What is FTD Research?

Research is happening now to better diagnose, treat, and, one day, cure FTD. Research fosters hope for a world without FTD. We need all hands on deck – as successfully testing these treatments will require research volunteers from across the US and around the globe.

Research is NOT the same as medical care. The goal of research is to answer important questions that can benefit **everyone**, while the goal of medical care is to help **you**, personally feel or get better. Your health is important to the research team and regulations are in place to protect your safety, privacy, and confidentiality as a research volunteer.

**Who can participate in research studies?**

Everyone! While each given study has specific criteria for who can participate, there are opportunities for everyone. 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 specific types of FTD, such as FTD caused by variants in the GRN and C9orf72 genes. Additional studies focused on other genes and sporadic forms of FTD are in the planning stages. What is learned in these studies will benefit everyone – including those who do not have one of these FTD types.

**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.

Scan the QR code for more information on FTD research.

The Association for Frontotemporal Degeneration  
theaftd.org  |  HelpLine: 1.866.507.7222  |  info@theaftd.org
Be a Part of the Solution

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

Join the FTD Disorders Registry (FTDregistry.org) which can connect you to research opportunities and helps researchers better understand FTD to plan research studies for new tools and treatments.

Participate in clinical trials. Today, the most opportunities are available for families with a specific type of FTD, such as a PSP or FTD caused by a progranulin (GRN) variant. However, there are opportunities for all to participate in research!
- Sign 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.

Your experience makes you an expert. AFTD works to bring the diverse values, priorities, and concerns of people diagnosed with FTD, their care partners, and family members to researchers to make sure research is designed in a way that aligns with what is needed by people living with FTD. If you are interested in sharing your experience with FTD as a way to inform research, reach out to Dr. Shana Dodge, AFTD’s Director of Research Engagement, at sdodge@theaftd.org.

Volunteer with AFTD. Sign up via AFTD’s Get Involved webpage to connect with FTD volunteer and policy advocacy opportunities.

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.

Spread the news! Share research information about 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.