



FTD DISORDERS REGISTRY FAQ

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

The FTD disorders include: behavioral variant FTD (bvFTD), 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 a 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 protect your privacy, participant information is made anonymous.

AM I ELIGIBLE TO JOIN THE CONTACT REGISTRY?

To join the Contact Registry, you must be a person diagnosed with FTD, or a family member, caregiver, or friend of a person diagnosed with FTD. Contact Registry enrollment is open to anyone in the world. **You must be at least 18 years of age (19 in states and provinces where the age of majority is 19).** When you join, you will receive the latest FTD news, research updates, and notices about studies. *International 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, or a family member, caregiver, or friend of a person diagnosed with FTD. **You must be at least 18 years of age and a resident of the United States or Canada (19 in those states or provinces where the age of majority is 19; Alberta, Saskatchewan, and Newfoundland and Labrador currently excluded).**

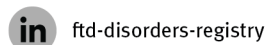
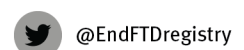
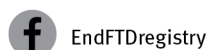
WHAT HAPPENS IF I TAKE PART IN REGISTRY RESEARCH?

If you participate, you will fill out 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 other research or a clinical trial. **For most people, each survey will take less than 30 minutes to do.** As a research participant, you may also be asked to participate in other studies. These studies may have a separate consent form and will be explained in detail before you decide whether to participate.

WHAT IS INFORMED CONSENT?

Research studies only include people who choose to take part. The Registry has a form that describes your participation. This form is called “informed consent,” and it says that you freely choose to participate.

FTD Disorders Registry LLC
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HOW LONG MUST I PARTICIPATE?

Your participation in this Registry has no set time limit. You can stop 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 the FTD community **by helping researchers better understanding these rare and debilitating disorders.** Collected data may help speed up research to find and test potential treatments, and result in other medical advances to improve the outlook for individuals diagnosed with FTD. In addition, Registry participants can choose to receive updates about clinical research studies or trials in which they can enroll.

WHAT ARE THE RISKS OF PARTICIPATING IN THE REGISTRY?

The risks of taking part in the FTD Registry are low. By looking at the data contributed by all participants, you may learn information that is difficult or upsetting to you. You may find some questions asked in the surveys embarrassing, hard, or uncomfortable to answer. It is important to know 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. Voluntary compliance to HIPAA (Health Insurance Portability and Accountability Act) rules and standards, Canadian privacy laws, and the European Union's General Data Protection Regulation (GDPR) help minimize risks. The personally identifiable information that you give to join the Registry is only seen by select FTD Disorders Registry staff on a strictly "need-to-know" basis and **is never shared.**

HOW DOES THE REGISTRY DE-IDENTIFY MY 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 (numbers and letters) to your profile called a Global Unique Identifier, or GUID. The GUID is associated with the data that you entered so that **your identity cannot be linked to a research survey or other study.** Only select members of the FTD Registry team have access to this code on a strictly "need-to-know" basis. **The Registry will not keep or report data in a way that someone 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 anonymous 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?

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

QUESTIONS?

If you have questions about the Registry or research participation, please contact us by email at manager@FTDregistry.org or by phone at 888-840-9980.

Join the Registry. Tell your story. Advance the science.

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