

TSEngage

Request for Research Participants

To enroll or to discuss any questions you have about participating in our study, please contact:

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Phone: +1 (855) 219-7486 (toll-free)



Public Health
Agency of Canada

Agence de la santé
publique du Canada



Eligible Participants:

Those who have received a diagnosis of
Creutzfeldt-Jakob disease (CJD)

Those who carry a genetic mutation
associated with a Transmissible Spongiform
Encephalopathy (TSE)

Those who are a family member of individuals
who fit the above criteria

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WHAT IS THE STUDY ABOUT?

All human prion diseases, both genetic and sporadic, are broadly referred to as **Transmissible Spongiform Encephalopathies or TSEs**. Tests to diagnose human TSEs include measuring the levels of proteins, the small building blocks of cells, in cerebrospinal fluid to look for biological fingerprints that can indicate disease. These are called biomarkers. This procedure can be uncomfortable, so it is performed infrequently and after the onset of symptoms.

This study will investigate biomarkers from bodily fluids that are easier to collect such as saliva, tear, and nasal fluid. The goal of the study is to develop markers from easily-accessible bodily fluids that can be used to detect disease in early stages (such as before the appearance of symptoms) and to track disease progression.

About Us

TSEngage is a research initiative of the Prion Diseases Section (PDS) operated by the National Microbiology Laboratory of the Public Health Agency of Canada. The PDS team is the sole provider of diagnostic testing for TSEs in Canada and conducts research to enhance our understanding of human prion diseases.



WHAT WILL I BE ASKED TO DO?

Participants will be asked to donate saliva, tear, and nasal fluid using at-home testing kits once a year. Participants will also be requested to donate blood annually at their local clinic. For participants showing symptoms, samples will be collected every 3 weeks by medical staff.



WHAT IS THE BENEFIT?

Participating in this study will not directly benefit you. However, the information gathered may help identify patients in the early stages of disease, contribute to therapeutic development, and increase diagnostic accessibility in remote Canadian populations.



WHAT ARE THE RISKS?

Participants may experience some discomfort when collecting tears and nasal samples. However, neither collection technique should cause pain. While the collection methods are generally safe, it is important to acknowledge that all procedures carry some level of risk, albeit very small. All bodily fluids collected for this study are classified as non-infectious and therefore there is no risk of spreading disease through these sample donation techniques.



HOW DO I JOIN?

If you are interested in joining this research study or would like more information, please contact our research team!