



Poster Presentation

## Breakdowns in Parent and Professional Communication

Sydney Randle, Tim Hartshorne, PhD

CHARGE Syndrome Research Lab at Central Michigan University

### Presenter Information

Sydney Randle is a junior at Central Michigan University and a member of the CHARGE research lab led by Timothy Hartshorne. I am also a caregiver for Jacob Hartshorne and therefore have direct experience in working with individuals with CHARGE.

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

Parents or guardians of children with CHARGE sometimes feel unheard or ignored when communicating concerns, observations, or interpretations to medical and other professionals. This lack of professional listening to parents can lead to medical and health problems in the individual of CHARGE, and lead to parents feeling mistrust and frustration towards professionals working with their child. For my study I have investigated (1) the degree to which parents and guardians feel "heard" when addressing professionals about their child with CHARGE, (2) methods used by parents to get professionals to listen, (3) potential situations that arise when parents are ignored by professionals, and (4) the important factors that comprise the relationship between parents and professionals. My research is based on gathering stories from the CHARGE community on their experiences with professionals in order to understand where problems are arising, and from a survey to determine the extent of the problem. I have also been investigating methods parents and professionals may use to better nurture and respect the professional/parent relationship to provide the best outcome for a child with CHARGE syndrome.





# Breakdowns in Parent and Pediatrician Communication in CHARGE Syndrome

Sydney Randle, Dr. Timothy Hartshorne • Psychology Department • Central Michigan University

## Proposed Study

### Study Learning Objectives:

- The degree to which parents and guardians feel “heard” when addressing professionals about their child with CHARGE.
- Methods used by parents to get professionals to listen.
- Potential situations that can arise when parents are ignored by professionals.
- The important factors that comprise the relationship between parents and professionals.

### Methodology:

The study will be performed as a survey of the CHARGE community in the form of a questionnaire. The participants will be parents of children with CHARGE syndrome and consist of both qualitative and quantitative rating scales regarding several aspects of the relationship between parents and their child’s pediatrician.

The overall goal of this study is to gain an insight into the communication and interactions that occur between parent and professional, and the impact that they have on their overall relationship.

## Introduction

Parents or guardians of children with CHARGE sometimes feel unheard or ignored when communicating concerns, observations, or interpretations to medical and other professionals. This lack of professional listening to parents can lead to medical and health problems in the individual with CHARGE, and lead to parents feeling mistrust and frustration towards professionals working with their child.

## Why is Communication Important?

### Trips to the doctor

- Because of the wide range of medical and behavioral symptoms observed in CHARGE syndrome, children may have to go to the doctor many times.
- For Example Blake, MacCuspie, Hartshorne, Roy, Davenport, & Corsten (2008) found in 9 individuals with CHARGE the average number of surgeries was 21.9.



<https://www.chargesyndrome.org/for-families/communication/>



<https://www.cmich.edu/colleges/class/Psychology/charge/Pages/CHARGE-Syndrome.aspx>

## What is CHARGE Syndrome?

A genetic syndrome that describes a group of common symptoms that include:

- Coloboma of the eye
- Heart abnormalities
- Atresia of the choanae
- Retardation of growth
- Genitourinary
- Ear abnormalities and hearing loss

Many of these symptoms are indicative of lapses in several sensory systems, especially in vision and hearing.

(Hartshorne, Hefner, Davenport, & Thelin, 2011)

### Adaptive Communication in CHARGE syndrome

- “Typical” modes of communication may not develop normally in CHARGE children due to lack of certain sensory systems such as sight and hearing (Thelin & Fussner, 2005).
- Communication is higher in communication “bubble”. (Hartshorne & Hissong, 2014)
- Includes a spectrum of communicative abilities that ranges from using full sentences to displaying a cryptic collection of physical and verbal behaviors.
- Some common modes of communication: American Sign Language, derived sign language, grunting, rocking, and use of visual pictures and symbols.

### The interpreters of Children with CHARGE Syndrome

- Due to lapses in communication, children with CHARGE syndrome rely strongly on partners in communication who can assist them in interacting with the world (Rose & Haubrich, 2013).
- The people that are closest to a child with CHARGE syndrome (usually parents or other caregivers) typically become experts in the child’s communication.
- Parents and caregivers are able to understand how to decipher and interpret certain behaviors to infer meaning and cause.
- Though doctors are trained in some areas of understanding communication, it is impossible for them to understand each individual’s meaning behind certain communication mechanisms.

### Physician and Parent Communication

- Latour, Van-Goudoever, et al. (2011) found that the attitude of healthcare professionals and management/communication of information was very important to parents.
- It has been brought up in the CHARGE community that doctors sometimes act superior to parents and ignore opinions or interpretations of behavior that parents express.
- Parents become advocates for their CHARGE affected child because they are often able to understand their child’s communication.

- Doctors ignoring parental questions, opinions, and interpretations could lead to misdiagnosis and mistrust

## Contact Information

Please contact Sydney Randle or Dr. Timothy Hartshorne if you have any questions:

Phone: 616-929-2183

E-mail: [randl1sr@cmich.edu](mailto:randl1sr@cmich.edu) E-mail:

[randl1sr@cmich.edu](mailto:randl1sr@cmich.edu), [harts1ts@cmich.edu](mailto:harts1ts@cmich.edu)