

2017 CFC Family Conference

June 28 – July 1, 2017
Marriott Sugar Land Town Square
Sugar Land, Texas

Research Declaration of Interest Form

On behalf of CFC, we would like to thank you for your interest in our family conference. The 2017 family conference will bring together children and adults from all over the world with CFC syndrome and provide an unprecedented wealth of resources and opportunities for researchers from around the world to evaluate and study our children.

The family conference will be held **Wednesday, June 28 through Saturday, July 1, 2017** at the **Marriott Sugar Land Town Square**. **Medical research day is set up for Thursday, June 29.**

CFC International and our families understand the rich value of clinical research. We seek research teams dedicated to unraveling the mysteries and discovering new treatments for the characteristics of these genes by participating in studies conducted during the international conference.

To register your research team to conduct one or more studies at this family conference, please complete the form below. Your information will be automatically submitted to the Research Committee for review and you will be contacted in a timely fashion.

We thank you for your interest in supporting individuals with Cardio-Facio-Cutaneous syndrome with the research you plan to conduct!

Policy for Conducting Research

As professionals who wish to conduct research at the family conference or at events sponsored by CFC International, you may do so only upon agreeing to the following stipulations, and receiving written approval from the Research Committee.

Completion and submission of this form constitutes an understanding of and agreement to the following stipulations:

- All research must have current IRB approval or the equivalent for those outside the US.
- Researchers agree to provide CFC International with a report on the progress of the study within 12 months of the event date.
- Researchers agree to disclose to CFC International (if any) standardized assessments they will be administering.
- Researchers understand that there may be hotel room fees to accommodate their space needs.
- Should you require internet services for your research room, you would be responsible for fees charged by the hotel.

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General Information

Date	
Lead Researcher	
Credential(s)	
Position	
Division/Dept	
Organization	
Street	
City	
State	
Country	
Zip	

Phone Number:	
Alt Phone Number:	
Fax:	
Email:	
Alt Email	

Alt Contact Name:	
Alt Contact Email	
Alt Contact Phone:	

Research Study - 1 of 1

A. Title _____

B. Please answer the following in lay language. If you have a document that answers the questions below, you may attach that document. Description attached.

1. Goals of the research

2. Description of the procedures involved

3. Approximate time expected to conduct research/consult for each person

4. Will the study require any sample collection (i.e. blood, saliva, etc)? If so, what sample and how much?

C. Desired age range of participants: _____

D. Research Team Members in addition to the Lead Researcher above:

Name: _____	Credential(s): _____	Role: _____
Name: _____	Credential(s): _____	Role: <u>Co-investigator</u>
Name: _____	Credential(s): _____	Role: <u>Co-investigator</u>
Name: _____	Credential(s): _____	Role: <u>Co-investigator</u>
Name: _____	Credential(s): _____	Role: _____

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E. Please describe your space needs - both ideal and minimum (may require payment to hotel) (i.e number of tables, number of chairs, etc.).

F. Please list any other needs (materials, supplies, information, etc.) that the hotel may need to provide (may require payment to hotel):

If approved, please email us a copy of the following:

1. A copy of your IRB/Ethics Approval document for the research you're conducting at the conference
2. A copy of the informed consent
3. A photograph of the lead researcher
4. A brief summary of the research in plain English for the conference program.

Please list any medical information/records that you would like families to bring or make available to you:

Having medical records sent directly to you using a Medical Release form could make it easier for families to obtain records, give you earlier access to records for review prior to your encounter, and in many instances save families costs involved in getting needed medical records. If you would like to request medical records on any individuals, please provide families a Medical Release form at the time of enrollment.

Thank you so much for your interest in conducting research at the 2017 CFC International Conference! If you have any additional comments or details to provide, please do so here:

Please print additional forms as needed.

**Please scan and email completed form(s) to Gina Peattie at gina@cfcsyndrome.org
If you have additional questions, contact Gina Peattie at the same email address.**

All applications must be received by May 1, 2017.

Thank you.

CFC International