

# Research Project

## Experiences of Fatigue Among Adolescents and Adults with CHARGE Syndrome

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**We are investigating what the experience of fatigue is like for adolescents and adults with CHARGE Syndrome through an online survey and individual interviews. If you have been diagnosed with CHARGE Syndrome, you may be eligible to participate.**

**What is this for?** The purpose of this project is to begin to explore how adolescents and adults with CHARGE Syndrome view their experiences with fatigue, what fatigue coping strategies are being used, if any, how effective those strategies are perceived as being, and how the severity of fatigue compares to same-aged peers without CHARGE Syndrome.

**Who can participate?** Any individual with CHARGE Syndrome ages 15 years and older who is able to complete an online survey, willing to participate in an individual interview, and is able to communicate using spoken English and/or American Sign Language.

**What would participants need to do?** Complete an online survey that includes questions about fatigue symptoms (5-15 minutes) and schedule an interview time. Participate in an interview at the CHARGE Conference (30min to 1 hour) during your scheduled time.

**How do participants sign up?** Those who wish to participate in the study should contact Anna Weatherly directly at [weath1a@cmich.edu](mailto:weath1a@cmich.edu) and they will be sent a link to the online survey. People will also be able to sign up for the study the Research Table during the CHARGE Conference.

**If you want more information:** If you have questions, you can contact Anna Weatherly at [weath1a@cmich.edu](mailto:weath1a@cmich.edu) or Dr. Timothy Hartshorne at [harts1ts@cmich.edu](mailto:harts1ts@cmich.edu). Thank you for your interest in this study.