School of Medicine
Neuroscience Center of Excellence

To whom it may concern:

I would like to let you know about a research study that may be of interest to you or someone you know and ask you to consider referring them for possible participation.

Usher syndrome is a hereditary disorder characterized by varying degrees of hearing, balance and visual loss, depending on the genotypic diagnosis. Despite having identified mutations responsible for Usher, a genotype-phenotype correlation is not well understood. We are conducting an Usher syndrome type 1C (USH1C) Natural History Study and attempting to contact all patients throughout the world with USH1C and encourage them to participate. The overall goals of the study are to gather population data through a retrospective chart review of USH1C patients to determine the worldwide prevalence and clinical natural history of the different USH1C alleles. We are requesting that you provide the attached Natural History Study flyer to anyone you know with USH1C so that they can contact us.

Individuals that meet the following criteria may be eligible:

Inclusion criteria includes:
- Patients diagnosed with Usher Syndrome type 1C (USH1C)
- Minimum 3 months follow up

Exclusion criteria:
- Those who do not wish to participate

We look forward to speaking with you or someone you know who may be interested in participating in this study. Please feel free to contact me with questions using the contact information provided below.

Thank you for your time and consideration.

Sincerely,

Jennifer J. Lentz, PhD
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Please leave a message with a contact number and your call will be returned within 1 to 2 business days.