



## 11<sup>th</sup> International Costello Syndrome Family Conference

**July 31-August 4, 2019**  
**Delta Hotels Baltimore Hunt Valley**  
**Hunt Valley, MD USA**

### Research Declaration of Interest Form

On behalf of the Costello Syndrome Family Network (CSFN), we would like to thank you for your interest in our family conference!

The 2019 family conference will assemble the largest gathering of individuals diagnosed with Costello syndrome from all over the world and provide an unprecedented wealth of resources and opportunities for researchers. This conference will be held Wednesday, July 31 through Sunday, August 4, 2019 at the Delta Hotels Baltimore Hunt Valley, Hunt Valley, MD USA.

CSFN and our families affected by Costello syndrome understand the rich value of clinical research. We seek research teams dedicated to unraveling the mysteries and discovering new treatments for the characteristics of this syndrome by participating in studies conducted during the international conferences that have been held biennially since 1999. We count on these research teams to also share what is learned with CSFN to pass on to the families.

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 Costello syndrome with the research you plan to conduct!

#### **Policy for Conducting Research**

As professionals who wish to conduct research at the Costello Syndrome Family Conference, 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 CSFN with a report on the progress of the study within 12 months of the event date.
- Researchers agree to disclose to CSFN which (if any) standardized assessments they will be administering.

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- Should you require internet services for your research room, you would be responsible for fees charged by the hotel.

**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 \_\_\_\_\_**

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: \_\_\_\_\_

Name: \_\_\_\_\_ Credential(s): \_\_\_\_\_ Role: \_\_\_\_\_

Name: \_\_\_\_\_ Credential(s): \_\_\_\_\_ Role: \_\_\_\_\_

Name: \_\_\_\_\_ Credential(s): \_\_\_\_\_ Role: \_\_\_\_\_

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

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

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Please email us a copy of the following along with your completed application:

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(s)
4. A short biography of the lead researcher(s)
5. 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:

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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.

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Your interest in conducting research at the 11<sup>th</sup> International Costello Syndrome Family Conference sponsored by the Costello Syndrome Family Network (USA) is greatly appreciated! If you have any additional comments or details to provide, please enter them here: \_\_\_\_\_

Please scan and email completed form(s) to Sandra Taylor and Ellyn Farrelly at [Research@costellosyndromeusa.org](mailto:Research@costellosyndromeusa.org). If you have additional questions, contact Sandra Taylor at the same email address.

**All applications must be received by May 1, 2019. However, it would greatly assist us in our planning if you could submit your application as soon as possible so the information can be included in registration for the families.**

On behalf of the Conference Research Committee (Sandra Taylor and Ellyn Farrelly), the CSFN Board of Directors, and the Costello families, Thank You!

Sandra Taylor, Executive Director  
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[www.CostelloSyndromeUSA.org](http://www.CostelloSyndromeUSA.org)