

*What makes up a family in CHARGE: Family Dynamics and Demographics*  
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1) All individuals involved in the research project are students of Dr. Kasee Stratton. There will be approximately 12 students who may assist with data collection: Johnna Dowdy, Megan Anderson, Beth Struna, Matthew Ferrigno, Savannah Trice, Tierra Kilbert, Emily Mathis, Hailey Ripple, Amanda Cosgriff, Alex Clarke, Jordan Parker, & Chathuri Illapperuma.

2) Description:

The purpose of the proposed study is to acquire information on the general demographics and relationships in a family with a child who has CHARGE Syndrome. Presently, there is limited information on the family system, family composition, and how these families compare to other families who have a child with a developmental disability/genetic conditions (e.g., ADHD, Autism, and Down Syndrome). Therefore, we are interested in identifying the family composition in CHARGE Syndrome families. An eligible participant is any adult who is a parent or legal guardian of an individual with CHARGE Syndrome. This study is open to an international population and is not restricted by geographic location or gender; however, the participant must be able to read and write in English. Access to the online questionnaire will be available at the conference during the poster session as well as, through social media (e.g. Bulldog CHARGE Syndrome Lab Facebook page, CHARGE Syndrome Facebook Pages, and Twitter).