

HELP & SUPPORT

Participate to Help Drive Breakthroughs in FTD Research



Scientists are closer than ever to breakthroughs that will bring meaningful change to families facing FTD. Participation from the AFTD community makes their work possible!

Join the FTD Disorders Registry (FTDregistry.org) to learn about opportunities to get involved in research and share insights about living with FTD.

Participate in clinical trials. Today, the most opportunities are available for families with a progranulin (*GRN*) or *C9orf72* gene variant. However, there are opportunities for all to participate in research!

- By signing up for the **FTD Disorders Registry**, you can get notified on specific opportunities for study participation.
- Visit AFTD's **Studies Seeking Participants** webpage.

Seek genetic counseling. Learn more about familial FTD, see if genetic testing is right for you, and learn how it relates to clinical research by visiting **AFTD's Genetic Counseling** webpage.

Enroll in a brain donation program. People with and without an FTD diagnosis can help scientists target the microscopic pathology that causes this disease. See the steps on AFTD's **Brain Donation** webpage.

Determine your eligibility for ALLFTD or GENFI. Observational studies such as **ALLFTD** (allftd.org) or **GENFI** (genfi.org) help scientists understand the natural course of FTD.

Volunteer with AFTD. Sign up via AFTD's **Take Action and Volunteer** webpage, indicating your interest in research, and you will be contacted about ways of sharing your personal experience to lead to more impactful FTD research.

Donate to AFTD. AFTD supports scientists to advance understanding of FTD, create new approaches to diagnosis and treatment, and develop assistive technologies for people and families facing FTD. Click **Donate+** on our website to support our mission.

Spread the news! Share information about research opportunities with your family, friends, and healthcare providers.



Scan the QR code to easily access **AFTD's Ways to Participate** webpage that has links to all the research resources listed above.

Why Participating in Research Matters

FTD research is gaining momentum, with more opportunities than ever for everyone to participate in a study that can lead to a breakthrough. The National Institutes of Health (NIH) has doubled the number of FTD projects they have funded from a decade ago, and a growing number of private companies are investing in finding treatments for different forms of FTD.

We need all hands on deck – as successfully testing these treatments will require research volunteers from across the US and around the globe.

Who can participate in research studies?

Everyone! While each given study has specific criteria for who can participate, there are opportunities for all. Each FTD research study brings us closer to treatments and better care for all people with FTD. Participation can vary from completing surveys, to undergoing MRI scans, to participating in studies testing experimental medicine.

Why is there so much emphasis on people with genetic variants?

Many of the studies testing experimental medicines today are looking for participants with variants of the *GRN* and *C9orf72* genes that are known to cause FTD. Additional studies focused on other genes known to cause FTD are in the planning stages. What is learned in these studies will benefit everyone – including those who do not have one of these gene variants.

Why should I consider genetic counseling?

Talking with a genetic counselor can help you better understand your risk of familial FTD and help you to determine if and what type of genetic testing might be right for you and your family. They will walk you through the process, identify questions for you to consider, and help to identify clinical trials that you could be eligible for based on your results.

Is participating in research safe?

Many laws, rules, and regulations are in place to protect research participants' safety, privacy, and confidentiality. Informed consent is always required, which means that each person is given details of a study before deciding if participation is right for them.

Benefits of Participating in FTD Research:

- Take an active role in your own care that could potentially improve your condition or quality of life.
- Gain access to interventions, specialists, or assessments that may not otherwise be available.
- Learn more through the results of tests you may undergo as part of research.
- Help future generations by furthering our understanding of how to diagnose, prevent, treat, or cure FTD.