



# FTD DISORDERS REGISTRY

**Participating  
in Research**

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AFTD 2019 Annual  
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*FTD Disorders Registry LLC  
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# *FTD Disorders Registry LLC*

Founded as an independent, non-profit entity  
March 2015 by AFTD & the Bluefield Project.

**Mission:** *To facilitate and advance research into the spectrum of FTD disorders.*

**Goal:** *To create and curate a patient/caregiver registry to serve as a resource for the entire FTD disorders community, including persons diagnosed, their families, caregivers, clinical care providers and researchers.*

# Registry Format

## ➤ **Contact Registry-** *International*

- Access to informational updates & e-Newsletters

*Community organizing & communication*

## ➤ **Research registry-** *U.S. & Canada*

- Informed consent to participate
- Password-protected account
- Coded identifier assigned to protect privacy
- Access to surveys & data collection tools

*Health outcomes research & study recruitment*



# Target Population

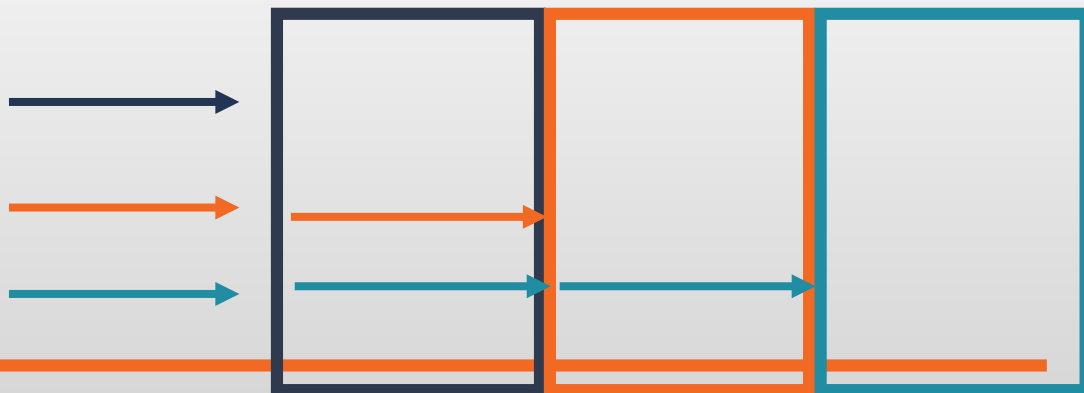
## Who can Join?

- Persons diagnosed with FTD → *bvFTD*  
*PPA*  
*PSP*  
*CBD*  
*FTD-ALS*
- Current or former spouse, family members, caregivers or friends

**FTD diagnosed person**  
*Self-enroll or with helper*

**Biological family member**

**Spouse/Caregiver/Friend**



# *Opportunity to participate*

## **Fewer barriers than traditional research**

- Broad enrollment groups
- Doesn't interfere with other studies
- Participate from home

## **Benefits**

- Have a voice
- Contribute to science



*Thank YOU!*

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

*Participation has the power to make a difference*

*Tell Your Story*