



FTD DISORDERS REGISTRY

A Patient and
Caregiver
Registry to
Advance Science

FTD Disorders Registry LLC

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PSP/CBD Research Update & Family Conference
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The FTD Disorders Registry

Secure online database designed to be the ‘home’ of all individuals wishing to participate in FTD research



Community where you can share your experience of FTD to help us understand these diseases better and support the development of new treatments

FTD Disorders Registry LLC

Fully independent entity with the patient/caregiver registry as sole non-profit mission

- Founded March 2015 by AFTD & Bluefield Project for the Cure
- Funded by grants
 - AFTD
 - Bluefield Project
 - Rainwater Charitable Fdn's Tau Consortium
- Oversight by Management Committee & Scientific Advisory Board



FTD Disorders Registry Format

Contact & Research registry

- Contact registry- *International*
 - Info updates & e-Newsletters
- Research registry- *U.S. & Canada*
 - Health outcomes research
 - Support clinical trial & research study recruitment
 - IRB-approved & HIPAA-compliant platform
 - Self-report, participant-entered data
 - Personally identifiable information is masked with coded identifier (de-identified)



FTD Disorders Registry Research Tools

Surveys/questionnaires via online data collection

- FTD Disorders Registry intake surveys

- Demographics
- Disease impact
- Research ready

- Clinical partner surveys (ARTFL)

- Lifestyle questionnaire
- Autoimmune history
- Clinical trials

- Additional surveys to be added



FTD Registry Homepage

www.ftdregistry.org

Why Join?

- Your experience can improve our knowledge of FTD, impact care, and help others
- Participating in research surveys will provide data to advance the science
- The Registry will be the go-to site to recruit for FTD clinical trials

The screenshot shows the homepage of the FTD Disorders Registry. At the top, there's a navigation bar with links for 'WHY JOIN', 'FIND A STUDY', 'WAYS TO HELP', 'FOR RESEARCHERS', 'FTD DISORDERS RESOURCES', and 'ABOUT THE REGISTRY'. A 'PARTICIPANT LOGIN' link is also present. The main header features a large image of a woman and a child, with the text 'IN THE WORLD OF FTD, EVERY STORY ADVANCES THE SCIENCE. Starting with yours.' and a 'JOIN THE REGISTRY' button. Below this, a section titled 'WHAT IS THE FTD DISORDERS REGISTRY?' explains the registry's purpose and includes a 'LEARN MORE ABOUT THE REGISTRY AND FTD SPECTRUM' link. A central section, 'AND NOW WE WORK TOGETHER', highlights three ways to participate: 'I AM DIAGNOSED WITH FTD', 'I AM A FAMILY MEMBER (BIOLOGICAL RELATIVE)', and 'I AM A SPOUSE, CAREGIVER, OR FRIEND'. The 'UPDATES' section lists recent news items like 'ARTFL - The study for Advancing Research and Treatment for Frontotemporal Lobar Degeneration is now enrolling persons affected with FTD variants (PSA and C9orf72)', 'LEFTD5 - The study for the Longitudinal Evaluation of Familial Frontotemporal Degeneration Genetics is now enrolling individuals and families who have inherited the Tau, Progranulin or C9orf72 gene mutation (PSA and Careful)', and 'COMING SOON! QUESTION OF THE DAY'. There's also a 'Care, Connection, Discovery.' logo and a '2017 FTD Education Conference' announcement. The 'WAYS TO HELP' section includes 'JOIN US TODAY', 'PARTICIPATE IN RESEARCH', and 'SPREAD THE WORD'. The footer contains the 'FTD DISORDERS REGISTRY' logo, a list of partner organizations (AFTD, Huntington's Disease Society of America, etc.), and a 'JOIN THE REGISTRY' button. Social media icons and a feedback link are also present.

FTD Registry Target Population

FTD DISORDERS REGISTRY

ABOUT US | PRESS | CONTACT US
→ PARTICIPANT LOGIN

WHY JOIN | FIND A STUDY | WAYS TO HELP | FOR RESEARCHERS | FTD DISORDERS RESOURCES | ABOUT THE REGISTRY

IN THE WORLD OF FTD, EVERY STORY ADVANCES THE SCIENCE.
Starting with yours.

TOGETHER WE CAN FIND A CURE FOR FTD

The FTD 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.

JOIN THE REGISTRY →

Your privacy is important! We promise to protect it. We will not share your contact information.
[Read Full Privacy Statement](#)

WHAT IS THE FTD DISORDERS REGISTRY?

→ LEARN MORE ABOUT THE REGISTRY AND FTD SPECTRUM

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 aphasia (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.

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

Who can Join?

- Persons diagnosed with FTD → *bvFTD*
PPA
PSP
CBD
FTD-ALS

FTD diagnosed person
Self-enroll or with helper

Biological family member

Spouse/Caregiver/Friend

AND NOW WE WORK TOGETHER > *Will you join the community working to end FTD?*

YES →

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

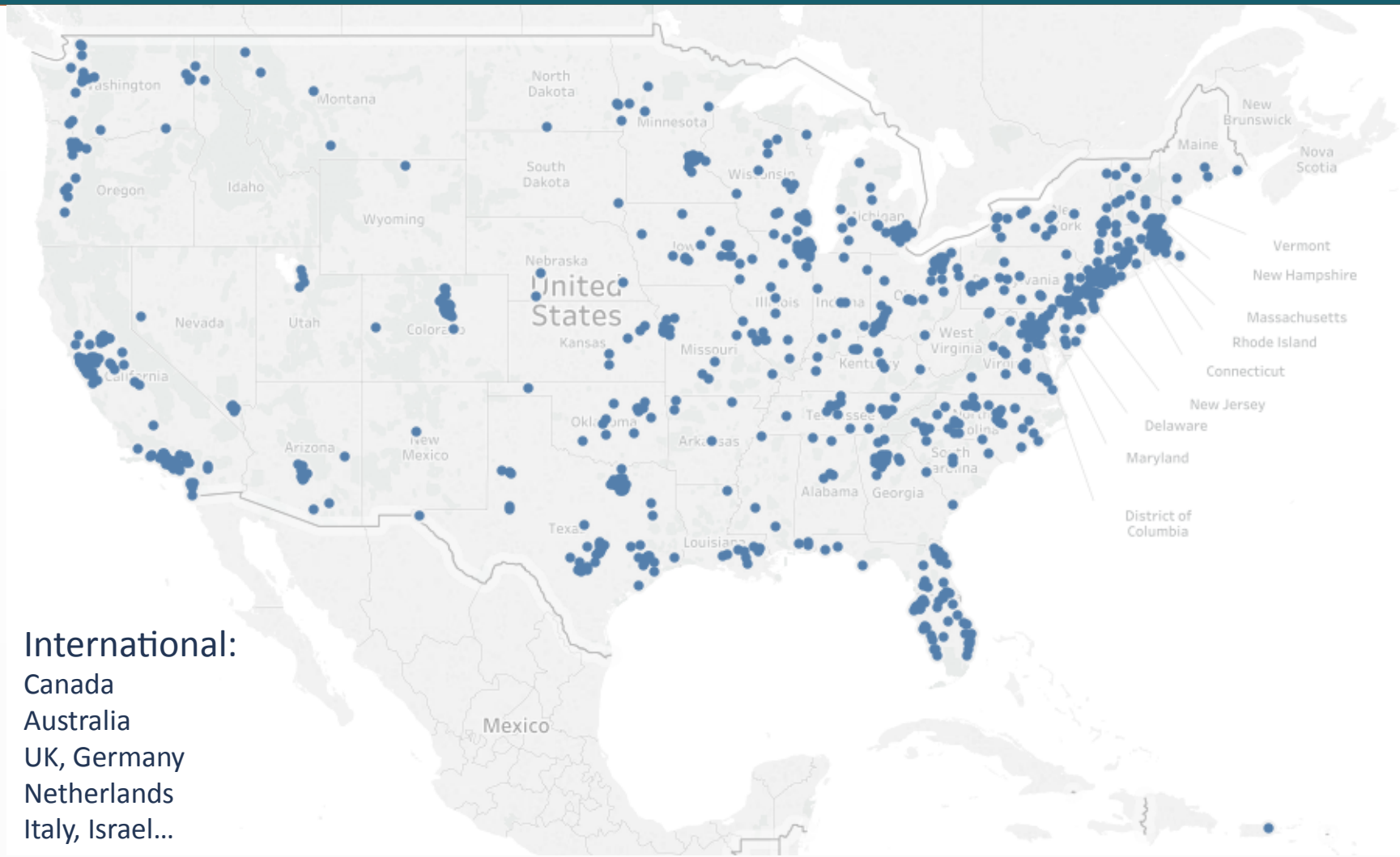
YES →

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.

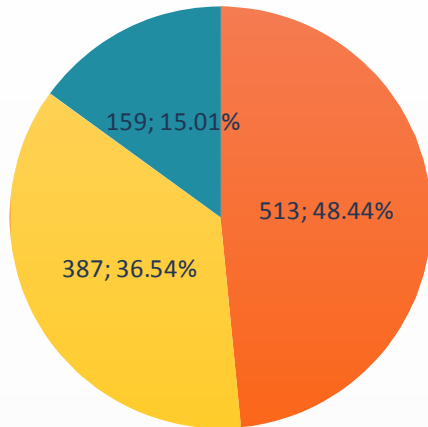
FTDDR Enrollment by Geographic Distribution: 1059



International:
Canada
Australia
UK, Germany
Netherlands
Italy, Israel...

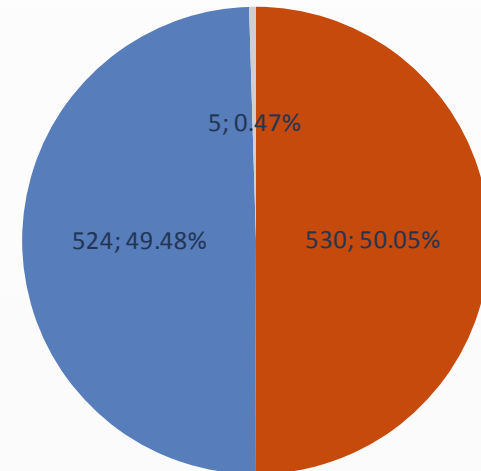
FTDDR Enrollment Statistics: 1059 total registrants

Category



■ Spouse/Cgvr/Friend ■ Biological Family
■ FTD dx

Participation Type



■ Contact ■ Research ■ Not validated

What Can We Do With the Data?

Tabulate who, where, how many...but goes beyond basic demographic characteristics

- Build a clearer picture of the impact of FTD from a patient, caregiver, and family perspective
 - May help us ask better questions, drive new hypotheses
- Assess research study/clinical trial feasibility
 - Patient-centric design & outcome measures
 - Facilitate recruitment
- Use the data to raise awareness, and advance research and facilitate advocacy throughout the FTD community
 - Partner and collaborate to make the FTDDR a key resource for all

➤ Your participation has the power to make a difference

FTD Disorders Registry: Thank You!

- Join the FTD Disorders Registry.
- Tell your story.
- Advance the science.



 www.ftdregistry.org

www.facebook.com/EndFTDregistry



@EndFTDregistry