

The VOICE of FTD

SPRING 2021

FTD Registry Surpasses 4,200 before 4th Anniversary: March 28, 2021

Highlights from 2020, a historic year!

As the FTD Disorders Registry (FTDDR) reached its 4th Anniversary on March 28, 2021, we continue to surpass enrollment goals despite the challenges faced this past year.

The coronavirus pandemic due to COVID-19 shut down the world in 2020, changing the primary means in which people gained knowledge and connected with others from in-person gatherings to online events.

Like others, we at the Registry reached out by increasing our online presence and educating the frontotemporal degeneration (FTD) community through news blogs, social media posts, and emails. We even ventured out to co-host our first research webinar.

Here are a few of the significant highlights for the FTD Disorders Registry in 2020.

Enrollment Goal Met Early

For the fourth year in a row, the Registry exceeded its annual registration goal of enrolling 1,000 new registrants per year. This occurred more than four months prior to the March 28, 2021, anniversary

date when participant number 4,000 registered on November 5, 2020.

“We were concerned about enrollment during the coronavirus pandemic,” said Registry Director Dianna Wheaton, M.S., Ph.D., CHES. “With so much uncertainty and competing priorities last year, we weren’t sure whether people would still seek out the Registry for participation.”

By mid-March 2021, there are more than 4,220 people enrolled in the Registry. This includes 816 persons diagnosed with FTD (19%), 1,739 biological family members (41%), and 1,663 spouses, caregivers, and friends (40%). While most participants live in the United States or Canada, there are over 400 international registrants who represent more than 30 countries.

With an estimated 60,000 FTD-diagnosed persons in the United States – and many more around the world – plus their family members and caregivers, there are still numerous people affected by these devastating diseases who are eligible to enroll in the Registry. Each person who joins is counted and has their voice heard as we seek treatments and cures.

4th continues on Page 2

FTD Disorders Registry LLC

2700 Horizon Dr., Suite 120
King of Prussia, PA 19406
888-840-9980
manager@FTDregistry.org



www.facebook.com/EndFTDregistry



www.linkedin.com/company/ftd-disorders-registry



[@EndFTDregistry](https://twitter.com/EndFTDregistry)



bit.ly/YouTubeFTDregistry

4th continued from Page 1

As a challenge to reach more people, the Registry’s Strategic Plan lists a new enrollment goal: double the number of participants by the end-of-year 2022.

First Strategic Plan

Last year, the Registry developed and published its first Strategic Plan. Covering the years 2020-2022, it focuses on expanding the Registry’s reach and continuing to provide value to participants and partners.

“As the Registry’s first formal strategic plan, we have set challenging, and a few slightly audacious, goals,” noted Dr. Wheaton. “Our intent is to strengthen and evolve the Registry to better serve the myriad and dynamic needs of the FTD research community.”

The Registry’s mission is to facilitate and advance research into the spectrum of FTD disorders and to accelerate the development of treatments. The plan is to do this by providing tools and resources that promote and support research participation, enable access and sharing of data with researchers, and amplify the voice of the patients’ and families’ lived experiences.

[READ THE STRATEGIC PLAN](#)

Registry Research Survey Results

Also in 2020, the Registry shared results from its Research Readiness Survey. This is one of three core surveys (Demographics, Disease Impact, and Research Readiness) available for persons who sign up to participate in research. The survey gathers information about people’s understanding, perceptions, and preferences pertaining to research and indicates what people are willing to do to contribute to the understanding of FTD.



“Participating in research has many advantages to persons diagnosed with FTD and their families,” said FTD Registry Director Dianna Wheaton, Ph.D. “These include providing special access to medical expertise and current information on emerging treatments.”

It also means contributing to the growing knowledge base for FTD disorders. By advancing the science, others who are affected by FTD in the future will also benefit.

[READ MORE RESULTS](#)

[VIEW THE INFOGRAPHIC](#)

[VIEW THE SLIDESHOW](#)

FTD Insights Survey

Persons affected by FTD had an opportunity in early March 2021 to enlighten representatives of the U.S. Food and Drug Administration (FDA) during an [Externally-Led Patient-Focused Drug Discovery \(EL-PFDD\) meeting](#) hosted by the Association for Frontotemporal Degeneration (AFTD).

The meeting’s agenda was guided by the FTD Insights Survey, launched in fall 2020 in partnership between

4th continues on Page 3

FTD Disorders Registry LLC

2700 Horizon Dr., Suite 120
King of Prussia, PA 19406
888-840-9980
manager@FTDregistry.org



www.facebook.com/EndFTDregistry



www.linkedin.com/company/ftd-disorders-registry



[@EndFTDregistry](https://twitter.com/EndFTDregistry)



bit.ly/YouTubeFTDregistry

4th continued from Page 2

AFTD and the Registry. Responses from October 2020 were considered when setting the meeting’s focus, and results from all responses collected through March 31, 2021, will be added to a Voice of the Patient report.

“We have had a tremendous response from the FTD community,” said Registry Director Dianna Wheaton, M.S., Ph.D., CHES. “We are grateful to the more than 1,700 people who have already completed the survey.”

The survey collects information about the experiences, opinions, and preferences of patients, family members, and caregivers affected by FTD. The data collected is anonymous; names are not asked, and responses cannot be linked to specific individuals.

[READ ABOUT EL-PFDD MEETING](#)

Educational Webinars

The Registry, also in collaboration with the AFTD, initiated an educational webinar series, Perspectives in FTD Research. The first webinar was presented on December 5, 2020. Gene Therapy in FTD covered basic genetic information, familial FTD, gene therapy, and the roles that people and families affected can play in research.

Gene therapy is showing promise for treating a wide range of diseases, and related clinical trials are emerging for FTD. An increasing number of FTD clinical trials are requiring potential participants to know their genetic status as being an eligibility requirement.

These webinars feature experts who provide the latest information on FTD research in their area of study. Watch for the announcement of the next webinar!

[WATCH THE FIRST EDUCATIONAL WEBINAR](#)

Expanded Resources Section

Whether you recently received a diagnosis of frontotemporal degeneration (FTD) or have been living with it or caring for a diagnosed loved one for several years, you do not have to face this journey alone. The Registry updated and expanded the Resources section on its website by creating a list of resources to help you find the information and support you need.

“Information is powerful,” stated FTD Disorders Registry Director Dianna Wheaton, Ph.D., CHES. “When someone receives such a diagnosis as FTD, we want to arm them with the necessary information and resources they can use so that they are empowered to cope with the disease. This information provides guidance and enables people to engage in tangible actions.”

The section is organized by topic. Browse the categories to access resources to help you learn more and cope with FTD:

- [About FTD](#)
- [Finding A Specialist](#)
- [Living with FTD](#)
- [Caregiving](#)
- [Finding Support](#)
- [Participating in Research](#)
- [Brain Donation](#)
- [FTD Registry FAQ](#)
- [FTD Glossary](#)

[FIND RESOURCES](#)

4th continues on Page 4

FTD Disorders Registry LLC

2700 Horizon Dr., Suite 120
King of Prussia, PA 19406
888-840-9980
manager@FTDregistry.org



www.facebook.com/EndFTDregistry



[@EndFTDregistry](https://twitter.com/EndFTDregistry)



www.linkedin.com/company/ftd-disorders-registry



bit.ly/YouTubeFTDregistry

4th continued from Page 3

Collaboration with ALLFTD

ALLFTD is a comprehensive study targeting most varieties of frontotemporal lobar degeneration (FTLD). This project is co-directed by Dr. Brad Boeve at Mayo Clinic in Rochester, MN, and Drs. Adam Boxer and Howard Rosen at the University of California in San Francisco, CA. The study focuses on testing specific predictions about changes over time that could be measured in FTD and about what images and measurements from body fluids could be most useful as biomarkers.

As part of the study, ALLFTD study participants are enrolled into the FTD Disorders Registry. To facilitate enrollment, the Registry developed an Alternative Registration Pathway (ARP) for study coordinators to use for enrolling participants from the various 18 clinic sites. Enrollments began in February. Additionally, remote data collection between clinical site visits will be conducted by the Registry.

[READ MORE ABOUT THE ALLFTD STUDY](#)

World FTD Awareness Week

On October 3, 2020, presenters from around the globe participated in the 2020 World FTD Marathon by sharing information, resources, and updates on FTD through an online program. The event began in Australia before moving to Europe and finally to North and South America.

While hearing international speakers usually requires traveling to far-away conferences, the coronavirus pandemic brought experts to the people through these

virtual presentations. The one-day Marathon was the climax of World FTD Awareness Week, which is held each year at the end of September or in early October.

FTD Registry Manager Lakecia Vincent, MPH, MCHES, gave an overview of what a registry is and what the FTD Disorders Registry does, who we serve, and why it is important to share your story in the search for treatments and cures of these disorders.

[READ MORE & WATCH THE VIDEO REPLAYS](#)

“As we face another year, our intent is to bring value to participants and partners while also bringing hope to those affected by FTD,” said Dr. Wheaton.

“The Registry encourages broad-based collaboration and welcomes your partnership to help us reach our goals,” she said. “Together we can make a difference, change the course of these diseases, and find a cure.”

**Join the Registry.
Tell Your Story.
Advance the Science.**

“Together, we can make a difference!”



FTD Disorders Registry LLC

2700 Horizon Dr., Suite 120
King of Prussia, PA 19406
888-840-9980
manager@FTDregistry.org



www.facebook.com/EndFTDregistry



www.linkedin.com/company/ftd-disorders-registry



[@EndFTDregistry](https://twitter.com/EndFTDregistry)



bit.ly/YouTubeFTDregistry