



## 9th CFC International Family Conference

June 28–July 1, 2017

Marriott Sugar Land Town Square

16090 City Walk, Sugar Land, Texas, USA

1(281) 275-8400

The following pages will help you prepare to complete your online registration form. If you will take time to read through this information the registration process will go more smoothly, especially if this is your first time attending. You may even want to print it out and make notes to use as you complete your online registration.

We highly recommend that you complete your registration when you have at least 30 minutes and you are not in a rush or distracted. **Under Registrant Type, everyone (except doctors) will be selecting “Families.”** If you skip over something that should have been filled in, it will tell you the registration is incomplete and highlight in red the questions that need completion. Just scroll through and look for items in red. (There are a few highlighted instructions in red also.) If you are running out of time, you can save the registration and return to finish it later. Also, if you change your mind about a meal or attending an activity, you may return and make edits until May 25, 2017.

**It is very important to note that the Early Bird registration rate expires at midnight on April 30, 2017 Eastern Time.** It will then automatically change to the regular rate. **Registration must be complete, which includes payment, before the rate expires to take advantage of the reduced early bird rate.** Here are the deadlines:

April 30, 2017 Midnight Eastern Time.....Early Bird Rate Expires

May 25, 2017..... Deadline to Register for 2017 Conference

We hope your concerns and questions are all answered here. It would help if you could register as early as possible since we have to provide a great deal of information to the hotel and the companies we hire to come in and assist with events on site.

If you have questions, please email and we will be glad to help you. See you in Texas!

Brenda Conger & Gina Peattie  
Executive Directors & Conference Coordinators  
[info@cfcsyndrome.org](mailto:info@cfcsyndrome.org)

## LOCATION HIGHLIGHTS

The Marriott Sugar Land Town Square is just 19 miles southwest of downtown Houston, where contemporary comfort and classic Texas charm converge. This beautiful hotel is located in the heart of the vibrant new Sugar Land Town Square, surrounded by fabulous dining and delightful shopping venues all within walking distance. All year long, visitors can enjoy premier festivals and events on the Town Square Plaza. Families can enjoy outside dining, shopping and entertainment in an atmosphere of bustling main street, centered around a fountain monument of Stephen F. Austin emerging from the Brazos River, the very river that gave life to Sugar Land.

First Colony Mall is just a short shuttle van ride from the hotel. Sugar Land's mall has over a million square feet of shopping and dining indoors and out, featuring Macy's, Dillard's, Lululemon, Cheesecake Factory, Grimaldi's Pizzeria and more. The hotel offers a free shuttle van to this mall.

Sugar Land is less than 30 minutes from some of the best attractions in the Greater Houston area. The Greater Houston Convention & Visitors Bureau is great resource for these attractions and more!  
[www.visithoustontexas.com](http://www.visithoustontexas.com)

Houston, Texas has many attractions to visit that appeal to both children and adults. From boat tours on Buffalo Bayou to one of the top children's museums in the U.S., Houston offers endless attractions.

## CONFERENCE HOTEL INFORMATION

The 9<sup>th</sup> CFC International Family Conference will be held at the Marriott Sugar Land Town Square hotel. CFC International negotiated a rate of **\$119/night with tax of 13%** for a regular guestroom in our reserved block with 2 double beds or 1 king bed. Reservations MUST be guaranteed with a major credit card. You may reserve your room after March 15, 2017.

Here is the reservation link to make online reservations:

[Book your group rate for CFC INTERNATIONAL FAMILY CONFERENCE](#)

You may also call the Sugar Land Marriott at: 1-800-228-9290. When you call, be sure to mention that you are with CFC International.

No room reservations at the discounted rate will be taken after June 1, 2017.

## INFORMATION TO HELP YOU COMPLETE THE REGISTRATION

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### ***WEDNESDAY, JUNE 28, 2017 – NEW FAMILY ORIENTATION/WELCOME RECEPTION***

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#### **New Family Orientation**

If you are attending the family conference for the first time, please make plans to attend our new family orientation on Wednesday afternoon from 4:30-5:00pm. You will have an opportunity to meet other families and board members, review the schedule and ask questions. This will get you started off with the information you need to gain the most from the days ahead and feel right at home with new friends.

### **Welcome Reception and Registration**

Please note that our long-standing Thursday evening reception has now been moved to Wednesday evening. We kick off with our official welcome to everyone. You will register and pick up your conference packets and name badges prior to the reception. Refreshments and dessert will be served.

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## ***THURSDAY JUNE 29, 2017 – RESEARCH & MEET THE EXPERTS***

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All meals on this day are on your own. The hotel has a restaurant and a Starbucks. There are also restaurants you can walk to right outside the front doors of the hotel in the town square.

### **Research**

You will have the opportunity to participate in research that has the potential to not only help your child but also help others diagnosed with CFC syndrome now and in the future. Imagine! What you do this day could have a significant impact on another child's life and his or her entire family. However, the choice is entirely up to you. If you decide to participate, each researcher will require that you review and sign a consent form for their research. You may ask questions before the research is done so you are fully informed. You are free to opt out at any time.

### **Enroll in the CFC International Registry**

A computer, scanner and staff will be on hand to assist families who would like to enroll in the CFC Registry. CFC International recognizes the importance of global collaboration. One of the goals of the registry is to enable researchers from around the world to work together to speed research progress. The CFC Registry connects all those interested in accelerating CFC syndrome research – affected individuals, families and researchers – with a resource that has never before been available in one place. If you are interested in enrolling, please bring your child's gene mutation testing report if available.

### **Meet the Expert Appointment Selections**

We are fortunate to have so many experts available in person at the conference. Remember that these doctors are not the treating physicians for your child. They are sharing their expert knowledge on the topics you wish to discuss, so come prepared with your most important questions related to CFC syndrome. Please bring medical records in case you wish to share information or have questions on specific reports. If your child has a DNA testing report, please bring it with you.

Following is a list of the experts who have agreed to be available to speak with our families. You will be asked to tell us how many experts you would like to speak with, if any, and to number them in order of preference. Once everyone has registered, this will greatly assist our coordinators in scheduling the appointments for all the families. We cannot guarantee you will speak with your first selection or receive all your choices, but with so many wonderful experts, you will be sure to learn something new!

Once everyone has made their selection of both researchers and experts, a "Passport" will be made with all your appointments and included in your registration packet. We often have waiting lists to get in with certain experts so if you cannot attend after signing up, you need to immediately contact us so others can be given your slot.

Experts Include:

- \* Dr. Bruce Gelb, Cardiology/Genetics
- \* Dr. Ines Kavamura, Dermatology
- \* Dr. Mary Ella Pierpont, Cardiology
- \* Dr. Rene Pierpont, Psychology
- \* Dr. Kate Rauen, Genetics
- \* Dr. Kent Reinker, Orthopedics
- \* Dr. Amy Roberts, Genetics
- \* Dr. Suma Shankar, Ophthalmology
- \* Dr. Matthew Steensma, Orthopedics
- \* Dr. David Stevenson, Genetics

In the evening, we will honor the memory of the children we have lost with a special ceremony. Following the ceremony, we will have a family pool party.

On Thursday evening we have our traditional Guys Night Out in the Steven Austin Suite for our adults to visit and share experiences in a relaxed setting.

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## **FRIDAY, JUNE 30, 2017 –TENTATIVE PRESENTATIONS**

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Breakfast and lunch are included with your registration. This day is packed with information from our medical experts from a full range of topics. Child care is provided for those attending the lectures as children under 18 are not permitted in the lecture rooms.

It will be a fast-paced day with some talks back-to-back. Hold on to your pens and notebooks!

### **General Session Lectures**

*The History of CFC syndrome*  
*CFC & the MAPK Pathway: What Does It All Mean?*  
*CFC Research: Dishing, Fishing & Wishing*  
*Growth Hormone Use in CFC syndrome: Are the Benefits*  
*Greater Than the Risks?*

*Pilar Magoulas, MS, CGC*  
*Katherine Rauen, MD*  
*Bruce Gelb, MD*  
*Brad Miller, MD*

### **Afternoon Break Out Sessions**

*Skin Care & Treatments; Tips & Tricks*  
*Sensory Sensitivity & the Impact on Behavior*  
*Getting to the Gut Problem in CFC*  
*Vision*  
*Orthopedics*

*Ines Kavamura, MD*  
*Rene' Pierpont, PhD*  
*TBA*  
*Suma Shankar, MD*  
*Drs. Kent Reinker, Matthew Steensma,*  
*David Stevenson*

In the evening we have our traditional Ladies Night Out in the Steven Austin Suite for our adults to visit and share experiences in a relaxed setting.

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## **SATURDAY, JULY 18, 2017 – FAMILY OUTINGS, CLOSING BANQUET/DANCE & AUCTION**

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Breakfast, lunch and dinner are included with your registration.

### **NEW! Family outings that leave the hotel right after breakfast:**

**For ages 2-12, join us at Fort Bend Children's Discovery Center.** We are limited to 40 children and 15 adult chaperones, so only one parent chaperone per family will be able to attend. Experience new worlds and make new discoveries about science, the environment, culture, math and the arts through their continuously-changing exhibitions, innovative workshops and exciting activities. Kids will discover the joy of learning just by exploring the hands-on exhibits!

**Movie time for ages 12 and up!** We will take the hotel shuttle van over to the nearby AMC Movie theater at the First Colony Mall. AMC Theatres in 2007 started the AMC **Sensory Friendly** Films program in partnership with the Autism Society to bring a unique **movie** experience to the special needs community! As part of the program, the **film** showings have their lights turned up and the sound turned down. An adult family chaperone is required to attend with their children.

Both groups return back to the hotel for lunch.

### **Afternoon Topics**

*Parent to Parent Round Table Groups*

*Families divided up by child's age*

*From Stress to Strength*

*Baylor Children's Hospital*

*How to Tell Other People About CFC Syndrome*

*Genetic Counselor*

### **All New Day of Caring Events thanks to a grant from Global Genes. Come join the fun!**

The "Day of Caring" schedule will include a number of activities for children, their siblings, their parents and grandparents, including: "Stress to Strength" class, yoga, chair massages, a grandparents' social and other activities to help families connect with each other in a relaxed and fun atmosphere.

We wrap up the evening with our fabulous fun banquet and silent auction. If you wish to invite guests, you will be able to purchase tickets in advance. Tickets will not be sold on site. Our location at Sugar Land Town Square provides us access to entertainment on the town square lawn so we will move out to enjoy the Blues and Brews event later in the evening. If you are driving to the conference, pack a blanket or lawn chairs to sit on.

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## **MEALS**

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### **Registration**

Meals are included in your registration for the conference. On your registration form, you will be asked to enter the number of people in each age group joining us for each meal. Please carefully consider each day whether you will be eating at the conference or elsewhere. We want to be sure fundraising dollars are not wasted on uneaten meals. Here is a worksheet that you might use to help you in your planning:

	Adults 13 & Up	Children 7-12	Children 0-6
<b>Wednesday, June 28:</b>			
Welcome Reception (Dessert)			
<b>Thursday, June 29:</b>			
Meet CFC Expert & Research Stations	Meals on your own	Meals on your own	Meals on your own
<b>Friday, June 30:</b>			
Breakfast			
Lunch			
Dinner	On your own	On your own	On your own
<b>Saturday, July 1:</b>			
Breakfast			
Lunch			
Dinner/Auction/Dancing			

### **Special Dietary Needs**

You will have a place to enter any special dietary needs for a registrant such as dairy free, vegetarian, or gluten free. We have to notify the hotel in advance to have these meals prepared or there is an additional charge. If your child is on a pureed diet, please plan to pack your blender since the hotel staff cannot blend all extra meals.

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### ***AUCTION ITEM DONATIONS***

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If you would like to donate any items/baskets for the auction, we are grateful for your contributions! Items for the Saturday night silent auction may be turned in at the Reception Desk anytime on Thursday when it is open. We ask that you to let us know in advance if you plan to bring something for the Saturday night silent auction or children's auction table so we can plan accordingly. Items should be new. We appreciate your support of the auction and helping CFC International raise funds for our ongoing support, educational and research initiatives!

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## **ATTENDEE DIRECTORY RELEASE**

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At each conference, we compile a list of the families attending and share it only with the families at the conference in print form. If you want to be on the list and receive a copy, you will have an opportunity to check “yes” and a copy will be in your registration packet. If you do not check that you agree, you will not be on the list or receive a copy.

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

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There is also a release for the photos we take around the conference that we use in preparing pamphlets, forms, registrations, on our website, closed Facebook page, etc. Sometimes they are taken in groups like in the dining room or a talk, and sometimes individual photos are taken. Please take time to read the Release on your Registration Form.

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## **REGISTRATION FOR ATTENDING THE FAMILY CONFERENCE**

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Everyone attending the sessions or eating a meal must register. There is no partial registration. Payment must be made for registration to be complete. There is no paper registration – all registration is done online. You register for the conference by going to our website ([www.cfcsyndrome.org](http://www.cfcsyndrome.org)) and finding the Conference under “News & Events” and then “Conference Information.” No partial payments will be accepted and no holds on medical consult spots or childcare are granted until your registration is complete.

### **2017 Fundraising Incentive for Families**

Thank you to our CFC International families and friends who supported our conference fundraising incentive program. Through everyone’s efforts we are able to offer a special incentive. CFC International families helped to raise more than \$25,000 collectively towards our conference! Therefore, all CFC families that attend the conference will receive **1 free early bird registration (up to 1 adult, up to 1 sibling)!** You must register within the Early Bird period to receive the incentive.

Please note that incentives are non-transferable and cannot be given to another family. **Incentives apply only to the families with an individual diagnosed (or passed away) with CFC syndrome. A “CFC family” is considered the direct family/guardians raising the child. The incentive does not apply to other extended family members or friends.**

**Registration Fees:**

Early Bird – Registration and payment must be submitted online **by April 30, 2017**

6 years and under	Free
7-12 years old	\$55
13 years and older	\$120
Person with CFC	Free

Regular Registration - Registration and payment submitted **May 1, 2017 and later**

6 years and under	Free
7-12 years old	\$85
13 years and older	\$180
Person with CFC	Free

**Childcare & CFC Lounge:**

We have hired Corporate Kids Events, Inc. to staff our childcare program. They are insured and have professional staff who are trained to work with special needs children. <https://conferencechildcare.com>

**CFC Lounge**

**CFC individuals 16 and older**

**\$20 per person for 2 days**

**Childcare**

**Ages 1-12 for siblings**

**\$45 per child for 2 days**

**Ages 1-15 for CFC children**

**\$45 per child for 2 days**

*Please note: one-day rates are not available. Childcare/CFC fees are non-refundable. Space is limited, so register early. Your reservation is not complete until you make payment and send in the Childcare Registration Form found on the conference registration home page.*

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***EXTRA TICKETS FOR THE SATURDAY NIGHT BANQUET/AUCTION/DANCING***


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Occasionally a few people would like to invite others to attend the Saturday Night Banquet. You may purchase tickets for them with your registration – Adults (13 and older) are \$38 and Children (ages 7-12) are \$19. There is no charge for children ages 0-6 but we ask that you “buy tickets” for them as well so we will have a seat for them. You do not need to purchase banquet tickets if you have registered as Saturday night is included in your registration free. Tickets for this dinner will not be sold on site.

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***REGISTRATION FOR CHILD CARE & CFC LOUNGE***


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Onsite childcare services with Corporate Kids [<https://conferencechildcare.com>] is available for the individual with CFC syndrome and their siblings (ages 1-12) on Friday and Saturday. For a nominal fee of \$45 per child, professional caregivers from Corporate Kids Events will care for your children so that you may give your undivided attention to the information presented at the sessions. The actual cost we are billed is \$154 per child so please decide very carefully if your child will access these costly services or if you will bring another



adult to watch your child. Please note: we cannot provide one-on-one childcare or nursing care. You are required to be staying at the hotel and also be on location at the hotel if your child is in childcare! Other guests are not permitted in childcare since it is limited by space and cost. CFC children under 18 are not permitted in the speaking sessions, and caregivers electing to use childcare are required to attend the sessions. The fee is the same for one or both days. Please note that we may need to adjust children from one age group to another depending on the number of children who register. The CFC Lounge (ages 16 and up) is only for individuals with CFC syndrome and siblings may not be part of the Lounge.

**CFC Childcare room is for ages 1-15**  
**Sibling Childcare is for ages 1-12**  
**CFC Lounge is for CFC individuals age 16 and up**

Children are picked up by parents to enjoy lunch with their families on both days. The CFC Lounge will be in a large suite where we will have adult chaperones, movies, games, and arts and crafts. We have also hired a magician, Zumba instructor and music therapist so everyone will have a great time!

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## ***SIBSHOP***

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The 9<sup>th</sup> CFC International Family Conference is excited to bring you Sibshops. Often we focus on the needs of the individuals with special needs and their parents. What about the brothers and sisters in the family?

Sibshops are lively, engaging celebrations of the many contributions made by brothers and sisters of kids with special needs. Sibshops acknowledge that being the brother or sister of a person with special needs is for some a good thing, others a not-so-good thing, and for many, somewhere in-between. They reflect a belief that brothers and sisters have much to offer one another — if they are given a chance. Sibshops are lively events for brothers and sisters of kids with special needs. With an emphasis on wellness and fun, Sibshops give kids a chance to meet other sibs, play outrageous games, talk about the good (and not-so-good) parts of having a sib with special needs with others who “get it” and have even more fun!

Sibshops are not therapy, although their effect may be therapeutic for some children. Sibshops acknowledge that most brothers and sisters of people with special needs, like their parents, are doing well, despite the challenges of an illness or disability. Consequently, while Sibshops facilitators always keep an eye open for participants who may need additional services, the Sibshops model takes a wellness approach.

**Who participates in Sibshops?** The Sibshop program will be offered to siblings ages 7 to 12 on Friday morning.

**Who facilitates Sibshops?** We will have two trained facilitators. Assisting them will be teen and young adult siblings of individuals with special needs.

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## TRANSPORTATION OPTIONS FROM TWO REGIONAL AIRPORTS

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This hotel does not provide shuttle service. You can use Super Shuttle, or use a taxi or Uber at the airport.

### Estimated Costs:

Uber: \$48-\$63 (for smallest size car); larger cars/SUVs range in price and start at \$92+

Taxi cost \$90 (one way)

### Super Shuttle:

We have secured a discount with **Super Shuttle**. *With the discount, the approximate cost is \$42.30 per person for round trip transportation from George Bush Airport to the hotel.*

**DISCOUNT CODE:** ECL79

**DISCOUNT VALID DATES:** June 23<sup>rd</sup> to July 7<sup>th</sup>

**LINK :** <http://www.supershuttle.com/default.aspx?GC=ECL79>

**WHERE TO ENTER YOUR CODE:** To use your code simply enter it in the “DISCOUNT CODE” box on the first page of the website when making your reservations at: <http://www.supershuttle.com>

**SPECIAL INFORMATION:** When entering the address for the hotel, please enter the physical address (16090 City Walk) instead of the hotel name.

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

**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.

### **Area Airports: William P. Hobby Airport and George Bush Intercontinental Airport:**

William P Hobby Airport – HOU

Hotel direction: 23 miles SW

Alternate transportation: AAmbassador

Limo; fee: 95 USD (one way) reservation required

Estimated taxi fare: 85 USD (one way)

George Bush Intercontinental Airport – IAH Hotel direction: 42 miles SW

Alternate transportation: AAmbassador

Limo; fee: 110 USD (one way) reservation required

Estimated taxi fare: 90 USD (one way)