Breakout 4**

**Breakout tracks will be geared to three audiences:**

**Track 1** Newly Diagnosed Families or First Time Conference Attendees

**Track 2** Diagnosis beyond 3 Years or Prior Conference Attendance

**Track 3** Families of Individuals with CFC Syndrome Transitioning to Adulthood or in Adulthood

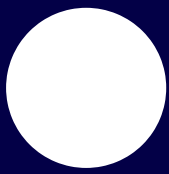


Tracks are simply a guide to assist you in making decisions about sessions, but **you may choose to go to any breakout session** at any time regardless of diagnosis length or age of your child.

**\*Dinner is on your own.**

### **7 p.m. - 10 p.m. Mom's Night Out**

An offsite evening for moms to relax and enjoy getting to know their fellow CFC moms. Refreshments and light fare will be served.



# Schedule of Events

## Saturday, July 13, 2019\*



**7 a.m. 8 a.m. Breakfast**

**8 a.m. - Take Children to Childcare or Teen Lounge**

**8:30 a.m. to 12 p.m. Family and Caregiver Workshop** (Please take advantage of childcare or Teen Lounge for this session.)

**12 p.m. - 1 p.m. Lunch** (Please bring children from childcare and Teen Lounge. They may return to childcare or Teen Lounge after lunch.)

**1 p.m. - 3 p.m. BREAKOUT SESSIONS**

**3 p.m. - 4 p.m. Age Range Support Groups:**

Families will be broken out and facilitated based on the following ages of individuals with CFC Syndrome:

Birth to 3 years old;

4 to 6 years old;

7 to 12 years old;

13 to 16 years old;

Adult transition;

Adults;

Families of Deceased Children

**6 p.m. 20th Anniversary Family Celebration!**





AS JOSE GASPAR ONCE INVADED THE SHORES OF  
TAMPA BAY, OUR PIRATES AND PRINCESSES WILL  
TAKE HOLD OF THE SUN COAST

# 2019 FAMILY CELEBRATION

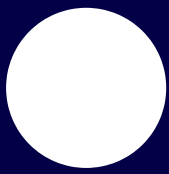
07.13.19 | SATURDAY | 6:00PM

DINNER, CEREMONY, DANCING, AUCTION

THE GRAND HYATT TAMPA BAY

TICKET IS INCLUDED WITH CONFERENCE REGISTRATION. ALL OTHER  
GUESTS MAY PURCHASE A TICKET FOR THE CELEBRATION FOR \$50  
(ADULT) OR \$25 (CHILD).

MAKE SURE YOU WEAR YOUR BEST PIRATE OR PRINCESS ATTIRE,  
SO YOU DON'T HAVE TO WALK THE PLANK!



# Onsite Childcare

We encourage our families to get the most out of their conference experience by taking advantage of our fun and safe onsite childcare options. Childcare providers are insured and trained to work with children who have special needs.

We have contracted with Kiddie Corp to provide childcare for our families. This service is **available for children with CFC Syndrome and their siblings**, only. For individuals with CFC Syndrome 16 and over, we are excited to once again offer our CFC Lounge, a fun and engaging experience for teen and young adults with CFC Syndrome. The CFC Lounge will be led by CFC parent volunteers, **Childcare and the CFC Lounge rates are for 2 full days. Single day rates are not available.** CFC International will subsidize a portion of the \$150 per child rate with Kiddie Corp. We cannot provide one-on-one childcare or nursing. Childcare and CFC Lounge staff and volunteers cannot manage feeding devices or administer medications. However, families may make arrangements to visit childcare rooms to administer feeding through pumps, manage medical devices, or administer medications. CFC Lounge volunteers cannot change diapers.

## **Childcare and the CFC Lounge will be open:**

Friday, July 12: 8 a.m. - 5 p.m.

Saturday, July 13: 8 a.m. - 4 p.m.

## **RATES**

### **CFC Teen & Young Adult Lounge**

(For Individuals 16 or over with CFC Syndrome Only):

\$25/person

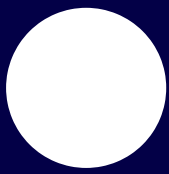
### **Childcare:**

Children with CFC Syndrome

ages 12 months to 15 years

& siblings ages 1 to 12: \$50/child





# Sibshop

**Friday, July 12: 8 a.m. - 12 p.m. (Ages 7 - 12)**

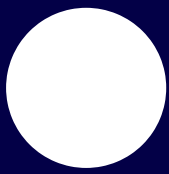
At the Family Medical Conference we work hard to focus on the needs of every member of a family affected by CFC Syndrome. Once again, we will be offering our Sibshop. Sibshop is not a therapeutic program, but a place where siblings of individuals with CFC Syndrome can go to be a kid and engage with others that "get it."

Siblings will play games, talk about the good and not-so-fun parts of having a sibling with CFC Syndrome, and have outrageous fun.

**Sibshop is led by two trained volunteers, and supported by teen (13-18 years old) siblings.** If your teen would like to be a volunteer for Sibshop, please reach out to [info@cfcsyndrome.org](mailto:info@cfcsyndrome.org).

Sibshop is **free** to all siblings of individuals with CFC Syndrome.





# MEALS

## Included in Registration

5 Meals and 1 Desert Reception are included in your registration for the conference. During registration, please indicate the number of people registering in each age group.. Please consider the **age of children at the time of the conference (July 11, 2019)**. Unfortunately, we will not be able to accommodate changes at the event.

During registration, please provide the number of registrants in the following age ranges:

- Adults 13 and up
- Children Ages 7 - 12
- Children 6 and under

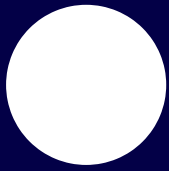
Knowing the age ranges of attendees will allow us to select menu options all registrants will enjoy

## Special dietary needs:

Please include any dietary needs when registering. The hotel can accommodate the following requests: dairy free, vegetarian, and gluten free. If your child is on a feeding tube, please prepare meals in advance or bring necessary nutritional supplementation. The hotel cannot provide a blender for blended diets. If this is something you will need special assistance with, please contact [info@cfcsyndrome.org](mailto:info@cfcsyndrome.org) before June 15, 2019..







# Quick Sheet

**Conference Registration:**

[www.http://www.rsvpbook.com/CFC2019Conference](http://www.rsvpbook.com/CFC2019Conference)

**Deadline: May 31, 2019**

**Cancellation Deadline: May 31, 2019**

**Hotel and Conference Site:**

Grand Hyatt Tampa Bay

Tampa, Florida

Book here: <https://www.hyatt.com/en-US/group-booking/TPARW/G-CFCI>

\$139/night

**Deadline to Book Room at Group Rate: June 10, 2019**

Complimentary (Free) Airport Shuttle from Tampa International Airport (TPA).

**Quick Schedule of Events, July 10 - July 13, 2019:**

July 10, 2019: New Family Orientation and Welcome Reception

July 11, 2019: Meet the Experts, Research, Pool Party, Dad's Night Out

July 12, 2019: Keynote and Breakout Sessions, Mom's Night Out

July 13, 2019: Family Group Session, Breakouts, Age Roundtables,

EVENING FAMILY CELEBRATION!

**Additional Contact Information: [info@cfcsyndrome.org](mailto:info@cfcsyndrome.org)**

*See you in  
Florida!*

