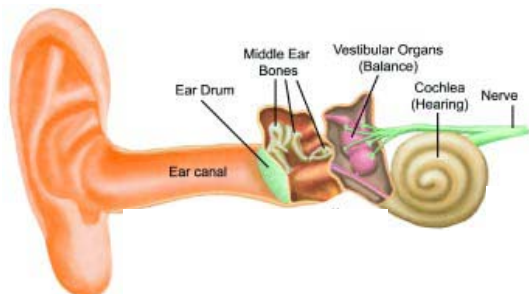


## Hearing Loss

The ears have many parts, all of which can be damaged to cause hearing loss. Of all types of disabilities, hearing loss is the most common.

Many things can cause hearing loss, including infections, noise exposure, injury, some medications, and genetic changes.

## Anatomy of the ear



## Hereditary Hearing Loss

Hereditary hearing loss, which occurs because of changes to genes, may be passed on from generation to generation. Discovery of the genetic cause of a hereditary hearing loss can help us to:

⌘ Predict which family members will be at risk for the loss and provide proper testing and services to them.

⌘ Predict whether the hearing loss will remain the same or worsen over time.

⌘ Help determine if problems besides hearing loss may be present.

## Additional Information

⌘ Information about you and your family, collected during the study, will be kept strictly confidential.

⌘ If you agree to take part in the study, none of your relatives will be contacted without your permission.

⌘ You or any family members taking part may withdraw from the study at any time.



## CONTACT INFORMATION

**Carol Negrijn**  
Room 1756, Level 1, HSC  
300 Prince Philip Drive  
St. John's, NL, A1B 3V6

**Phone:** 709-777-8499  
**Toll Free:** 1-888-908-4988  
**Fax:** 709-777-8532  
**E-mail:** cnegrijn@mun.ca

## Newfoundland and Labrador Hereditary Deafness Study



A research project is currently underway at MUN's Faculty of Medicine to identify genes involved in hereditary hearing loss. We need the assistance of many people to do this research. We are hoping that you can help.

## What is this study about?

Some forms of deafness are hereditary. This means that the deafness is inherited as the result of an altered gene.

A gene is a piece of genetic material (DNA) which is passed from parents to children.

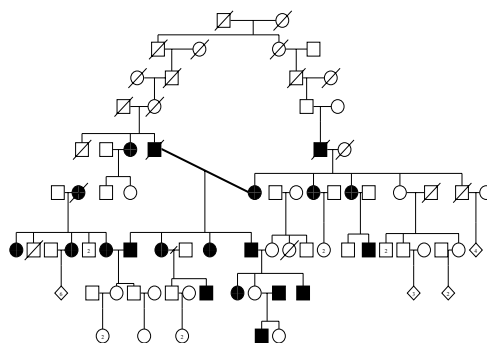
If we can identify the genes in each family that are altered, we might learn what goes wrong in some forms of deafness and how it might be treated. This will lead to better treatment and management of the disability.

## Why study genes and hearing loss?

The purpose of our research is to identify all genes that cause hearing loss and deafness in the Newfoundland and Labrador population.

## What will you be asked to do?

⚡ We will ask the first person we contact in the family to complete a hearing loss questionnaire. Then we draw a family tree:



### Legend:

□	Male, hears well	■	Male, hearing loss
○	Female, hears well	●	Female, hearing loss

⚡ We will ask you to give a blood sample, about two tablespoons of blood, in order to obtain your DNA.

⚡ We will ask you to sign a consent form allowing us to look at your family tree, access the medical records related to your deafness, and examine your DNA.

⚡ Depending on the number of people in your family with hearing loss/deafness, we may ask that some of your relatives take part in the study.

⚡ You may be asked to have your hearing tested.

## Are there any risks in taking part in this study?

There is no risk to your health.

However, it may be uncomfortable giving a blood sample; the questionnaire, if you were asked to complete one, will take 30 to 60 minutes of your time; and it may be difficult to discuss and recall your family's history of deafness.

## What are the benefits of taking part in this study?

⚡ Knowledge gained from the study will be shared with families, as well as doctors and genetic counsellors, to benefit those at risk.

⚡ You will have the opportunity to learn what hereditary hearing loss means.

⚡ You will have the opportunity to contribute to our understanding of hereditary hearing loss and deafness.

⚡ You may be informed about future studies in hearing loss and deafness in which you would like to take part.