

Invitation to perform research at 14th International CHARGE Syndrome Conference August 2-5, 2019 | Dallas, Texas

With more than 1000 attendees, including more than 200 individuals with CHARGE, the International CHARGE Syndrome Conference presents a unique opportunity for research and The CHARGE Syndrome Foundation wants to accommodate as many research projects at conference as possible. We know your plans may not be complete this far in advance, but our planning starts now. If you might be in a position to conduct research at the 2019 Conference in Dallas, please **send a draft proposal** (as outlined below) to me as soon as possible. Keep in mind that no research of any type may be conducted at the International CHARGE Syndrome Conference without the approval of the CHARGE Syndrome Foundation. If you submit a proposal and later are not able to do the research at the conference, that is not a problem.

Submit your draft proposal as a Microsoft Word attachment to meg@chargesyndrome.org by March 1, 2019

Your proposal must include:

- 1) Information on the people conducting the research
 - Name as you wish it to appear in the program (Example: John Smith, PhD.)
 - Institutional, professional, or business affiliation, if any
 - Contact Info: Full Mailing Address, Email address, Telephone Number
 - Professional Bio (please keep to approximately 1000 characters) -- how would you like yourself identified to this group? Please tell us a bit about yourself and your connection to CHARGE:
- 2) A brief description of the rationale and goals of the research
- 3) Information on how the research will be conducted. Some examples might include
 - i. General target participants (e.g. older children with balance problems; everyone)
 - ii. Questionnaires or interviews
 - iii. Sample collection
 - iv. Assessment, examination or testing of child or parents
- 4) How the research will be conducted at conference. For example
 - i. Will you want to contact families prior to conference to sign up?
 - ii. Timing – will this happen throughout conference or at specific times during conference?
 - iii. Will you have Questionnaires available to complete or do interviews?
 - iv. Any space/equipment needs (we do our best but make no promises!)
 - v. Will you need an outlet? Private room? Other?

All research must have proof of local IRB approval prior to Conference.

IRB approval does not need to be in place to submit a proposal.

Proposals will be evaluated as appropriate for our population. If we have any concerns, we will contact you to discuss. Please feel free to contact me (meg@chargesyndrome.org) with any questions or concerns.

I will be in touch with you in the spring for additional details, including a description of research to distribute to conference attendees ahead of time, and I will provide you with more information about what space is available, etc.

And just a reminder, the Call for Presentations deadline is coming up soon (January 31).

Get those proposals in! Here is the link in case you have misplaced it:

<http://www.cvent.com/c/abstracts/b9789c84-1efc-442c-bb98-49f75203bf87>

If there are other researchers that you think would be interested in this conference, please share this information with them.

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