

SCALING RECRUITMENT, STRENGTHENING CONNECTIONS, ACCELERATING FTD & ALS RESEARCH

INTRODUCTION

Frontotemporal Degeneration (FTD) is an umbrella term for a group of related neurodegenerative disorders, including FTD and Amyotrophic Lateral Sclerosis (ALS) which can co-occur as a combination of motor and cognitive disorder. Variants in the *C9orf72* gene are the most common cause of both genetic FTD and ALS, and both disorders can present within the same family. The FTD Disorders Registry is an international, secure, online platform designed to accelerate FTD research by connecting individuals living with or at risk for FTD-spectrum disorders, including FTD-ALS, with research opportunities and by providing scalable, accessible tool for remote data collection.

OBJECTIVE

Demonstrate that the Registry can be used to effectively identify and engage individuals impacted by and at risk for FTD-ALS and their care partners for clinical research participation, increasing trial readiness for FTD and ALS clinical trials.

ABOUT THE FTD DISORDERS REGISTRY

The FTD Disorders Registry is a nonprofit, 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 electronic health record (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 REGISTRY?



Persons Diagnosed



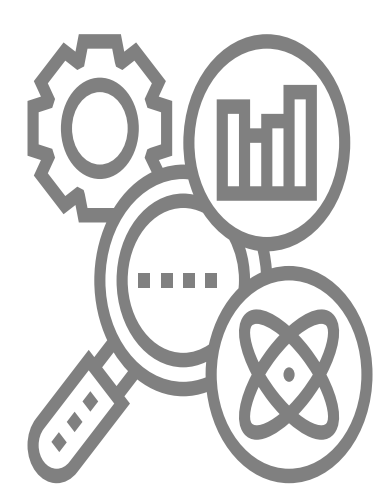
Biological Family



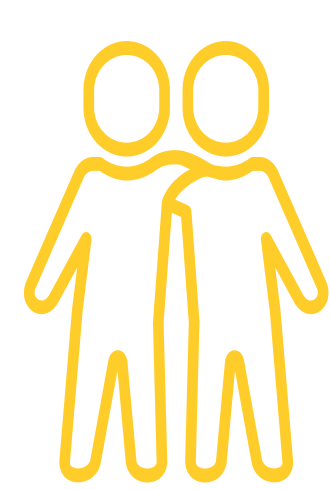
Healthcare Professionals



Caregivers



Researchers



Friends

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

WHAT INFORMATION IS SHARED?



Survey Data



Medical Records

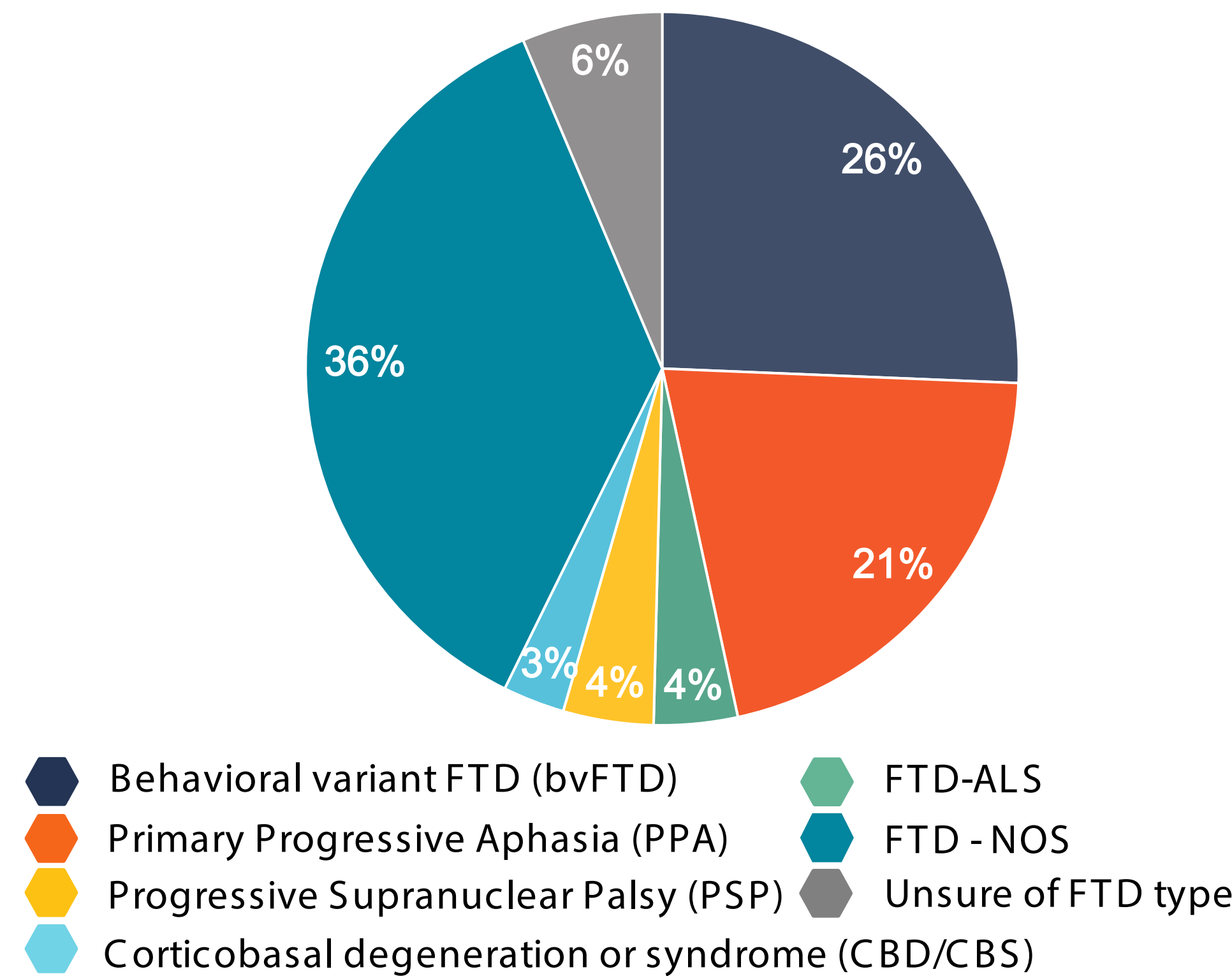


Diagnostic Journey

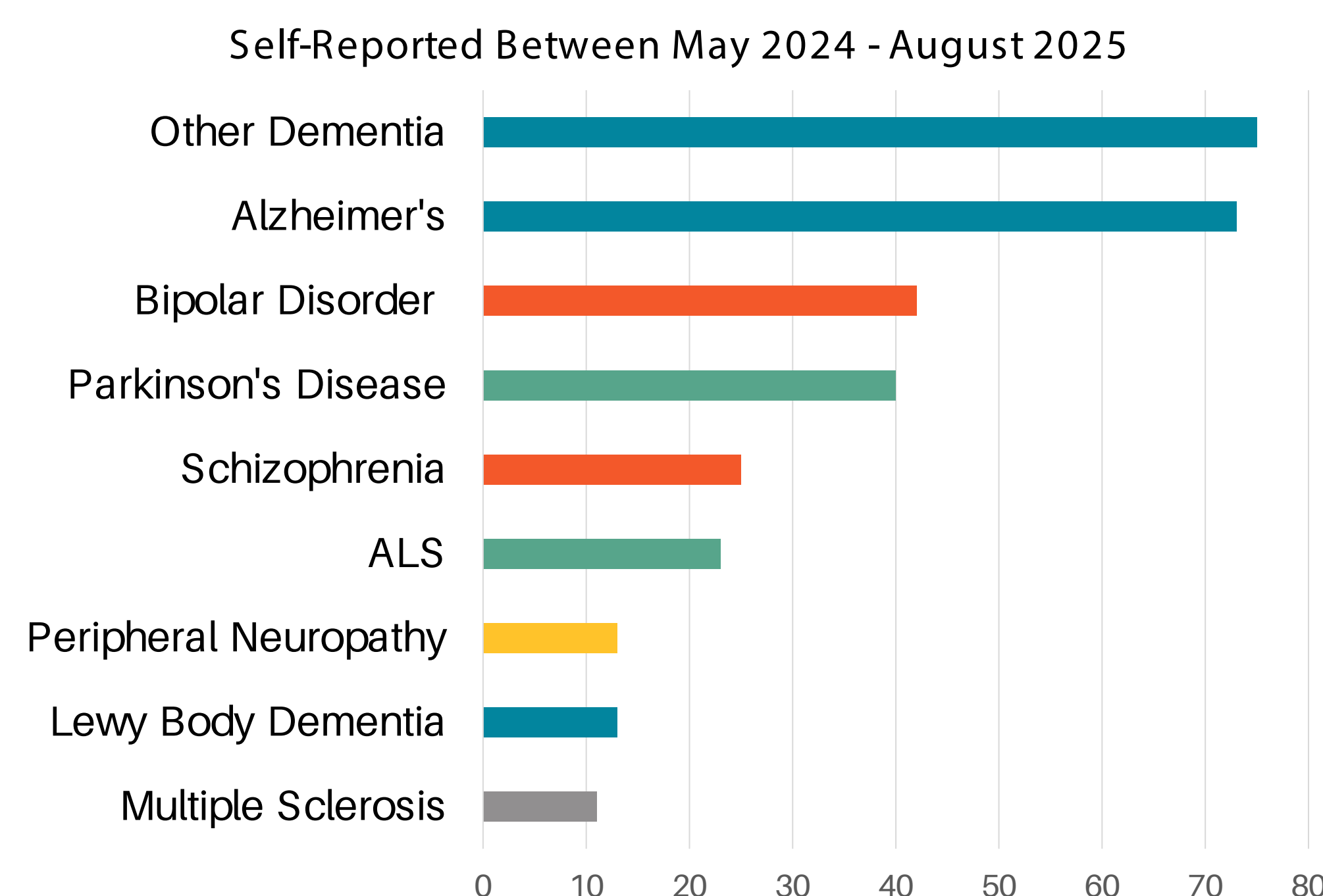


Genetic Test Results

WHAT FTD DISORDERS ARE REPRESENTED?

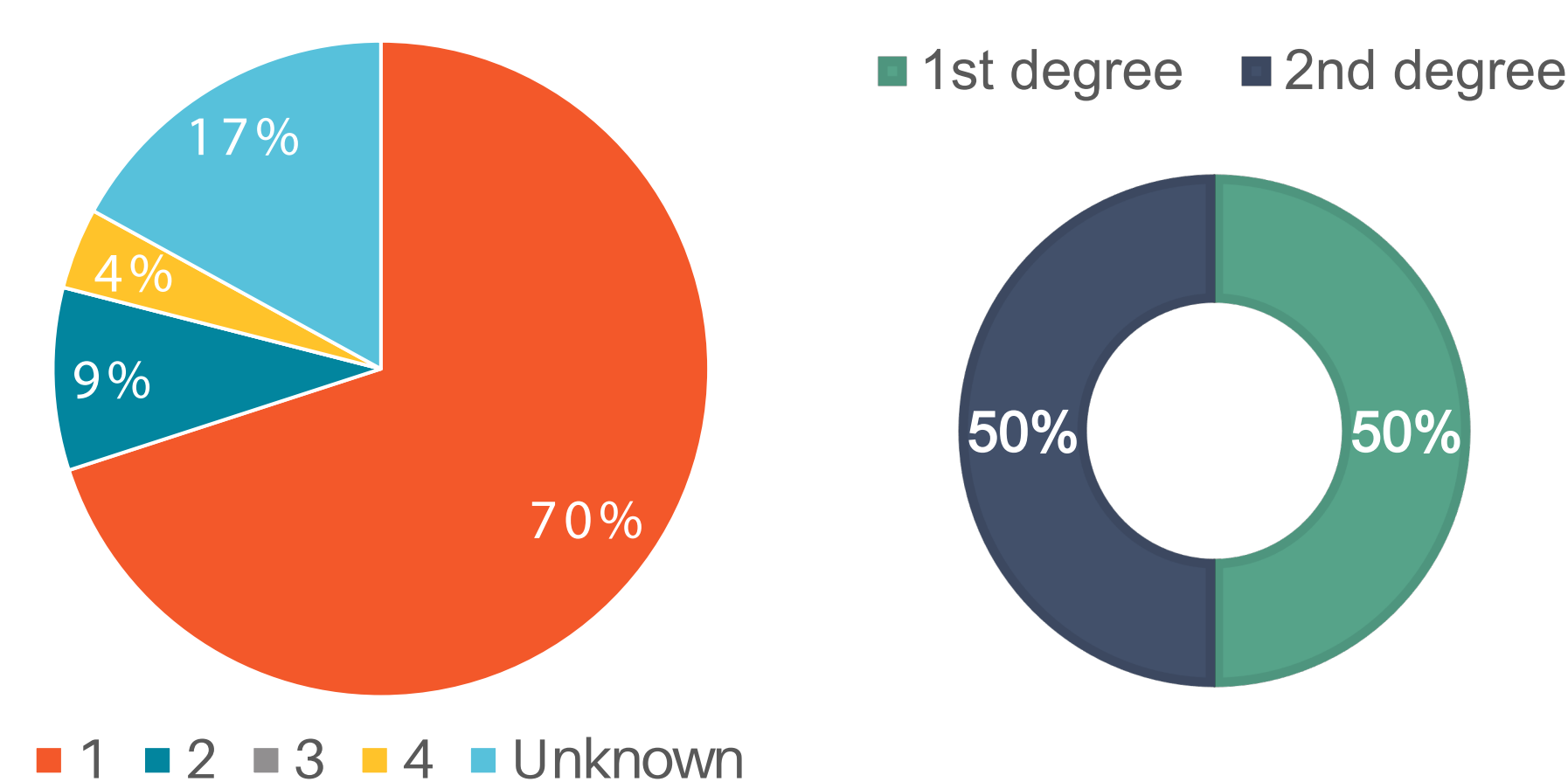


NEUROLOGIC & PSYCHIATRIC FAMILY HISTORY

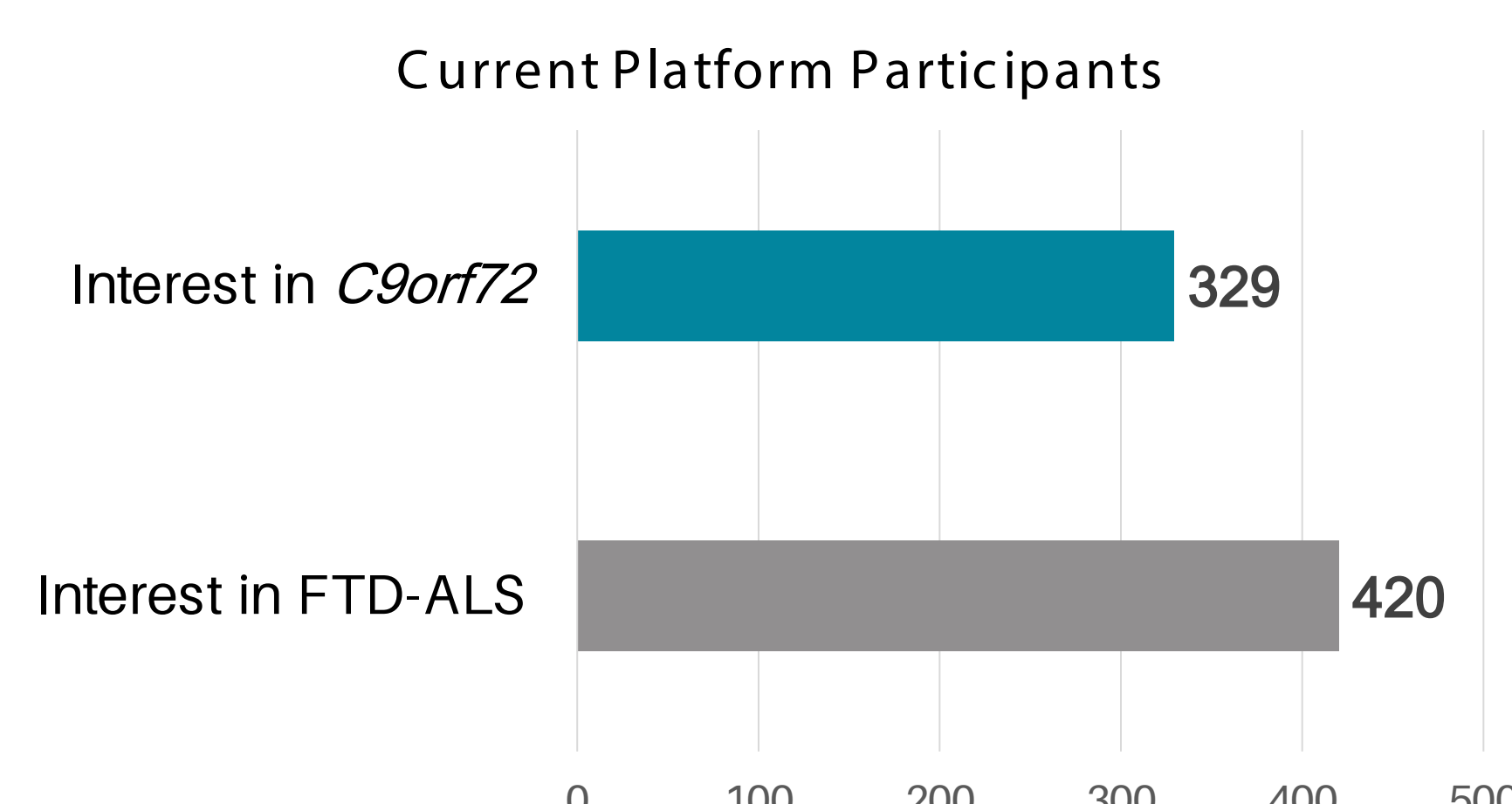


NUMBER OF RELATIVES WITH ALS

For those above reporting a family history of ALS, number of people in their family with an ALS diagnosis



INTEREST IN INFORMATION ON FTD-ALS



METHODOLOGY

Registry data from January 2017 through June 2025 was analyzed to identify participants who reported an interest in FTD-ALS, self-reported a diagnosis of FTD-ALS, a family history of ALS, or had a pathogenic *C9orf72* genetic test result in the system.

ANALYSIS

As of August 2025, 108 Registry participants self-reported either a personal diagnosis of FTD-ALS or being a care partner to someone with FTD-ALS. Additionally, 21 participants uploaded a genetic test confirming a *C9orf72* mutation, with 7 of these not overlapping with the self-reported group. Among participants enrolled since the launch of the updated Registry platform in May 2024, 23 reported a family history of ALS, including 11 individuals who do not identify as having FTD-ALS themselves. Furthermore, 420 participants indicated FTD-ALS and 329 indicated *C9orf72* as a diagnosis or gene of personal interest, expressing a desire to receive information about relevant clinical trial opportunities.

CONCLUSION

These findings support the feasibility of using the Registry to identify individuals with FTD-ALS for clinical research. The Registry's international reach, scalable infrastructure, and data collection tools make it particularly suited for engaging this population in decentralized trials. Strengthening connections between ALS and FTD research communities through shared recruitment strategies may improve trial efficiency and accelerate therapeutic development for FTD-ALS.

CONTACT US

Registry Director:

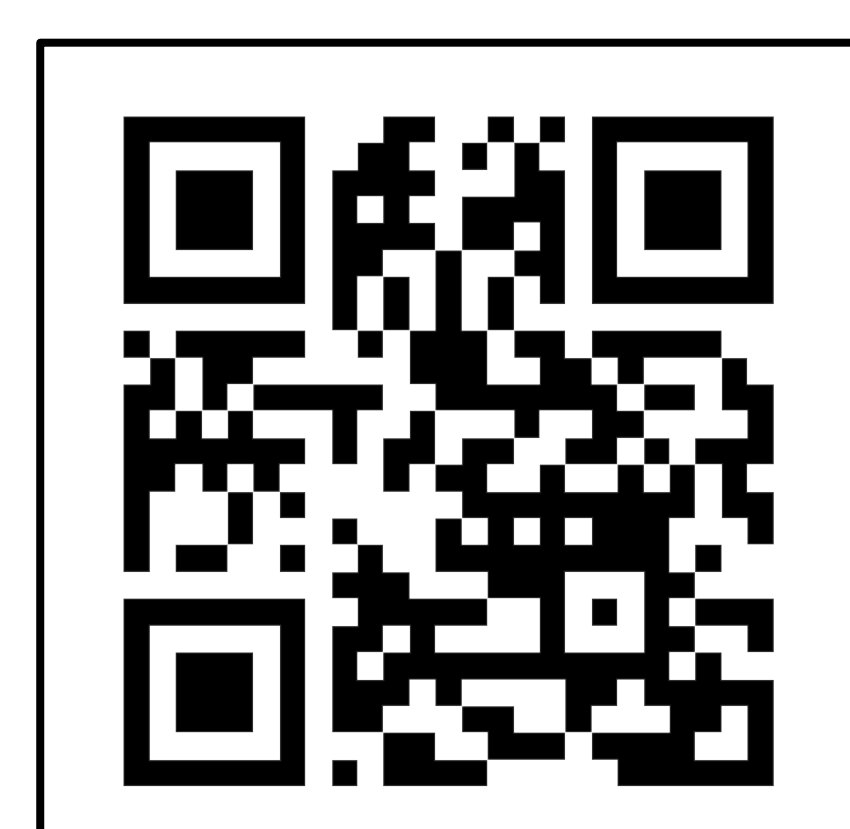


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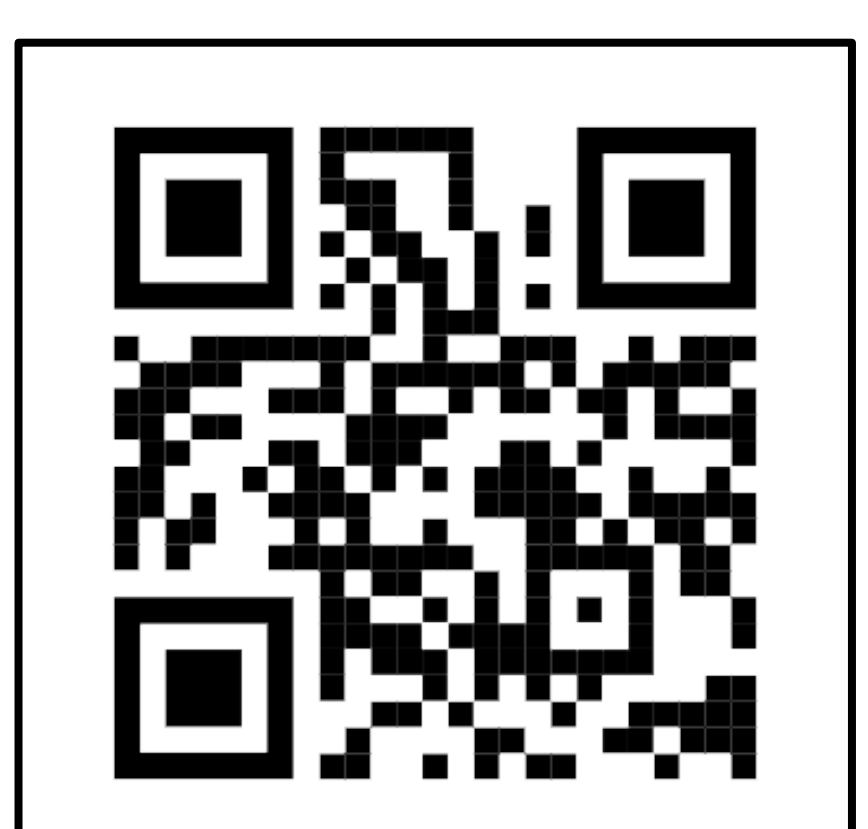


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AFTD and the FTD Disorders Registry are affiliated non-profits. Check out AFTD for resources such as diagnostic checklists, CME, support groups, research funding, and more. The Registry is a partner to researchers, healthcare providers, and persons with lived experience to connect people to clinical research and to gather data. Please join us!



www.ftdregistry.org



www.theaftd.org