

**Study Title: Radiological Imaging in Individuals with CHARGE Syndrome**

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We are conducting a research study to better understand the amount and different kinds of **major diagnostic imaging tests** (such as CT scans, MRIs and feeding studies) that are used in the care of individuals with CHARGE syndrome. Often individuals with CHARGE syndrome undergo numerous radiological imaging tests throughout their care, however, we do not currently know how many radiological imaging tests are being used in the CHARGE population. Our aim is to describe the number of radiological imaging tests and what types of imaging are currently being used in the care of individuals with CHARGE syndrome.

We are seeking caregivers who care for individuals with CHARGE syndrome up to 30 years old, to participate in our study. If you decide to participate in the research study, a member of our research team will ask you to answer questions regarding some major diagnostic imaging tests (such as MRI and CT scans) that your child/ adult with CHARGE syndrome has had done over the course of their care. We will also ask you to provide details of their demographics and CHARGE characteristics. We anticipate this questionnaire will take approximately 20 minutes and will be completed on site at the conference.

If you are interested in participating or have any questions about this study, please come find our research table at the conference or feel free to contact Lauren Fogarty ([lauren.fogarty@dal.ca](mailto:lauren.fogarty@dal.ca); 1-902-229-6267).