



Poster Presentation

Fatigue: A Proposed Study on the Experiences of Adolescents and Young Adults with CHARGE Syndrome

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Presenter Information

Anna Weatherly is a third-year school psychology doctoral student at Central Michigan University. She has been a member of the CHARGE Syndrome Research Lab at Central Michigan University since August of 2016. Anna's particular interests include examining the experience of fatigue among individuals with CHARGE Syndrome, strategies employed to reduce fatigue and how effective these strategies are. She also holds a Master's Degree in Environmental Psychology from the University of Surrey.

Tim Hartshorne is a professor of psychology, specialized in school psychology, at Central Michigan University. His doctoral degree is from the University of Texas at Austin. He also has a master's degree in counseling and is a licensed professional counselor. He is the grant holder for DeafBlind Central: Michigan's Training and Resource Project, which provides support to children who are deafblind in Michigan. Much of his work is influenced and motivated by his son Jacob, who was born in 1989 with CHARGE syndrome. Tim's particular interests include understanding the challenging behavior exhibited by many individuals with deafblindness, CHARGE, and related syndromes, and also how severe disability impacts the family. He is the lead developer of a deafblind intervener training module on behavior for the National Center on Deaf-Blindness. He has been awarded the Star in CHARGE by the CHARGE Syndrome Foundation. His research was recognized in 2009 with the Central Michigan University President's Award for Outstanding Research. He is a frequent presenter on CHARGE and deafblindness.

Presentation Abstract

Fatigue is something that is experienced by everyone, yet there is reason to suspect that individuals with CHARGE syndrome may experience fatigue at a higher rate or with greater intensity than individuals without CHARGE syndrome. This belief largely stems from the assumption that difficulties commonly experienced by individuals with CHARGE, such as sleep problems, sensory impairments, and problems with emotional-regulation, lead to an increase in the frequency of fatigue symptoms. However, there has been no systematic research into the experience of fatigue among individuals with CHARGE to empirically support this belief. This poster presentation will present a proposed empirical study into the experiences of fatigue among adolescents and young adults with CHARGE syndrome.