

Information Sheet

TITLE OF RESEARCH: Otoscope Experience: Impact of Early Diagnosis of Usher Syndrome

IRB PROTOCOL NO.: E160712002

INVESTIGATOR: Caitlin Wright

SPONSOR: UAB Genetic Counseling Training Program

Purpose of the Research

The purpose of this research is to assess the psychosocial implications on parents of children with early diagnosis of Usher Syndrome. Individuals who are affected with Usher syndrome typically have congenital profound hearing loss, and begin to experience vision loss around adolescence. Historically, Usher syndrome has been diagnosed based on ophthalmologic findings. Therefore, individuals were not diagnosed with Usher syndrome until adolescence, once they started to experience vision loss. Since the recent advent of molecular genetic testing for hearing loss, Usher syndrome has been diagnosed during infancy and early childhood. Essentially, children are diagnosed with Usher syndrome before they begin to experience vision loss. The knowledge that their child will eventually experience vision loss could lead to psychosocial implications, such as increased anxiety. With this study, we hope to compare parent experiences for those whose children received a diagnosis at a young age to those who received a diagnosis at a later age. You have been invited to participate in this research because you are the parent of a child who has been diagnosed with Usher syndrome. This study will enroll around 15-20 participants.

Explanation of Procedures

If you choose to participate in this study, you have the option of participating in either a phone interview or an in-person interview. Each interview will take approximately 30-45 minutes. Your responses will be confidential.

Your participation in this research interview is strictly voluntary. You may choose to withdraw from the study at any time by cancelling or stopping the interview.

Risks or Discomforts

We do not anticipate any risks involved in this study, as we are collecting information during the interview on your feelings and impressions. We are not collecting identifiable information and do not anticipate any risks related to privacy.

Benefits

You may not benefit directly from taking part in this study. However, this study may help us better understand how the diagnosis of Usher syndrome in children of younger ages affects parents, and how to better care for these families.

Confidentiality

We will not collect identifying information such as your name, address, date of birth, or place of employment. All data is stored in a password protected electronic format. Information obtained will be kept confidential to the extent allowed by law. The results of the study will be used for scholarly purposes only and may be shared with The University of Alabama at Birmingham representatives and any peer reviewers for publication purposes.

Voluntary Participation and Withdrawal

Your participation in this research interview is strictly voluntary. There will be no penalty if you decide not to participate in the study. You have the option of choosing to participate in either a phone interview or an in-person interview. You may choose to withdraw from the study at any time by cancelling or stopping the interview. Your care at UAB will not be affected by whether or not you choose to participate in this study.

Cost of Participation

There will be no cost to you for taking part in this study. If you choose to have an in-person interview, you are responsible for your travel to UAB to meet in person. If you choose a phone interview, there are no anticipated costs.

Payment for Participation in Research

There will be no compensation for participating in this study.

Questions

If you have questions or concerns about this research study, please do not hesitate to contact me (the principal investigator). I will be happy to answer any questions.

Caitlin Wright

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If you have questions about your rights as a research participant, or concerns or complaints about the research, you may contact the Office of the Institutional Review Board for Human Use (OIRB) at (205) 934-3789 or 1-800-822-8816. If calling the toll-free number, press the option for “all other calls” or for an operator/attendant and ask for extension 4-3789. Regular hours for the Office of the IRB are 8:00 a.m. to 5:00 p.m. CT, Monday through Friday. You may also call this number in the event the research staff cannot be reached or you wish to talk to someone else.