LEVERAGING THE DIRECT-TO-PARTICIPANT FTD DISORDERS REGISTRY (FTDDR) TO ENABLE RESEARCH ON FTD DISORDERS

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FTD DISORDERS REGISTRY®

CONNECTING PATIENTS, POWERING DISCOVERY, ADVANCING FTD RESEARCH

BACKGROUND

Frontotemporal Degeneration (FTD) is an umbrella term for related disorders with neurodegeneration of the frontal and temporal lobes, leading to progressive dysfunction in behavior, motor symptoms, language, and/or cognition. Although clinical trials for potential disease-modifying therapies are underway, recruitment and retention of eligible participants have become a rate-limiting factor, as clinicians and families often lack the tools to stay informed about new research opportunities. Direct-to-participant registries can help to characterize the population, identify barriers to participation and clinical care, support study recruitment, and empower families to make informed research decisions.

ABOUT THE FTD DISORDERS REGISTRY

The FTD Disorders Registry is a non-profit, online direct-to-participant registry established in 2017 and relaunched in 2024 on an enhanced platform. Any adult can create a secure account to access curated content and study recruitment information. Participants eligible for the online research study are offered e-consent and share data through longitudinal and validated survey instruments as well as uploaded genetic test results, autopsy results, and EHR linking. To diversify the perspectives documented, research participation is open to persons diagnosed, biologically family members, and caregivers in the USA or Canada. Reporters can be invited to complete additional surveys for dyad insights.

WHO CAN JOIN THE FTD DISORDERS REGISTRY?

Persons Diagnosed

Biological Family

Healthcare Professionals

Caregivers

Researchers

Friends

Anyone with an interest in FTD research is welcome to join!

BY THE NUMBERS

Since inception, 7,361 participants have joined the Registry and 2,774 have consented to the online research study.

The FTD Disorders Registry has connected participants with over 45 research studies and shared aggregate data through 16 abstracts or publications. Deidentified data is available to researchers through the Registry Researcher Portal and by request.

WHAT INFORMATION IS SHARED IN THE REGISTRY?

Survey Data

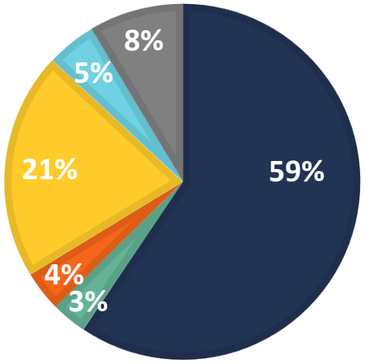
Medical Records

Diagnostic Journey

Genetic Test Results

WHAT FTD DISORDERS ARE REPRESENTED?

- bvFTD
- PPA
- PSP
- FTD-ALS
- CBD (CBS)
- No Diagnosis / Other



CONCLUSION

The progress of FTD research relies on understanding lived experience, having an informed and empowered trial-ready population, and building the infrastructure to streamline research and reduce travel burden. The FTD Disorders Registry offers resources, information, and data to enable clinicians, researchers, and those impacted by FTD disorders to stay informed and actively advance FTD research.