



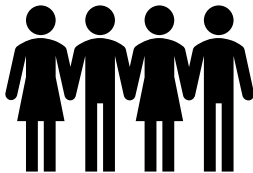
**FTD DISORDERS**  
**REGISTRY**<sup>®</sup>

## Engaging in Research thru the Registry

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Project Manager  
FTD Disorders Registry

# What is a Patient Registry?

- Tool for facilitating research
  - Provides a flexible platform for developing research
  - Important in rare diseases such as FTD
- A system to collect and securely store standardized information about a group of people, usually focused on a specific **diagnosis or condition**
  - Cancer (disease and genetic)
  - Kidney Transplant
  - Coronavirus (COVID-19)



# FTD Disorders Registry (FTDDR) Overview

*A patient/family/caregiver registry with a nonprofit mission*



**Mission:** To facilitate and advance research into the spectrum of FTD disorders and to accelerate the developments of treatments by providing tools and resources that:

- Promote and support research participation
- Amplify the voice of patients' and families' lived experience
- Enable access and sharing of data with researchers

# FTDDR Overview Continued

## Why Join

- Share your insights into FTD to improve knowledge of FTD and guide improvements to research design and clinical care
- Participate in research and advance the science from the comfort of your home
- Stay informed about FTD research, including when studies are recruiting for people like you

The screenshot shows the homepage of the FT Disorders Registry. At the top left is the logo, which consists of a cluster of colorful hexagons next to the text "FTD DISORDERS REGISTRY". To the right of the logo are links for "ABOUT US | PRESS | CONTACT US" and "PARTICIPANT LOGIN". Below the logo is a navigation bar with five tabs: "WHY JOIN", "FIND A STUDY", "WAYS TO HELP", "FOR RESEARCHERS", and "FTD DISORDERS RESOURCES". The main content area features a large image of a woman and a young girl smiling together. Overlaid on the image is the text: "IN THE WORLD OF FTD, EVERY STORY ADVANCES THE SCIENCE. Starting with yours." To the right of the image is a blue box with the heading "TOGETHER WE CAN FIND A CURE FOR FTD" and a paragraph: "The FT Disorders Registry is a powerful tool in the movement to create therapies and find a cure. Together we can help change the course of the disease and put an end to FTD." Below this is a "JOIN THE REGISTRY" button with a right-pointing arrow. Underneath the button is a small text block: "Your privacy is important! We promise to protect it. We will not share your contact information." and a link to "Read Full Privacy Statement". At the bottom of the page, there is a section titled "WHAT IS THE FTD DISORDERS REGISTRY?" with a link to "LEARN MORE ABOUT THE REGISTRY AND FTD SPECTRUM". To the right of this section is a paragraph explaining the registry's purpose: "The Registry is an online database to collect information from those affected by all types of Frontotemporal Degeneration: behavioral variant FTD (bvFTD), any one of the primary progressive aphasias (PPA), progressive supranuclear palsy (PSP), corticobasal degeneration (CBD), or FTD with motor neuron disease (also called FTD/ALS). Persons diagnosed, (current/former) caregivers, family, and friends can join. As a member of the Registry, you can help us advance the science and move faster toward finding treatments and cures. The first step is simple: tell us your story." Below this paragraph is the slogan: "Join the Registry. Tell your story. Advance the science."

# Enrolling in the FTDDR

[FTDregistry.org](https://FTDregistry.org)



The image consists of three vertical panels, each featuring a portrait of a person and a corresponding enrollment category. Each panel has a light blue background with a white arrow pointing right, containing the word 'YES' and a right-pointing arrow. The first panel shows a smiling Black man and is titled 'I AM DIAGNOSED WITH FTD'. The second panel shows a woman with long dark hair and a pink scarf, titled 'I AM A FAMILY MEMBER (BIOLOGICAL RELATIVE)'. The third panel shows a man with short brown hair, titled 'I AM A SPOUSE, CAREGIVER, OR FRIEND'.

**YES →**

**I AM DIAGNOSED WITH FTD**  
enrolling myself in the Registry  
or joining with help of a care partner.

**YES →**

**I AM A FAMILY MEMBER (BIOLOGICAL RELATIVE)**  
of a person who is/was diagnosed with FTD  
enrolling myself in the Registry.

**YES →**

**I AM A SPOUSE, CAREGIVER, OR FRIEND**  
of a person who is/was diagnosed with FTD  
enrolling myself in the Registry.



- Behavioral Variant FTD (bvFTD)
- Primary Progressive Aphasia (PPA)
- Progressive Supranuclear Palsy (PSP)
- Corticobasal Degeneration (CBD)
- Frontotemporal Dementia-Amyotrophic lateral sclerosis (FTD-ALS)

# Enrolling in the FTDDR Continued

[FTDregistry.org](http://FTDregistry.org)



Terms &  
Conditions

Privacy  
Policy

Today's Date

Name

Address

Contact  
Information

FTD  
Diagnosis

# Enrolling in the FTDDR Continued

Select either Contact or Research Account

## Contact Registry

- 01 International Participation
- 02 Informational Updates
- 03 Quarterly Newsletters

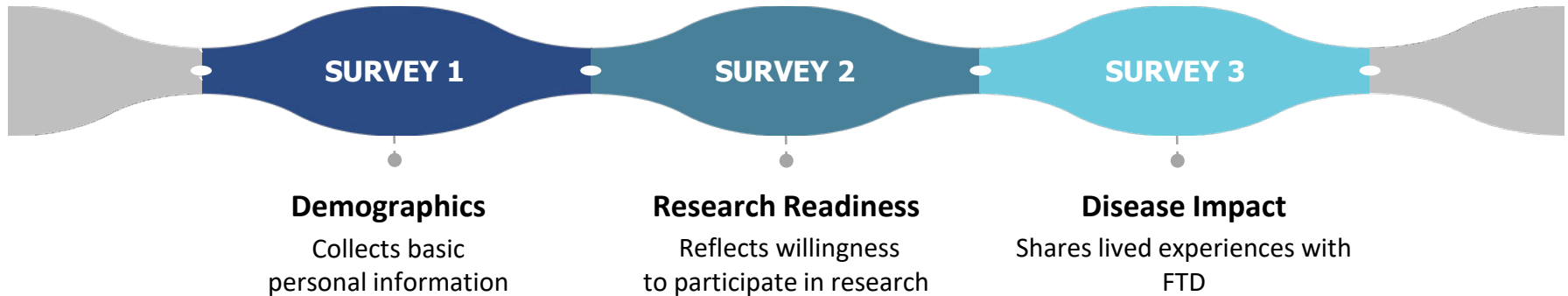
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## Research Registry

- 01 U.S. and Canada Participation
- 02 Informed Consent Required
- 03 Access to Research Surveys



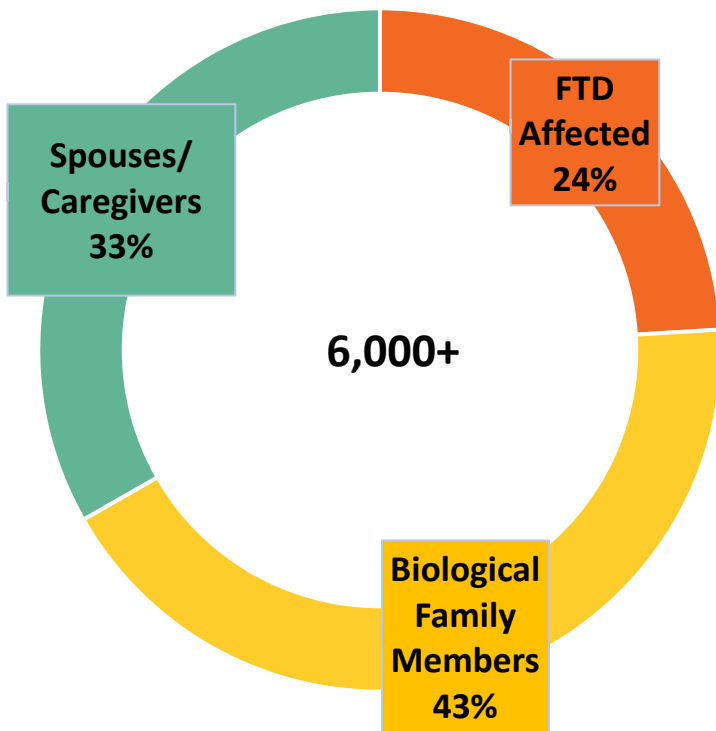
# Collecting FTDDR Registrant Data



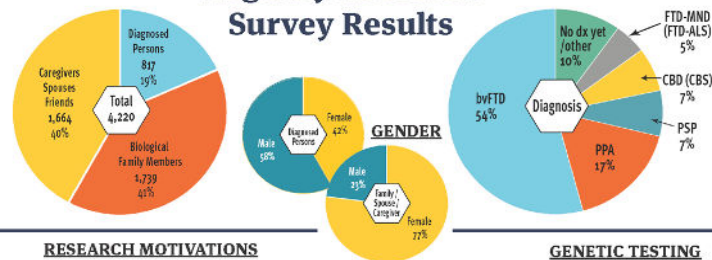
- Information that could identify participants is **NEVER** shared outside of the Registry
- Build a clearer picture of the impact of FTD from people with lived experience
- Collect data that can be used to raise awareness, improve access to diagnosis and resources, and advance the science
- Giving participants information about trials that may be right for them
- Aggregate, de-identified data shared with the public via website, newsletter, and publications



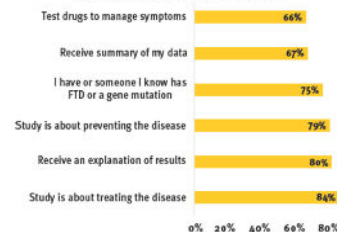
# Sharing FTDDR Registrant Data



## Registry Research Survey Results



### RESEARCH MOTIVATIONS



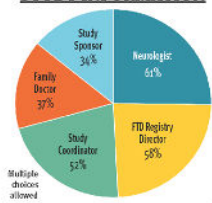
### BRAIN DONATION



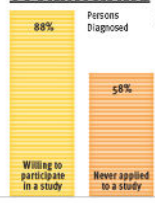
### GENETIC TESTING



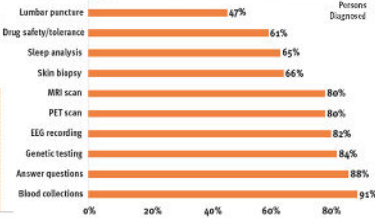
### SOURCES TO LEARN STUDY INFORMATION



### WILLINGNESS TO PARTICIPATE



### PROCEDURES WILLING TO DO



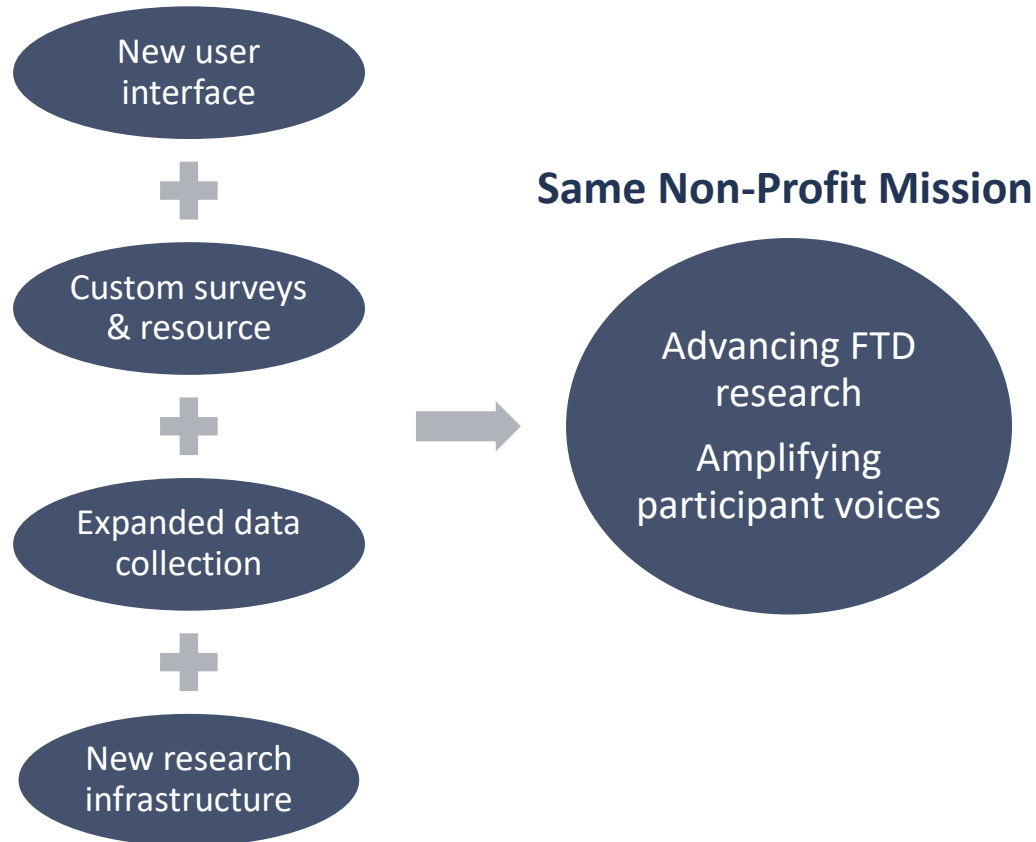
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→ [www.FTDregistry.org](http://www.FTDregistry.org)

March 2021 for APTD Virtual Education Conference  
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# Unwavering Priority on Security & Participant Privacy



**Launching Fall 2023**