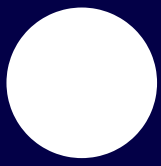




CONFERENCE  
AGENDA AND  
INFORMATION





# Are you ready for the time of your life?

Dear Families,

## **I am SO excited you are here!**

Along with our Board of Directors, Conference Planning Committee, and numerous volunteers, we have been planning and anticipating this day for a long time.



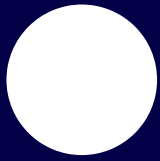
In it's 10th year, the CFC Family Medical Conference is truly one of the most memorable events for our families. We are excited that you'll be experiencing the conference... whether it's your first time, or 10th time! This year is also the 20th Anniversary of CFC International, and we have so much in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

This information booklet should help you have a truly memorable experience, but don't hesitate to ask for help from one of us if you need it. Please take the time to read through this booklet, as many of your questions will be answered here.

Welcome to sunny Florida! I'm so grateful to be with my CFC family!

Hugs,

Tuedi  
Mom to Emmett  
CFC Executive Director



# CFC International Leadership

## **Board of Directors**

Jennifer Iacobelli  
President  
New York

Elizabeth Rosenbaum  
Vice President  
Germany

Jeffrey Kohler  
Treasurer  
Missouri

Libby Airhart  
Secretary  
Louisiana

Cara Borian  
Pennsylvania

Richard Boyce  
Pennsylvania

Shelly Greenhaw  
Oklahoma

Glenda Hux, OT  
Louisiana

Pilar Magoulis  
Texas

CJ Mortimer  
United Kingdom

Leslie Rogers, MPA  
Oregon

## **Medical Advisory Board**

Bruce Gelb, MD  
Icahn School of Medicine  
at Mount Sinai

Mari- Ines Kavamura, MD  
Federal University  
of Sao Paulo, Brazil

Joseph Levy, MD  
NYU - Langone Medical Center

Mary Ella Pierpont, MD  
University of Minnesota

Katherine Rauen, MD, PhD  
University of California Davis

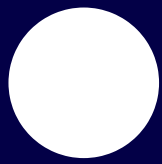
Amy Roberts, MD  
Boston Children's Hospital

Suma Shankar, MD, PhD  
University of California Davis,  
MIND Institute

David A. Stevenon, MD  
Stanford University

## **Executive Director**

Tuesdi Dyer, CFRE  
Arizona



# Location Info

The Grand Hyatt Tampa Bay 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 speak with a CFC International representative if you require the use of a freezer to store nutritional products for your child. The freezer will be located adjacent to the conference General Session area near the Audubon Ballroom.

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

**Grand Hyatt Tampa Bay**  
**2900 Bayport Drive**  
**Tampa, Florida 33607**

**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)

## **TRANSPORTATION**

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

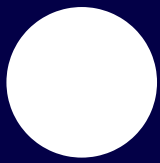
A complimentary shuttle is available to and from Tampa International Airport (5 minutes away) departing the hotel every half hour or upon request for pick up. To request airport pick up, claim your checked bags and call the hotel at 813.874.1234. Exit the side doors for Ground Transportation closest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

### **Driving**

Complimentary self-parking is available on-site at the Grand Hyatt Tampa Bay. Open surface lot parking is available for oversized vehicles. Valet is \$15/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. - p.m. Registration Desk Open**

**Tower Pool Windows**

**5:30 p.m. - 6:30 p.m. Family Liaison Meeting**  
(This event is for the Liaison Team Only)

White Ibis

**6:30 p.m. - 7 p.m. New Family Orientation**  
**Room: White Ibis North & South**

White Ibis

For families attending the conference for the first time.

*Thank you!*

**Stephanie Kohler Scholarship Fund**

**& The Kohler Family & Friends**

*For Making the 2019 Conference Possible for 9 Families!*

**7 p.m. - 8 p.m. Welcome Dessert Reception**

Audubon A

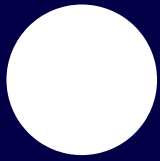
After you get settled in and enjoy dinner on your own, join us as we kick-off the conference with fun, desserts, and refreshments.

*Thank you!*

**Amelie's Army**

*For Sponsoring our Family Welcome Reception!*





# Schedule of Events

Thursday, July 11, 2019\*

**8 a.m. - 7 p.m. Event Registration Open**

**Tower Pool Windows**

**8 a.m. - 5 p.m. Meet the Experts\*\***

**All meetings are by pre-scheduled appointment only. You will receive a "passport" upon check-in with your appointment times.**

Genetics: David A. Stevenson, MD

Sandhill Crane South

Genetics: Amy Roberts, MD .

Sandhill Crane North

Cardiology: Bruce Gelb, MD

Snowy Egret South

Neuropsychology: Rene Pierpont, PhD, LP

Herring Gull

Gastroenterology: Dr. Joseph Levy, MD

Pelican

Dermatology: Maria-Ines Kavamura, MD

Cormorant

Physiatry: James Chinarian, MD

Roseate Spoonbill

Neurology: Darcy Krueger, MD,PhD

& Carlos Prada, MD

Audubon D

Endocrinology: Bradley Miller, MD, PhD

Conference

\*\*We we have worked hard to meet your time requests. Please be sure to check your times in your Meet the Experts passport, as there may be slight variations.

**8 a.m. - 5 p.m. Research Stations**

Seizure Disorders in CFC Syndrome

Audubon F

Communication Skills in the Rasopathies

Audubon E

**8 a.m. - 4 p.m. Join the CFC Registry!**

Audubon Foyer

CFC International volunteers will be available to assist 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.

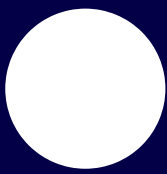
\*All meals for families are on your own.

*Thank You!*



**FJM**

*For Your Generous Financial Support;  
Making Meet the Experts Day possible!*



# Schedule of Events\*

## Thursday, July 11, 2019 Continued



### 4 p.m. - 6 p.m. Leah's Pool Party Oystercatchers/Bayside Pool

Join us at the Oystercatchers (Bayside) Pool for a family fun afternoon. Snacks and beverages will be served.

*Thank You!*

**Miss Leah Borian**

*For Sponsoring  
Our Family Pool Party!*

### 6 p.m. - 9 p.m.(ish) Dads' Night Out Bus Leaves at 6 p.m.Sharp!

Join your fellow dads for a relaxing and fun night out! Light refreshments will be served.

For those wishing to take their own transportation expect a 15 minute drive.

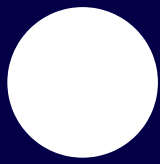
Location: George M. Steinbrenner Field  
1 Steinbrenner Drive in Tampa

*Thank You!*



*For Supporting Our Dads'  
Night Out!*

**6 p.m. - 8 p.m. Clinicians Dinner**  
(clinicians only) at Armani's Restaurant



# Schedule of Events

## Friday, July 12, 2019

**7 a.m. - 8:00 a.m. Breakfast**

Please bring children for breakfast before they go to childcare, Sibshop, or CFC Lounge. Meals will not be served in these areas.

**Audubon A,B,C**

**7:30 a.m. - 5 p.m. Childcare Open**

**Audubon D,E,F**

**7:45 a.m. - 5 p.m. CFC Lounge Open**

**Presidential Suite (Floor 14)**

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

**Tower Pool Windows**

**8 a.m. - 5 p.m. Research Stations**

We will be providing an opportunity for research teams to continue their work with our families throughout the day. Make an appointment to see one of the teams if you were unable to on Thursday, or stop in to check availability.

**Seizure Disorders in CFC Syndrome**

**Pelican**

**Communication Skills in the Rasopathies**

**Herring Gull**

**8 a.m. - 12 p.m. "SibShop" (Siblings only)**

**White Ibis**

A fun experience for siblings ages 7 -13. Participants will be invited to make art projects and participate in games that help them feel connected to other siblings of individuals with CFC Syndrome. These young participants will also contribute to a VERY special project to be unveiled at the Family Celebration Gala.

---

**8 a.m. - 12 p.m. GENERAL SESSION**

**Audubon A,B,C**

**8:15 a.m. Welcome, Tuesdi Dyer, CFRE, Executive Director**

**8:30 a.m. Keynote Address**

Forging Meaning, When Parenthood Suddenly Looks Totally Different From What You Imagine  
Presented by: Rachel Callander

*Thank you!*



*For Making Our  
Keynote Address  
Possible!*

**9:30 a.m. Welcome from the Rasopathy Network, Lisa Schoyer**

**9:45 a.m. CFC Syndrome and the Rasopathy Pathway**

Presented by Katherine Rauen, MD, PhD

**BREAK 10:30 a.m. - 10:45 a.m.**

**10:45 a.m. Expert Panel, Moderated by Pilar Magoulis, MS, CGC**

Panelists: Bruce Gelb, MD

Maria-Ines Kavamura, MD

Darcy Krueger, MD

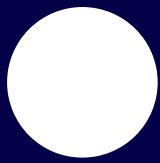
Joseph Levy, MD

Katherine Rauen, MD, PhD

Amy Roberts, MD

David A. Stevenson, MD





# Schedule of Events

Friday, July 12, 2019

## 12 p.m. - 1 p.m. Lunch

Audubon A,B,C

Please retrieve children from childcare, SibShop, or CFC Lounge before 12:10 p.m. and assist them in returning before 1 p.m. SibShop will not continue after lunch.

*Thank you to*  
**The Scutero Family**  
*for sponsoring our Family Lunch!*

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

Many breakouts are geared to age groups, life transitions, or diagnosis time. However, **you may choose to go to any breakout session** regardless of diagnosis length or age of your child.

### TOPIC

### ROOM

#### 1 p.m. - 1:50 p.m.

Neurology in CFC Syndrome

Presented by Darcy A. Krueger, MD, PhD

White Ibis (1st Floor)

Research Development in CFC Syndrome

Presented by David A. Stevenson, MD

Floor)

Sandhill Crane (2nd

Patient Centered Care for Teens and Adult Transition .

Presented by Paula Keyser, Family Resource Specialist

Snowy Egret (2nd Floor)

#### 2 p.m. - 2:50 p.m.

Growth in CFC Syndrome

Presented by Bradley Miller, MD, PhD

White Ibis (1st Floor)

Research Development in CFC for Newer Families

Presented by David A. Stevenson, MD

Floor)

Sandhill Crane (2nd

Preparing for the Future of your Child Now

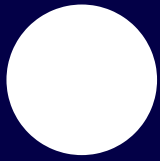
Presented by Travis Finchum, Special Needs Lawyer, PA

Snowy Egret (2nd Floor)

Cardiology Needs in Teen and Adult Years

Presented by Bruce Gelb, MD

Cormorant (2nd Floor)



# Schedule of Events

Friday, July 12, 2019\*

## BREAKOUT SESSIONS Continued

### TOPIC

### ROOM

#### 3 p.m. – 3:50 p.m.

Understanding Special Needs Trusts

Presented by Travis Finchum, Special Needs Lawyer, PA . White Ibis (1st Floor)

Advocating for Your Child in Early Childhood

Presented by Paula Keyser, Family Resource Specialist Snowy Egret (2nd Floor)

Providing Care in the Rasopathies

Presented by Carlos Prada, MD Sandhill Crane (2nd Floor)

#### 4 p.m. – 4:50 p.m.

An Overview of Cardiology in CFC Syndrome

Presented by Bruce Gelb, MD White Ibis (1st Floor)

Skin Conditions in CFC Syndrome

Presented by Maria-Ines Kavamura, MD Snowy Egret (2nd Floor)

Behavior and CFC Syndrome

Presented by Rene Pierpont, PhD, LP Sandhill Crane (2nd Floor)

A Genetic Understanding of CFC Syndrome

Presented by Katherine Rauen, MD, PhD Cormorant (2nd Floor)

#### 5 p.m. - 5:30 p.m. CPR Demonstration

**White Ibis (1st Floor)**

\*Dinner is on your own. Light fare served at Moms' Night Out

#### 7 p.m. - 10 p.m. Moms' Night Out

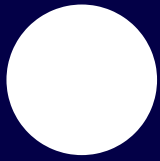
**Oystercatchers/Bayside Pool**

An evening for moms to relax and have fun!

*Thank You!*



*For making Moms'  
Night Out Possible!*



# Schedule of Events

## Saturday, July 13, 2019

**7 a.m. - 8:00 a.m. Breakfast**

**Audubon A,B,C**

Please bring children for breakfast before they go to childcare or CFC Lounge. Meals will not be served in these areas.



*For Sponsoring Our Family Breakfast*

**7:45 a.m. - 4 p.m. Childcare Open**

**Audubon D,E,F**

**7:45 a.m. - 4 p.m. CFC Lounge Open**

**Presidential Suite (Floor 14)**

Please note that the CFC Lounge volunteers will break from 12 pm. to 1 p.m. for lunch. All teens and adults with CFC Syndrome must be with their families for lunch during this time.

**8 a.m. - 3 p.m. Info Table Open**

**Promenade Foyer**

**8 a.m. to 12 p.m.**

**Audubon A,B,C**

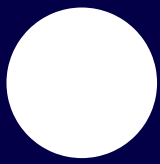
**Family and Caregiver Communication Workshop**

**Presented by Ellen Nastir, MEd, PCC**

This workshop will be a starting point for monthly coaching sessions with families over a 6 months period. By participating in this program you will be encouraged to complete the entire series of sessions. Please know that children are highly discouraged from attendance in this session, as discussions will be mature in nature.



**For Making this Session and Series Possible Through Your  
Rare Patient Impact Grant.**



# Schedule of Events

## Saturday, July 13, 2019\*

### **12 p.m. - 1 p.m. Lunch**

Please retrieve children from childcare and CFC Lounge before lunch, and assist them in returning after your meal and before 1 p.m. Families who do not pick up their children by 12:15 p.m. for lunch from Childcare OR CFC Lounge may be charged a \$15 late fee.

**Audubon A,B,C**

**During lunch, learn about CFC International's committees by visiting our committee tables.**

### **BREAKOUT SESSIONS (Please note 2 hour concurrent session)**

#### **TOPIC**

#### **ROOM**

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

Understanding the Need for Rehabilitative Medicine (Teens and Adults)  
Presented by James L. Chinarian, MD

Snowy Egret (2nd Floor)

Understanding Gastroenterology (GI) Needs  
Presented by Joseph Levy, MD

Sandhill Crane (2nd Floor)

Behavior in CFC Syndrome  
Presented by Rene Pierpont, PhD, LP

Cormorant (2nd Floor)

#### **Concurrent Open Workshop 1 p.m. - 3 p.m. (2 hours)**

Effective Communication Strategies for Better Health Outcomes  
Presented by Rachel Callander

White Ibis (1st Floor)

#### **2 pm. - 2:50 p.m.**

Understanding the Need for Rehabilitative Medicine (Infants and Adolescents)  
Presented by James Chinarian, MD

Snowy Egret (2nd Floor)

Understanding GI Needs of Teens and Adults  
Presented by Joseph Levy, MD

Sandhill Crane (2nd Floor)

#### **3 p.m. - 4 p.m. Age Range Discussion Groups:**

Join the group that corresponds to the age of your child with CFC Syndrome.

Birth - 3 years old

White Ibis

4 years old - 7 years old

Snowy Egret

8 years old - 12 years old

Sandhill Crane

13 years old - 20 years old

Cormorant

Adults with CFC Syndrome

Herring Gull

Families of Deceased Children: Led by Jeff and Linda Kohler and location to be determined by group.

Pelican Open



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

# 2019 FAMILY CELEBRATION

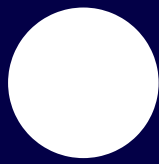
07.13.19 | SATURDAY | 6:00PM

DINNER, CEREMONY, AUCTION,  
AND THEN DANCING THE NIGHT AWAY  
THANKS TO DARIN AND JENNY IACOBELLI

THE GRAND HYATT TAMPA BAY  
AUDUBON A,B,C

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!



# Speaker Bios



## Keynote Speaker Rachel Callander

Sponsored by:



Rachel is a TEDx presenter, speaker, trainer, award-winning artist and the author of the Outstanding Book of the Year Award 2015 IPPY New York, Super Power Baby Project. This exceptional book celebrates the lives and abilities of children with chromosomal or genetic conditions and was inspired by Rachel's late daughter Evie, who was born with a very rare condition herself. In the two and a half years of Evie's life, Rachel learnt a lot about the use of language in the health system and has spent the subsequent years continuing to explore the impact and implications of how it is used by health professionals - To positive and negative effect. This book is Evie's legacy, as is Rachel herself, and both have much to teach us about ourselves, and how we negotiate conflict, grief, hope, uniqueness, celebration, and a meaningful life.

Rachel is a sought-after speaker at conferences globally, she speaks mostly to health professionals about the need to communicate using empowering language, especially at diagnosis. She teaches how the first words used at diagnosis critically shape how a parent perceives their future: The words can allow the parent/patient to be their best, and find meaning even in pain; or they can create anger, mistrust, frustration, and can break down the crucial relationship between the parent and the health professional. It's a conversation about empowerment - For the patient, and for the health professional.

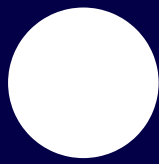
### Sessions:

**Friday: July 12th: 8:30 a.m. - 9:30 a.m. GENERAL SESSION**

**Audubon ABC**

**Saturday, July 13th: 1 p.m. - 3 p.m. BREAKOUT SESSION**

**White Ibis**



# Speaker Bios



**Keynote Coach**  
**Ellen Nastir, M.Ed, PC**

Funded by:



After thirteen years of growth in the training and coaching world, Ellen Nastir's professional programs have evolved into Innovative Team Solutions. Working hand-in-hand with corporations, small businesses & nonprofits, Ellen helps create more positive, appreciative and cohesive work environments. From her early days teaching hearing-impaired children (and their parents) to her current work in training and development, the common thread remains ... communication and education.

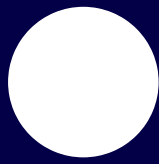
Ellen's expertise is developing employees' people-skills to complement their technical skills and abilities. With improvements in those areas, her clients achieve increased productivity and retention as well as stronger communication skills, problem-solving and conflict resolution. She helps people to better understand themselves and the perspectives of others, as well as leading educational team meetings for professional and personal development.

As a result, her clients report increased customer/client/patient satisfaction, higher retention rates and greater profitability. Her background in training and development, entrepreneurial sales and operations provides her with a unique perspective on resolving challenges and maximizing the opportunities that can be realized with teams. Ellen coaches individuals, partners and teams in a variety of ways.

She is a coach, trainer and consultant who brings real life experience into her interactive client engagements.

**Session:**

**Saturday: July 13th: 8 a.m. - 12:00 p.m. GENERAL SESSION Audubon ABC**



# Speaker Bios



## **James L. Chinarian, MD**

James Chinairan, MD is a Physician of Pediatric Rehabilitation Medicine, at Johns Hopkins All Children's Hospital in St. Petersburg, FL. He completed his BS in Cellular and Molecular Biology at University of Michigan, MD at Wayne State University School of Medicine, and Residency in Combined Pediatrics and Physical Medicine and Rehabilitation at Wayne State University School of Medicine. He is formerly an Assistant Professor in the Department of Physical Medicine and Rehabilitation and the Department of Pediatrics at Baylor College of Medicine, as well as an Assistant Professor at Wayne State University.

Prior to joining Johns Hopkins All Children's Hospital, Dr. Chinairan was the Medical Director of the Myelomeningocele Care Center, as well as the Inpatient Rehabilitation Unit, at Children's Hospital of Michigan

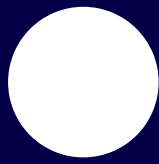
Dr. Chinarian's original research, peer reviewed publications include:  
Neurologic Improvement Following Shunt Placement for Post-Traumatic Hydrocephalus in a Child; Programmable Valve Adjustment after Exposure to Gait Analysis-A Case Report; Effect of a "Snug" Sensory Dynamic Orthosis on Gross Motor Function in Children with Cerebral Palsy; The Safety of High Dose Botulinum Toxin A in Children with Cerebral Palsy and Spasticity; Botulinum Toxin Therapy in Children: What role in Managing Spasticity and Dystonia.

### **Sessions:**

**Thursday, July 12th : Meet the Experts**

**Saturday, July 13th: 1 p.m. - 1:50 p.m. BREAKOUT SESSION      Snowy Egret**  
**2 p.m. - 2:50 p.m. BREAKOUT SESSION      Snowy Egret**





# Speaker Bios



## **Travis Finchum, Special Needs Lawyer, PA**

Travis D. Finchum has been practicing law since 1996 and has been a Board Certified Elder Law attorney since 2002. He is the President and founder of the law firm Special Needs Lawyers, P.A. Travis received his Bachelor's of Science and J.D. from the University of Florida. He is the Chair of the Special Needs Trust Committee of the Florida Bar's Elder Law Section and past chair of the Elder Law Board Certification Committee. He serves on the Advisory Board of the Academy of Special Needs Planners, and is a member of the National Academy of Elder Law Attorneys and the Academy of Florida Elder Law Attorneys.

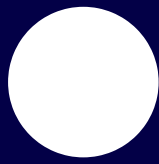
Travis has served on the boards of numerous non-profit organizations that serve the frail, elderly and those with disabilities that focus on advocacy and local services for those with disabilities and mental illness. He currently serves on the Board of Directors for Florida's Voice on Developmental Disabilities, the Arc Tampa Bay Foundation, the Guardian Trust Foundation, Inc., and on the Advisory Board for the National Alliance on Mental Illness, Pinellas County Chapter.

Mr. Finchum frequently speaks on the topics of Medicaid qualification, Special Needs Trusts, estate planning, including planning for incapacity and nursing home care, protecting assets from creditors, sheltering assets for family members with disabilities and public assistance programs. His practice also consists of probate, trust administration (particularly special needs trusts), trust reformation and sophisticated estate planning strategies. He sits on the faculty of the Lighting the Way Program providing statewide training on Guardianship and Guardianship Alternatives sponsored by the Florida Developmental Disabilities Council ([www.guardianshiptraining.com](http://www.guardianshiptraining.com)).

Mr. Finchum has been a resident of Pinellas County since 1977, where he lives with his wife Kiersten who is an RN, his son Ethan and daughter Lillian.

### **Sessions:**

**Friday , July 12th: 2 p.m. - 2:50 p.m. BREAKOUT SESSION    Snowy Egret**  
**3 p.m. - 3:50 p.m. BREAKOUT SESSION    White Ibis**



# Speaker Bios



**Bruce Gelb, MD**  
**Member, Medical Advisory Board**  
**CFC International**

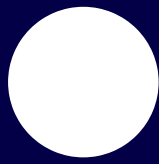
Bruce D. Gelb, M.D. is the Director and Gogel Family Professor of the Mindich Child Health and Development Institute at the Icahn School of Medicine at Mount Sinai. He is Professor of Pediatrics and of Genetics and Genomic Sciences. Dr. Gelb completed a pediatric residency and pediatric cardiology fellowship at Babies Hospital of Columbia-Presbyterian Medical Center and Texas Children's Hospital at the Baylor College of Medicine, respectively. He joined the faculty at Mount Sinai in 1991 after fellowship and has remained there since. He developed and now oversees an extensive program in genomics/gene discovery for congenital heart disease.

Dr. Gelb has received the E. Mead Johnson Award from the Society for Pediatric Research and the Norman J. Siegel New Member Outstanding Science Award from the American Pediatric Society. He was elected to the American Society of Clinical Investigation and the National Academy of Medicine (formerly, the Institute of Medicine). Dr. Gelb is the Past President for the American Pediatric Society and Treasurer for the American Society of Human Genetics. In addition to his research, he co-directs the Cardiovascular Genetics Program at Mount Sinai.

**Sessions:**

**Friday, July 11th: Meet the Experts**

**Friday, July 12th: 2 p.m. - 2:50 p.m. BREAKOUT SESSION    Cormorant**  
**4 p.m. - 4:50 p.m. BREAKOUT SESSION    White Ibis**



# Speaker Bios



**Maria-Ines Kavamura, MD**  
**Member, Medical Advisory Board**  
**CFC International**

Maria-Ines Kavamura, MD, PhD, is a Dermatologist and Geneticist from the Federal University of Sao Paulo (UNIFESP) Brazil and holds a PhD from the Catholic University, in Rome, Italy in conjunction with UNIFESP, Brazil, on Cardiofaciocutaneous (CFC) syndrome.

Dr. Kavamura has been working with CFC syndrome, its clinical, dermatological and molecular aspects, as well as natural history, since 1994 and is a proud member of CFC International from its genesis in July 2000.

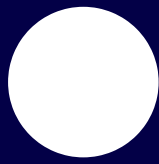
Dr. Kavamura is also a member of the United World Colleges International Board of Directors, serves on Hospital for Special Surgery (HSS) Advisory Board, HSS International Advisory Council and HSS Research Council, as well as on Mia Neri Foundation Advisory Board.

Born and raised in Brazil, Maria-Ines is a researcher at UNIFESP and is currently helping Brazilian families with Rasopathies to constitute a family support group.

**Sessions:**

**Friday, July 11th: Meet the Experts**

**Friday, July 12th: 4 p.m. - 4:50 p.m. BREAKOUT SESSION Snowy Egret**



# Speaker Bios



## Daniel Kenney-Jung, MD

Daniel Kenney-Jung received his MD from Tufts University School of Medicine in 2009. He did residency in pediatric neurology at the Mayo Clinic, and fellowships in clinical neurophysiology, pediatric epilepsy and epilepsy research also at Mayo Clinic. He is currently an assistant professor of neurology at the University of Minnesota, primarily seeing patients with epilepsy and neurogenetic disorders.

### Sessions:

**Thursday, July 11th: Seizure Research Team**

**Audubon F**

**Friday, July 12th: 10:45 a.m. - 12 p.m. GENERAL SESSION  
8 am. - 5 pm. Research Team**

**Audubon ABC  
Pelican**



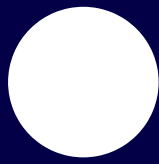
## Paula Keyser Family Resource Specialist

Paula Keyser began working as a Family Resource Specialist with the Early Steps Program at Johns Hopkins All Children's Hospital in December 2007. She previously worked in the Video Production and Graphic Design industries until her son, Jeremy was born. Jeremy spent two months in the NICU and had 3 brain surgeries before he was 6 months old. This experience spring boarded her into a world of Advocacy and Parent Involvement as she went through the challenges of health insurance denials and educational policy challenges. In 2004, she started a local support group called HUGS of Florida, Inc. to support families with Neurological Conditions. This 501c3 charity has an annual event in November in Largo Central Park to bring families together. Paula is also involved with the Family Advisory Council at Johns Hopkins All Children's Hospital and Pinellas County Schools ESE Advisory Committee. When she is not helping families navigate services, you can find her teaching Zumba® fitness classes which includes two classes every week for Special Needs.

### Sessions:

**Friday, July 12th: 1 p.m. - 1:50 p.m. BREAKOUT SESSION  
3 p.m. - 3:50 p.m. BREAKOUT SESSION**

**Snowy Egret  
Snowy Egret**



# Speaker Bios



## **Darcy Krueger, MD, PhD** **Pediatric Neurology**

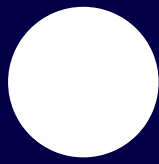
Dr. Krueger is Director of the Tuberous Sclerosis Clinic, Associate Professor of Clinical Pediatrics and Neurology, and Associate Director of Research in Neurology at Cincinnati Children's Hospital Medical Center. He is a founding member of the Tuberous Sclerosis Complex Clinical Research Consortium and served as its first Director from 2011 to 2013.

Dr. Krueger received PhD and MD degrees from Saint Louis University in 2000 and 2002, respectively, and completed a combined residency in pediatrics, neurology, and child neurology at Cincinnati Children's Hospital Medical Center (CCHMC) and the University of Cincinnati College of Medicine in 2007. Dr. Krueger was a leading investigator for the landmark clinical trial using mTOR inhibitors to treat subependymal giant cell astrocytomas that led to the first ever FDA-approved treatment for TSC in 2010. Dr. Krueger leads multiple clinical research studies in TSC, including the TSC Autism Center of Excellence Network (TACERN) funded by the National Institutes of Health and the TS Alliance. Additional projects are aimed at better understanding the underlying mechanisms of TSC disease pathogenesis and treatment response, with the ultimate objective of developing treatment strategies that reverse or prevent disease progression and secondary complications.

### **Sessions:**

**Thursday, July 11th: Meet the Experts**

**Friday, July 12th: 1 p.m. - 1:50 p.m. BREAKOUT SESSION White Ibis**



# Speaker Bios



## **Joseph Levy, MD** **Member, Medical Advisory Board** **CFC International**

Joseph Levy, M.D, is currently a Professor of Pediatrics at New York University School of Medicine and an attending in the Division of Gastroenterology at the NYU-Langone Medical Center. He was former Director of the Division and comes from Babies Hospital, Columbia Presbyterian Medical Center where he directed the Clinical GI Service. He has a keen interest in functional disorders of the GI tract in children and adolescents, including those on the autism spectrum.

Dr. Levy's practice focuses on the broad range of immune-mediated conditions affecting the GI tract, including food allergies, celiac disease, Crohn's disease and colitis, and more recently, eosinophilic esophagitis. In addition to over fifty publications and chapters in medical textbooks, he is the author of A Practical Approach to Pediatric Gastroenterology and My Tummy Hurts, a guide for parents and caregivers. He is a member of the American Gastroenterology Association and the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition.

### **Sessions:**

**Thursday, July 11th: Meet the Experts**

**Friday, July 12th: 10:45 a.m. - 12 p.m. GENERAL SESSION**

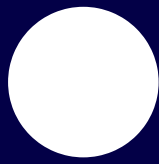
**Audubon ABC**

**Saturday, July 13th: 1 p.m. - 1:50 p.m. BREAKOUT SESSION**

**Sandhill Crane**

**2 p.m. - 2:50 p.m. BREAKOUT SESSION**

**Sandhill Crane**



# Speaker Bios



**Pilar Magoulis, MS, CGC**  
**Member, Board of Directors**  
**CFC International**

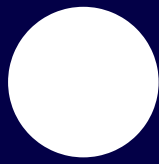
Pilar Magoulas is a certified genetic counselor and Assistant Professor in the Department of Molecular and Human Genetics at Texas Children's Hospital and Baylor College of Medicine. She received her Bachelor of Science degree in Psychology from the University of Florida in 2001 and a Master of Science degree in Genetic Counseling from Northwestern University in 2003. She currently works as a pediatric genetic counselor at Texas Children's Hospital where she serves as the Manager of the Pediatric Genetics clinic, and Chief of the Division of Genetic Counseling.

Pilar is a member of the National Society of Genetic Counselors and American College of Medical Genetics. She serves on the Board of directors for CFC International, support group for individuals with Cardio-facio-cutaneous syndrome, on the Scientific Advisory Council for the National Foundation for Ectodermal Dysplasias, and the RASopathies Network USA, and serves on the Program Committee for the American College of Medical Genetics and Genomics.

**Sessions:**

**Friday, July 12: 10:45 a.m. - 12 p.m. GENERAL SESSION**

**Audubon ABC**



# Speaker Bios



**Bradley Miller, MD, PhD**

Bradley S. Miller completed his MD and PhD in a combined program at the Medical University of South Carolina (1997). His doctoral thesis research focused on signal transduction of the insulin-like growth factor (IGF) receptor. Dr. Miller completed his Pediatric residency (2000) and Pediatric Endocrinology fellowship (2003) at the Mayo Clinic. He has been in the Division of Pediatric Endocrinology at the University Of Minnesota since 2003 and is a Professor of Pediatrics. He is currently the Director of Growth Programs in the Division of Pediatric Endocrinology at the University of Minnesota Masonic Children's Hospital.

Dr. Miller has an interest in the role of the growth hormone/IGF system and the regulation of growth at the growth plate in normal and abnormal growth in children. He is particularly interested in the growth of children with Russell-Silver, Noonan, Cardiofaciocutaneous Syndromes, Fanconi Anemia and Neurofibromatosis. He has been an active investigator in clinical trials and registries of treatments for growth, bone and puberty disorders. Dr. Miller is also interested in the growth, puberty and development of children following adversity including cancer and its therapies, fetal alcohol exposure, premature birth and international adoption.

Dr. Miller has a special interest in the growth and bone health of children with lysosomal storage diseases, including the mucopolysaccharidoses, and in the care of children with adrenoleukodystrophy.

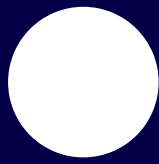
**Sessions:**

**Thursday, July 11th: Meet the Experts**

**Friday, July 12: 2 p.m. - 2:50 p.m. BREAKOUT SESSION**

**White Ibis**





# Speaker Bios



## Rene Pierpont, PhD, LC

Dr. Rene Pierpont is an Assistant Professor in the Department of Pediatrics at the University of Minnesota. She received her doctoral degree in psychology from the University of Wisconsin – Madison and completed her internship and fellowship in pediatric neuropsychology at the University of Minnesota. In clinical practice,

Dr. Pierpont works with a broad array of children and adolescents neurodevelopmental and mental health conditions. In her research, Dr. Pierpont primarily investigates the behavioral characteristics of individuals with genetic syndromes including CFC syndrome, Noonan syndrome, neurofibromatosis type 1, and adrenoleukodystrophy. She has completed several research studies to understand neurocognitive and behavioral features of CFC syndrome, and has recently published a children's book featuring a character who has Noonan syndrome.

Currently, Dr. Pierpont is partnering with Dr. Daniel Kenney-Jung to conduct research on neurological issues in CFC and the impact of seizure disorder on neuropsychological function and quality of life. She is passionate about working alongside the CFC community to develop better guidelines and avenues of care for children with CFC.

### **Sessions:**

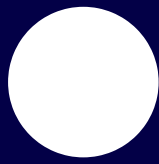
**Thursday, July 11th, Meet the Experts**

**Friday, July 12th : 4 p.m. - 4:50 p.m.: BREAKOUT SESSION**

**Sandhill Crane**

**Saturday, July 13th: 1 p.m. - 1:50 p.m. BREAKOUT SESSION**

**Cormorant**



# Speaker Bios



## Carlos Prada, MD

Carlos E. Prada, MD, is Associate Professor of clinical genetics at Cincinnati Children's Hospital Medical Center within the UC Department of Pediatrics. Dr. Prada is the clinical director for the RASopathies program at Cincinnati Children's Hospital. This is a multidisciplinary program across the institution to provide comprehensive care to our patients.

Dr. Prada completed a combined pediatrics and human genetics residency at Cincinnati Children's Hospital Medical Center, and then completed a fellowship in clinical biochemical genetics there as well. Dr. Prada's clinical and research efforts are to develop a comprehensive program for the diagnosis, management, and treatment of patients with RASopathies.

As an associate professor of human genetics at Cincinnati Children's within the UC Department of Pediatrics, Dr. Prada spends the majority of his time caring for patients with RASopathies, lysosomal storage diseases, and metabolic disorders. He participates in natural history studies of genetic diseases, biomarker discovery, and clinical trials for novel therapies including gene therapy. He is also actively involved in the education of health care providers regarding the application of genetics for patient care, including newborn screening, and gene therapy.

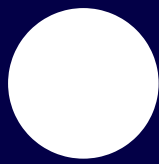
Dr. Prada has expertise in telehealth and he is the director for a Telegenetics program in the Caribbean. He has developed a partnership with the Centro de Ginecología y Obstetricia to follow children with complex rare diseases in Santo Domingo, Dominican Republic. In the Fundación Cardiovascular de Colombia, Dr. Prada is the director of the Center for Genomics and Metabolism.

### **Sessions:**

**Thursday, July 11th, Meet the Experts**

**Friday, July 12th : 3 p.m. - 3:50 p.m.: BREAKOUT SESSION**

**Sandhill Crane**



# Speaker Bios



## **Katherine Rauen, MD, PhD** **Member, Medical Advisory Board** **CFC International**

Katherine (Kate) Rauen, MD, PhD is a Professor in the Department of Pediatrics, Division of Genomic Medicine at the UC Davis where she currently serves as the Chief of Genomic Medicine and holds the Albert Holmes Rowe Endowed Chair in Human Genetics. She received a MS in Human Physiology and a PhD in Genetics from UC Davis doing research on gene dosage compensation and genetic evolution. She obtained her MD at UC Irvine where she also did research in cancer genetics. Dr. Rauen did her residency training in Pediatrics and fellowship in Medical Genetics at UC San Francisco.

Dr. Rauen is internationally known for her pioneering work in the early application of microarray technology in clinical genetics and as a leader and major contributor to the understanding of the "RASopathies", the Ras/MAPK pathway genetics syndromes. Her research program involves the clinical and basic science study of cancer syndromes with effort to identify underlying genetic abnormalities affecting common developmental and cancer pathways. Her current laboratory research includes the study of skeletal myogenesis in both Costello syndrome and cardio-facio-cutaneous syndrome (CFC). Dr. Rauen led the research team, including the CFC International Family Support Group that discovered the genetic cause of CFC and independently identified the genetic cause of Costello syndrome.

Dr. Rauen is committed to academic medicine, medical education, and advancing best practices for patients with RASopathies. She is the innovator of the world-renowned NF/Ras Pathway Clinic which she initiated in 2007 and this clinic has now been emulated around the globe. She serves on the medical advisory board of CFC International, is a Co-Director for the Costello Syndrome Family Network, and serves on the advocacy advisory boards for RASopathies Network USA and Global Genes.

Dr. Rauen was awarded the Presidential Early Career Award for Scientists and Engineers (PECASE) on her work for CFC and Costello syndrome. This Award is the highest honor bestowed by the United States Government on science and engineering professionals in the early stages of their independent research careers. This Presidential Award is awarded for innovative and far-reaching developments in science and technology.

### **Sessions:**

**Thursday, July 11th, Meet the Experts**

**Friday, July 12th, 9:45 a.m. - 10: 30 a.m. GENERAL SESSION**

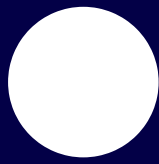
**10:45 a.m. o 12 p.m. GENERAL SESSION**

**Friday, July 12th : 4 p.m. - 4:50 p.m.: BREAKOUT SESSION**

**Audubon ABC**

**Audubon ABC**

**Cormrant**



# Speaker Bios



**Amy Roberts, MD**  
**Member, Medical Advisory Board**  
**CFC International**

Dr. Roberts obtained her M.D. degree from Dartmouth Medical School in Hanover, NH. Following Pediatrics residency at the University of Massachusetts Medical Center, she completed a second residency in medical genetics at Harvard Medical School. In 2007 she joined the Department of Cardiology at Boston Children's Hospital to direct clinical cardiovascular genetic research and to work in the cardiovascular genetics clinic caring for children with a variety of syndromic and nonsyndromic genetically acquired congenital heart diseases and cardiomyopathies.

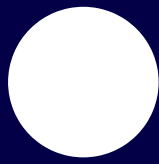
Dr. Roberts's early work focused on gene discovery for the Rasopathies. Over the last 18 years there has been a rapid evolution in our understanding of the molecular genetic causes of the RASopathies. Dr. Roberts is interested in understand connections between genotype (the specific genetic cause of a child's RASopathy) and phenotype (the resultant medical and developmental complications) and how best to address them.

**Sessions:**

**Thursday, July 11th, Meet the Experts**

**Friday, July 12th : 10:45 a.m. - 12 p.m.: GENERAL SESSION**

**Audubon ABC**



# Speaker Bios



## **Lisa Schoyer, MFA President, Rasopathy Network**

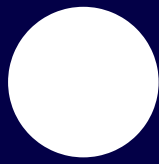
Lisa Schoyer is the mom of Quin Johnson, who had Costello syndrome (G12S) and died in 2002 at 6-1/5 years old, of embryonal rhabdomyosarcoma (eRMS) related to the syndrome. She is founder and President of the RASopathies Network USA. Lisa also is a trustee of the International Costello Syndrome Support Group (ICSSG), as well as Past President and Past Secretary for the American Costello Syndrome Family Network (CSFN).

Though trained as a professor of studio art, after Quin died, she was hired by the County of Los Angeles first as Chief of Family Support at the Department of Public Health's program for children with special needs (2003-2009), and, since then, for the County's Department of Mental Health in the Family and Community Partnerships Unit - where she is working to sustain/develop Subject Matter Mavens on providing mental health interventions for individuals with co-occurring developmental disabilities.

### **Sessions:**

**Friday, July 12th : 9:30 a.m. - 9:45 a.m.: GENERAL SESSION**

**Audubon ABC**



# Speaker Bios



## **David A. Stevenson, MD** **Member, Medical Advisory Board** **CFC International**

David A. Stevenson, MD - Pediatrician and Medical Geneticist, Stanford University. Dr. Stevenson completed his residency in Pediatrics at the University of New Mexico and a 3 year fellowship in medical genetics at the University of Utah. He was on faculty at the University of Utah for 10 years before joining the faculty in the Division of Medical Genetics at Stanford University. His initial research focused on neurofibromatosis type 1 (NF1), and since that time he has expanded his research to RASopathies focusing on the musculoskeletal problems and genotype-phenotype correlations.

Dr. Stevenson has received grant funding from the NIH, Doris Duke Charitable Foundation, Thrasher Research Fund, and Department of Defense to investigate the musculoskeletal system in syndromes of the Ras/MAPK pathway. He currently serves as a member of the CFC Medical Advisory Board, Costello Syndrome Family Support Network Professional Advisory Committee, is the co-chair of the Children's Tumor Foundation International NF1 Bone Abnormalities Consortium, and is a member of the National Prader-Willi Syndrome Association (PWSA) USA Scientific Advisory Board.

He has published over 120 scientific articles, and 2 GeneReviews focused on Ras/MAPK syndromes. Dr. Stevenson first attended multiple CFC conferences and is excited to visit with the families again at the next conference.

### **Sessions:**

#### **Thursday, July 11th, Meet the Experts**

**Friday, July 12th, 10:45 a.m. - 12 p.m. GENERAL SESSION .**

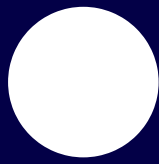
**1 p.m. - 1:50 p.m. BREAKOUT SESSION**

**2 p.m. - 2:50 p.m. BREAKOUT SESSION**

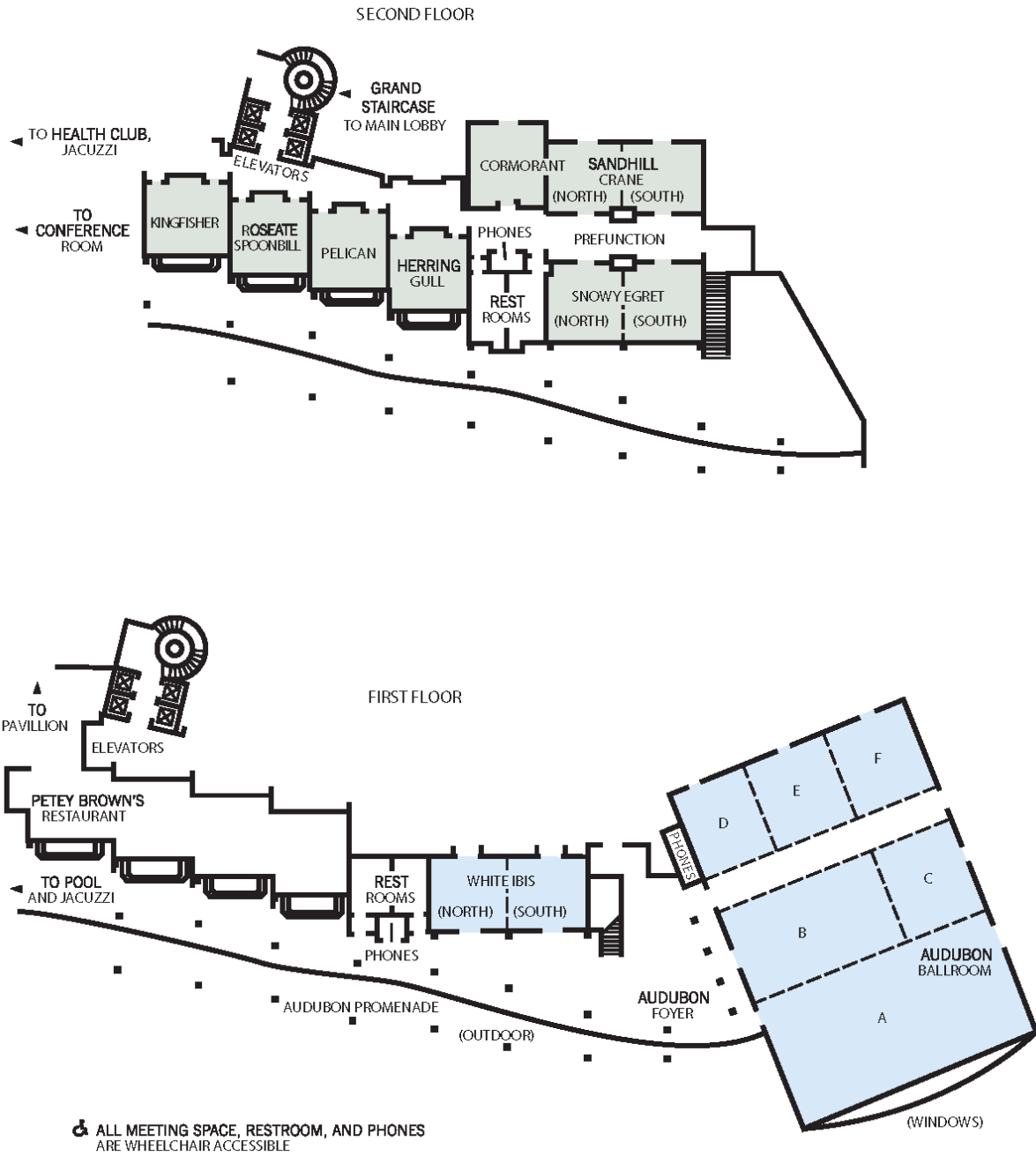
**Audubon ABC**

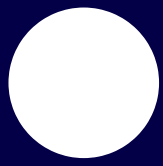
**Sandhill Crane**

**Sandhill Crane**



# Conference Floor Plan





# Directory and Photo Release

## **ATTENDEE DIRECTORY RELEASE**

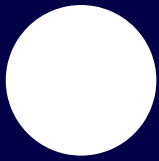
All registrants have been included in the attendee directory unless they have requested in writing to be removed. This list may not be used for personal or business purposes, solicitation, or sold for marketing purposes.

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

When registering for the conference, attendees waived, released and discharged 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 granted permission to CFC International to use their or their child's photograph in legitimate accounts and promotional and educational materials. Attendees received no compensation for the use of their or their child's photograph.







# Onsite Childcare

We have contracted with Kiddie Corp to provide childcare for our families. This service is only **available for children with CFC Syndrome and their siblings**. 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. 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. You must provide diapers and wipes for your child in the childcare lounge. Please label these items with your child's name. CFC Lounge volunteers cannot change diapers. You must visit the CFC Lounge to administer changes.

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

Friday, July 12: 7:30 a.m. - 5 p.m.

Saturday, July 13: 7:45 a.m. - 4 p.m.

**Please pick your children up promptly at noon for lunch, and at close. Our programs are managed by volunteers who depend on being able to participate in dining and other activities. If you are late picking your child up from Childcare or CFC Lounge, you may be asked to refrain from use of these programs.**

## **Locations:**

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

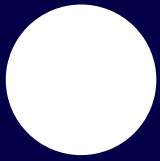
Presidential Suite (14th Floor)

## **Childcare:**

Audubon D,E,F

**Individuals must be pre-registered to participate in these programs.**





# 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."

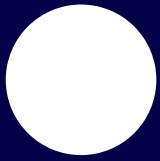
Siblings will play games, talk about the good and not-so-fun parts of having a sibling with CFC Syndrome, and have outrageous fun.

**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 the conference registration/info desk.

This year's Teen Captain is Olivia Greene and Adult Captain is Stephanie Hoffman. Olivia is an energetic, smart teenager whose 6 year old brother Lucas is affected by CFC Syndrome. She will be starting her sophomore year of high school in August. She loves singing and acting and has been in 3 productions. She wants to be a nurse, because being Lucas' sister has made her realize the value and greatness of helping other people.

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:

Wednesday: Welcome Dessert Reception

Friday: Breakfast and Lunch

Saturday: Breakfast, Lunch, and Dinner

Refreshments and food will be served at the Dads' and Mom's Nights Out. There will also be beverages and very light snacks at the Family Pool Party.

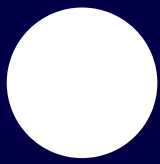
## **Restaurants:**

The hotel is conveniently located by International Plaza, which includes a food court, The Cheesecake Factory, Brio, California Pizza Kitchen, and numerous other chain eating options. The hotel is also conveniently located next to Westshore Plaza, where you can find P.F. Chang's, Maggiano's, a food court and other dining experiences. Both of the locations are accessible by free hotel shuttle, Uber, Lyft or taxi, and are only a 5-7 minute car ride. Located on the Courtney Campbell Causeway are Bahama Breeze and Whiskey Joe's. These two restaurants are mostly outdoor dining experiences and are accessible by a 3-5 minute car, Uber, Lyft, or taxi ride. These two dining experiences are also typically very busy on the weekends, offering a limited family atmosphere.

## **Special dietary needs:**

You should have provided any dietary restrictions at registration. 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. There is a freezer on property for anything that needs to be frozen for proper nutrition of your child with CFC Syndrome. Please see the registration/info desk for assistance.





# Quick Sheet

## **Hotel and Conference Site:**

Grand Hyatt Tampa Bay  
2900 Bayport Drive  
Tampa, Florida

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!

## **Closest Hospitals/ER:**

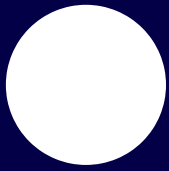
St. Joseph's Hospital  
and St. Joseph's Children's Hospital  
3001 W Dr. Martin Luther King Jr Boulevard, Tampa

Baycare Urgent Care (Adult and Pediatric)  
6909 W Waters Avenue: 8 a.m. - 8 p.m. M-F;  
9 a.m. - 6 p.m. Saturday & Sunday

**Additional Contact Information: See the registration desk or use the hotel house phone.**

*Welcome to  
Florida!*





Thank You to Our Amazing and Generous Sponsors!



**Global Genes®**

Allies in Rare Disease

**Stephanie Kohler  
Scholarship Fund**



*Kinley Klassic*  
& KAMI TOO!

CFC International  
Cardio-Facio-Cutaneous Syndrome

**The Scutero  
Family**



**Miss Leah Borian**



**Darin & Jenny  
Iacobelli**



**VOMAX®**

**Amelie's  
Army**



**Our "One in A Million" Families!**

[www.cfcsyndrome.org](http://www.cfcsyndrome.org)