



Poster Presentation

Unique Pattern of Social Skills in Individuals with CHARGE Syndrome

Dr. Lori Swanson, University of Wisconsin-River Falls

Meg Hefner, Saint Louis University

Jennifer Wilking, University of Wisconsin-River Falls

Presenter Information

Dr. Lori Swanson is a former board member of the CHARGE Syndrome Foundation. She was co-chair of the Education Committee with Kathy McNulty. She sponsored many of the educational webinars for the CHARGE Syndrome Foundation. She also contributed to the CHARGE Accounts newsletter. She is the author of a chapter on "Communication" and co-author of a chapter entitled "Forms and Functions in Communication" in the CHARGE Syndrome book (Hartshorne, Hefner, Davenport, & Thelin, Eds.). Dr. Swanson's primary research interest is the communication skills of individuals with CHARGE syndrome. She is a professor in the Department of Communication Sciences and Disorders and a practicing speech-language pathologist.

Meg is a genetic counselor with more than 35 years' experience with CHARGE syndrome. She was a founding member of the CHARGE Syndrome Foundation, Inc. and has written extensively on CHARGE for families (editor of the Management Manual for Parents), geneticists (American Journal of Medical Genetics special issues on CHARGE syndrome), and professionals working with children with CHARGE (CHARGE Syndrome, Plural Publishing). Recognition for her CHARGE syndrome work include the Stars in CHARGE award from the CHARGE Syndrome Foundation and the Diane Baker Alumni Award from the University of Michigan Genetic Counseling graduate program. Meg has presented at every CHARGE Syndrome Conference and actively answers genetic and medical questions via email and on several CHARGE Facebook pages.

Jennifer Wilking is a master's students in the Department of Communication Sciences and Disorders at the University of Wisconsin-River Falls. Ms. Wilking was previously a preschool teacher with the Community Action Partnership of Ramsey and Washington Counties.

Presentation Abstract

CHARGE syndrome is a rare genetic disorder (CHD7) which causes multisensory impairments. Most have vision loss, hearing loss, decreased sense of smell, and balance problems. Delays in language and social skills in young children with CHARGE have been described, despite their outgoing personalities. In a pilot study, individuals with CHARGE had impaired social skills and behaviors as measured by the Social Skills Improvement Systems (SSIS). They showed a unique pattern of social skills deficits as described in other studies. This study also examined the social skills of individuals who have CHARGE syndrome using the SSIS. Sixteen individuals with CHARGE and their parents participated. Individuals with CHARGE completed a student questionnaire, and their parents completed a parent questionnaire. The response format on the student questionnaire of the SSIS was modified to accommodate the needs of participants with multi-sensory impairments. All parent response forms provided valuable information. Most student response forms provided differential responses to the items on the questionnaire. The unique profile of social skill deficits will be discussed as well as implications for intervention.