

ENGAGED PARTICIPANTS. STRONGER STUDIES. FASTER BREAKTHROUGHS

BACKGROUND

Frontotemporal degeneration (FTD) is an umbrella term for a group of rare disorders characterized by neurodegeneration in the frontal and temporal lobes, leading to progressive impairments in behavior, motor function, language, and cognition. The rarity and clinical variability of FTD disorders present significant challenges to timely diagnosis and, consequently, to the recruitment of research-ready participants for clinical trials. There are currently no approved disease-modifying or symptomatic therapies for FTD disorders which underscores the substantial unmet medical need in this population.

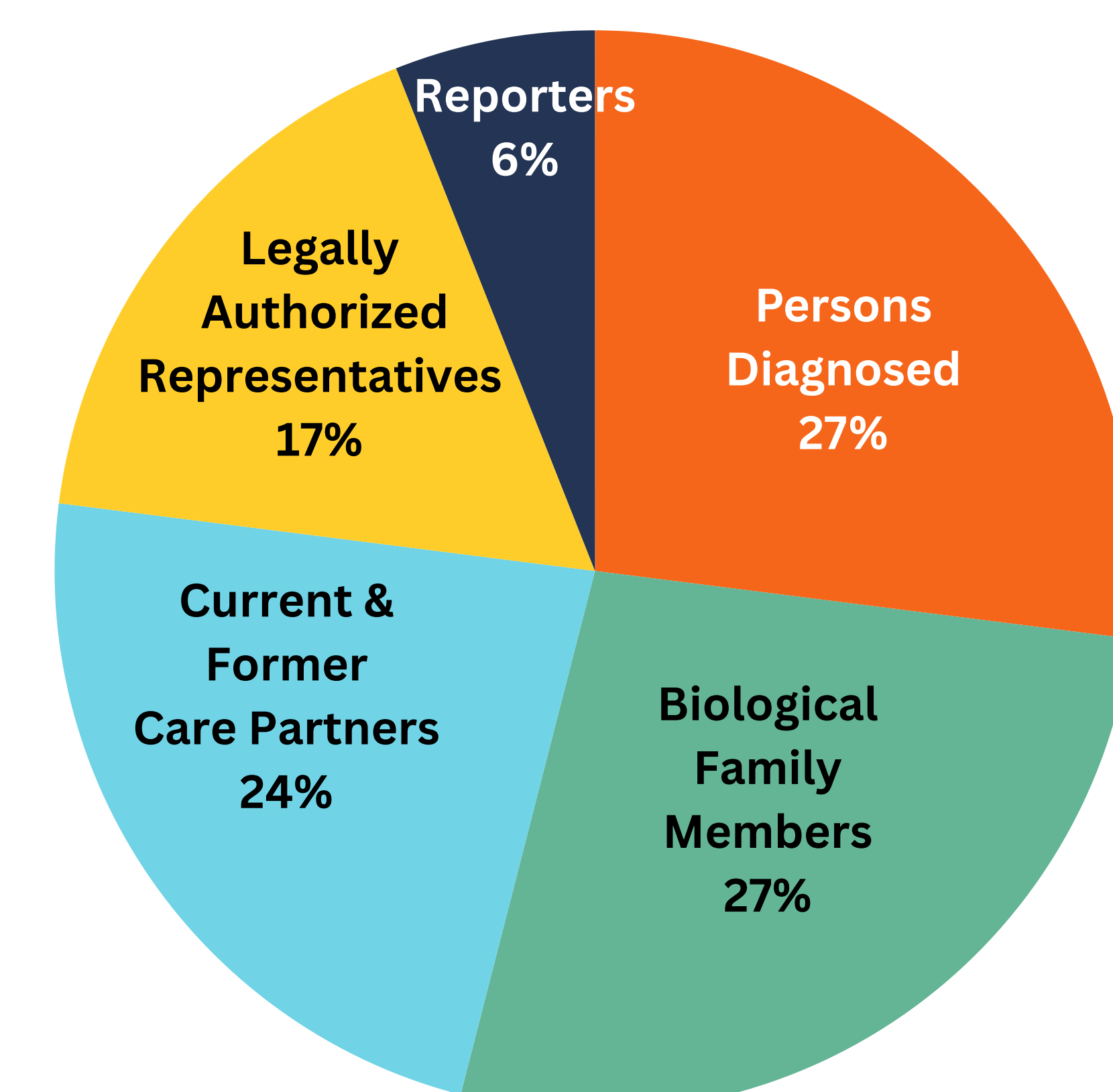
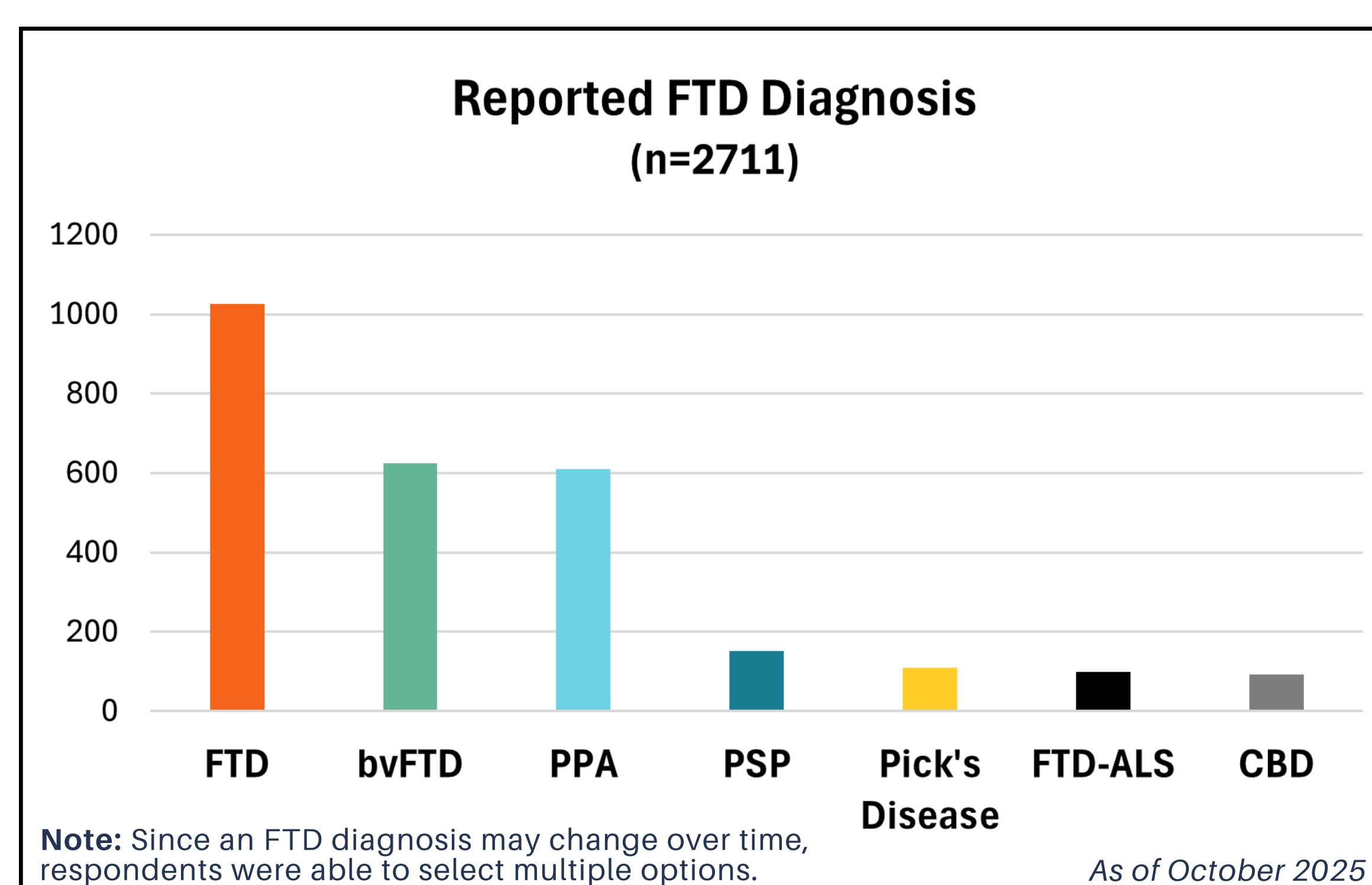
The FTD Disorders Registry, a direct-to-participant registry launched in 2017, was designed to address these challenges by connecting individuals diagnosed with an FTD disorder, biological family members, and care partners with research opportunities. By enabling rapid outreach to an engaged, self-identified population, the Registry offers a unique resource to accelerate recruitment, diversify study cohorts, and facilitate patient-centered trial design.

METHODS

The FTD Disorders Registry collects data through two primary mechanisms: a Contact Registry, which gathers basic demographic and disease interests, and the Registry Research Study, which collects longitudinal data on diagnosis, symptoms, caregiving, and research participation barriers. Adults living the United States and Canada, including those diagnosed with an FTD disorder, biological family members, and current or former care partners, are eligible to enroll in the Registry Research Study online. Anyone who joins the Registry can be notified about research opportunities.

To support clinical trial recruitment, the Registry:

- Collaborates with study sponsors to design and disseminate IRB-approved, tailored email outreach campaigns to eligible participants based on self-reported characteristics and interests.
- Conducts participant prescreening and matching to appropriate study sites based on eligibility criteria and geographic location.
- Provides aggregate, de-identified feasibility data to sponsors and investigators to assess recruitment potential.
- Offers the option of an integrated e-consent service, enabling researchers to efficiently obtain and manage informed consent from participants for their studies.



RESULTS

As of October 2025, the FTD Disorders Registry includes 3,271 contactable participants with 1,012 active Registry Research Study participants. The Registry Research Study includes representation across the spectrum of those impacted by FTD disorders including 27% individuals diagnosed with an FTD disorder, 27% biological family members, 23% current or former caregivers, 17% legally authorized representatives, and 6% reporters.

Among participants in the Research Study with diagnosed or suspected FTD, 96% report a diagnosis of FTD and/or a specific subtype of FTD. Of those who reported a specific subtype, 23% reported behavioral variant FTD (bvFTD), 22% primary progressive aphasia (PPA), 3% corticobasal degeneration (CBD), 6% progressive supranuclear palsy (PSP), 4% Pick's disease, and 4% frontotemporal dementia and amyotrophic lateral sclerosis (FTD-ALS).

From July 2024 - April 2025, the Registry facilitated recruitment for 22 studies. Targeted campaigns resulted in accelerated enrollment for many of these studies. For example, a study evaluating a mental health program for individuals recently diagnosed with an FTD disorder recruited 66% of its participants through the Registry.

CONCLUSIONS

The FTD Disorders Registry demonstrates a scalable, patient-centered approach to overcoming the recruitment challenges inherent in frontotemporal degeneration research. By directly engaging individuals and families impacted by FTD disorders and facilitating targeted outreach, the Registry has been able to rapidly connect eligible individuals with research opportunities and supported enrollment across a range of studies, from observational studies to interventional trials.

As the landscape of FTD therapeutics evolves, the Registry is well-positioned to serve as a critical infrastructure for accelerating trial readiness, improving cohort diversity, and amplifying the voice of the FTD community in research.

