



FTD DISORDERS REGISTRY FAQ

The purpose of FTD Disorders Registry research is to improve our understanding of FTD disorders, increase awareness, and facilitate additional research. To participate you must be an individual diagnosed with an FTD disorder, or a family member, caregiver, or friend of a person diagnosed with one of the FTD disorders.

The FTD disorders are: behavioral variant FTD, the primary progressive aphasia (PPA), progressive supranuclear palsy (PSP), corticobasal degeneration (CBD), and FTD-ALS.

WHAT YOU CAN DO

You can find out more about the FTD registry by visiting our website at www.FTDRegistry.org, and by following us on social media. You can also invite caregivers, family and friends to get involved by sharing the website and spreading the word on social media.

WHAT IS A REGISTRY?

A registry is an electronic database of information about individuals with a specific disorder or medical condition. Registries are often created by patient groups, researchers, or medical professionals to collect information into a central location.

WHAT IS THE FTD DISORDERS REGISTRY?

The goal of the FTD Registry is to be a Contact and Research Registry. It is designed to collect information from people diagnosed with FTD, their caregivers, family members and friends to study all aspects of life with these devastating diagnoses so scientists and clinicians can better understand them. To maintain privacy, FTD Registry research participant information is made anonymous.

AM I ELIGIBLE TO JOIN THE CONTACT REGISTRY?

To join, you must be a person diagnosed with FTD, a family member, caregiver, or friend of a person diagnosed with FTD. **When you join you'll receive the latest FTD news, research updates, and notifications about studies. International participant enrollment is Welcome and Encouraged!**

AM I ELIGIBLE TO PARTICIPATE IN REGISTRY RESEARCH?

To participate, you must be a person diagnosed with an FTD disorder, a family member of someone diagnosed with FTD, or a caregiver or friend of a person diagnosed with FTD. **You must be at least 18 years of age and a resident of the US or Canada (19 in those states or provinces where the age of majority is 19; Alberta, Saskatchewan, Newfoundland and Labrador currently excluded).**

WHAT HAPPENS IF I TAKE PART IN REGISTRY RESEARCH?

If you participate, you will complete a series of surveys. The surveys will ask things about you, what you or your loved one experienced recently, and whether you might be able to participate in more research or a clinical trial. **These basic surveys will take less than 30 minutes each to complete for most people.** As a research participant, you may also be invited to participate in additional study activities. These studies may have a separate consent form and will be explained in detail before you decide whether to participate.

HOW LONG MUST I PARTICIPATE?

Your participation in this registry has no set time limit, you can stop participating at any time. **Taking part in the research is completely voluntary—it is your choice.**

WHAT ARE THE BENEFITS TO YOU FOR PARTICIPATING IN THE REGISTRY?

Participation in the FTD Disorders Registry may not benefit you personally, medically or financially. However, your participation may benefit you and others with FTD or caregivers or family members of persons diagnosed with one of the FTD disorders **by helping researchers to improve their understanding of these rare and debilitating disorders**. Collected data may help speed up research to find and test potential treatments, and facilitate other medical advances to improve the outlook for individuals diagnosed with FTD disorders. In addition, Registry participants can choose to receive updates about clinical research studies or trials for which they may be eligible.

WHAT IS INFORMED CONSENT?

Research studies only include people who choose to take part. The Registry provides a form that describes your participation. This form is called “informed consent” and it documents your agreement to willingly participate.

ARE THERE ANY RISKS TO PARTICIPATING?

The risks of taking part in the FTD Disorders Registry are low. By looking at summarized data contributed by all participants, you may learn information that may be difficult or upsetting to you. You may find some questions asked in the surveys embarrassing, difficult or uncomfortable to answer. It is important to recognize that each person with an FTD disorder is unique, and the answers are important to learn about FTD.

IS MY DATA SAFE?

Loss of private or confidential information is a risk any time you share information. **To keep this risk low, your information is stored in a secure online database.** This database uses a security system with many safeguards and protections. Compliance to HIPAA (Health Insurance Portability and Accountability Act) rules and standards and Canadian privacy laws also serve to minimize risks to the participants. Only the Registry Director will have access to information that identifies you.

HOW DOES THE REGISTRY DE-IDENTIFY YOUR INFORMATION?

When you register as a research participant, a research account is created with a login name and a password. This information is used to assign a unique alpha-numeric code to your profile called a Global Unique Identifier, or GUID. The GUID is associated with the data that you entered in the registry **so that no personally identifiable information is ever linked to a research survey or other study**. Only the Registry Director has access to this code. The Registry will not maintain nor report data in a way that an individual registrant can be identified by their answer.

WHAT HAPPENS TO THE INFORMATION COLLECTED IN THE FTD DISORDERS REGISTRY?

Registry data may be used in scientific presentations and publications to help inform the research community and public about FTD disorders. Scientists, clinicians, and other researchers can request access to the data stored in the Registry. Only anonymized data will be shared with researchers or published/ presented at scientific meetings. **The Registry will never release any personal information such as name, address, email, or phone number.**

WHO “OWNS” THE DATA IN THE REGISTRY?

The FTD Disorders Registry LLC is the guardian of the information contained within the FTD Disorders Registry. The LLC is a not-for-profit corporation set up just for the purpose of building and maintaining this as a resource to the community.

QUESTIONS?

If you have questions about the FTD Disorders Registry or research participation, contact the Registry Director by email (director@ftdregistry.org) or by phone (888-840-9980).

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