



# CHARGE Syndrome Clinical Database Project



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**Who can do this?** Any adult with CS\* or parent/guardian of an individual with CS can enter data. If you/your child have been diagnosed with CHARGE syndrome (CS), we invite you to participate

**What is this for?** The purpose of this study is to create a comprehensive clinical database and registry of individuals with CS of all ages from all over the world. Information from this database will provide meaningful contributions to CS knowledge and research.

**How will data be used?** For CS research and to share with other CS researchers. See the official Recruitment and Consent [link to Recruitment] form and HIPAA Privacy [link to HIPAA] document. For details of how data may be used

**What sort of questions will be asked?** There are more than 10 sections covering prenatal history to current hearing and vision. For a list and description of the Sections, click here [link to Sections]

**How would I do it?** Participation in this project involves entering data (mostly medical information) into a web-based questionnaire. There are opportunities to directly upload photographs and certain medical records in some sections.

**How long will it take?** Completing the entire questionnaire will take several hours. It can be done in multiple sittings. We may contact you periodically for updates.

**What do I need?** You must have email and Internet access to participate in this project. You will need access to your/your child's medical history. The study is in English only.

**Will I get paid?** No. Your participation is strictly voluntary.

**I have more questions before I decide to participate.** Email your questions to the CSCDP team at [charge-survey@slu.edu](mailto:charge-survey@slu.edu), or contact Meg Hefner directly at [hefnerma@slu.edu](mailto:hefnerma@slu.edu).

**Can I start participating right now?** Yes! Click on this link or copy and paste it into your browser:

<https://redcap.slu.edu/redcap/surveys/?s=ob9YsEXASu>

**Questions about data entry?** See the CSCDP Frequently Asked Questions [link to CSCDP FAQ]  
Thank you for your interest in this study.

Saint Louis University IRB #22507; Approved 6-11-13; Board #3

\* If the individual with CS is over age 18: If you are the guardian, you can consent and enter information on that adult with CS. If the person with CS is an independent adult, he or she must consent to participation and provide HIPAA authorization. The adult with CHARGE may choose to designate someone else to enter their data.