Engaging in Research thru the Registry

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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

Founded March 2015 by AFTD and Bluefield Project
Nonprofit 501(c)3 status granted March 2016
Launched to the public March 2017
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
Enrolling in the FTDDR

**FTDregistry.org**

I AM DIAGNOSED WITH FTD

enrolling myself in the Registry or joining with help of a care partner.

I AM A FAMILY MEMBER (BIOLOGICAL RELATIVE)

of a person who is/was diagnosed with FTD

enrolling myself in the Registry.

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

Terms & Conditions
Privacy Policy
Today’s Date

Name
Address
Contact Information
FTD Diagnosis
Enrolling in the FTDDR Continued

*Select either Contact or Research Account*

<table>
<thead>
<tr>
<th>Contact Registry</th>
<th>Research Registry</th>
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<tbody>
<tr>
<td>01</td>
<td>U.S. and Canada Participation</td>
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<tr>
<td>02</td>
<td>Informed Consent Required</td>
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<td>03</td>
<td>Access to Research Surveys</td>
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<td><strong>International Participation</strong></td>
<td><strong>Informational Updates</strong></td>
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| **Quarterly Newsletters** | }
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 FTDDDR Registrant Data

FTD Affected 24%

- Spouses/Caregivers: 33%
- Biological Family Members: 43%

6,000+

FTD Disorders Registry

Registry Research Survey Results

RESEARCH MOTIVATIONS
- Test drugs to manage symptoms
- Receive summary of my data
- I have someone I know that has FTD or a genetic mutation
- Study is about preventing the disease
- Receive an explanation of results
- Study is about treating the disease

GENETIC TESTING
- FTD-Diagnosed Tested: 72% Yes, 5% No, 23% Unsure
- Want to be Tested: 64% Yes, 30% No, 6% Unsure

BRAIN DONATION
- 72% Yes, 5% No, 23% Unsure

Biological Relatives Tested: 96% Yes, 4% No
Want to be Tested: 60% Yes, 4% No, 36% Unsure

SOURCES TO LEARN STUDY INFORMATION

WILLINGNESS TO PARTICIPATE

- FTD Registry: 50%
- Family: 25%
- Study Information: 20%

PROCEDURES WILLING TO DO

- Neuronal proteins: 60%
- Skin biopsy: 50%
- BIOP: 30%
- Blood test: 25%
Unwavering Priority on Security & Participant Privacy

New user interface

Custom surveys & resource

Expanded data collection

New research infrastructure

Same Non-Profit Mission

Advancing FTD research
Amplifying participant voices

Launching Fall 2023