



NOTES TO MY YOUNGER SELF PROJECT

PARENTS OF CHILDREN WITH DEAFBLINDNESS AND/OR CHARGE SYNDROME EDITION

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The “*Notes to My Younger Self Project*” is a research initiative that attempts to gather the wisdom, perspectives, advice and encouragement of parents, grandparents, and guardians of children, youth and adults with Deafblindness and/or CHARGE Syndrome and create a repository of the thoughts from experienced parents and caregivers. The central focus of this study is to identify key themes and collective advice of parents with children who are deafblind and/or have CHARGE Syndrome through submission of a Letter written to themselves at the birth of their child expressing advice, encouragement and hope.

A simple vehicle to gather data has been developed and implemented in an on-line survey that asks identified parents one question or prompt:

Looking back, what advice would you give to your younger self at the beginning of this journey with your child with deafblindness and/or CHARGE Syndrome? You may consider writing a letter to yourself at the birth of your child with deafblindness and/or with CHARGE Syndrome expressing advice, encouragement and hope.

Please consider participating in the research study by accessing this online survey with the following link(s):

English: https://tcnj.co1.qualtrics.com/jfe/form/SV_5jM5DqUfrccVrue

Spanish: https://tcnj.co1.qualtrics.com/jfe/form/SV_795o8IaA3PAqdz8

French: https://tcnj.co1.qualtrics.com/jfe/form/SV_795o8IaA3PAqdz8

If you have any questions or need further clarity please contact: Jerry G Petroff, PhD at petroff@tcnj.edu. Thank You for considering participating in this study that focuses on yielding information by parents for parents.