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Patient Registry for Individuals with Otoferlin-Associated Hearing Loss

What is the Otoferlin Registry?

The Otoferlin Registry collects clinical information (various hearing tests and medical information) as well as genetic (otoferlin, *OTOF*) mutation details for research and therapy development. Through consent and participation, the Otoferlin Registry aims to advance scientific knowledge by connecting (pseudonymized) patient data with scientists at the Institute for Auditory Neuroscience at University Medical Center Goettingen who have shown decades-long interest in understanding the mechanisms of several forms of hereditary hearing impairment, among which includes otoferlin.

The Institute of Auditory Neuroscience and Institute of Human Genetics at University Medical Center Goettingen are collaborating to initiate a study in which we aim to collect and evaluate the clinical and genetic findings of individuals with mutations in the otoferlin gene. This will allow us to better understand the relationship between mutations and hearing loss and to improve patient care as new therapies are optimized. To support this goal, we have established a patient registry for voluntary participation and sharing of clinical and genetic information in questionnaire form.

This registry study was approved by the Ethics Committee of the University Medical Center Goettingen (Approval: 17/8/22; Study Center ID: 2023-02528).

Who can participate in the Otoferlin Registry?

The Otoferlin Registry is open to the global otoferlin community that includes parents and legal guardians, as well as individuals who have been diagnosed with hearing impairment due to otoferlin mutations.

Where can participants find out more information?

We invite prospective participants to review detailed study information and submit consent. This also includes information about the processing of personal data. This can be found here: http://www.auditory-neuroscience.uni-goettingen.de/otoferlin_registry.html

Who can participants contact for more information?

If you have questions or would like further clarification about the procedure, please contact the study manager, Dr. Barbara Vona via email: barbara.vona@med.uni-goettingen.de