

The VOICE of FTD

SPRING 2020

FTD Disorders Registry 3rd Anniversary

Enrollment surpasses 3,500 as Registry celebrates 3 years in March

On March 28, 2020, the FTD Disorders Registry (FTD-DR) turned 3 years old! Since that first day, more than 3,500 people affected by frontotemporal degeneration (FTD), including 669 diagnosed persons, have enrolled in the Registry.

FTDDR is an online database that collects information about those affected by all types of frontotemporal degeneration, including:

- behavioral variant FTD (bvFTD)
- primary progressive aphasia (PPA)
- progressive supranuclear palsy (PSP)
- corticobasal degeneration (CBD)
- FTD with motor neuron disease (also called FTD-ALS)

Through the course of their disease, persons affected by FTD may lose the ability to behave appropriately, make judgments, communicate, and carry out daily activities. Currently, there are no approved treatments or cures for FTD.

“The FTD Disorders Registry is a powerful tool to help us increase our understanding of these neurodegenerative disorders,” stated Registry Director Dianna Wheaton, Ph.D., CHES. “Registries play an important role for rare diseases like FTD where little is known and there are fewer people affected from which to draw information.”

As the number of people who enroll in the Registry increases, the information and knowledge about FTD

also grows. Persons diagnosed, caregivers (current and former), family members, and friends can all enroll and participate.

The Registry aspires to support the FTD community in several ways, including:

- Provides a centralized registry across the entire frontotemporal disorders spectrum
- Makes the de-identified, aggregate data we collect available to support health outcomes research.
- Uses Registry data to inform on the myriad issues in FTD, and thereby empower the FTD community to feel less isolated.
- Creates an environment to inform on patient-friendly clinical trial design and to stimulate new conversations with regulatory and policy groups as they work toward patient-focused drug development.
- Supports the efforts of pharmaceutical companies to drive therapies that could help to manage symptoms or treat FTD.
- Mobilizes a national (and eventually international) base of potential research study volunteers.
- Works to increase awareness and cultivate an environment of collaboration.

FTDDR is both an international **Contact Registry** and a North American **Research Registry**. During the past three years, the number of participants in each

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registry has been nearly equally divided. The first day saw the greatest gap with the Contact Registry at 58 enrollees (43 percent) and the Research Registry at 78 enrollees (57 percent). However, this has gradually changed where the Contact Registry now has 1,923 members (54 percent) and the Research Registry has 1,607 members (46 percent).

The Contact Registry includes enrollees from all 50 U.S. states and more than 30 countries, with the majority of international participants residing in Canada, Australia, and the United Kingdom. As FTDDR marks its third anniversary, there are 241 international participants, a number that has more than doubled in one year.

Research Registry enrollment is limited to the United States and certain Canadian provinces. Those who participate in research through surveys and clinical trials are providing much-needed information to help find treatments and a cure.

“We encourage everyone to tell their story to advance the science,” Dr. Wheaton said. “Together we can make a difference. Together we can change the course of these diseases and find a cure.”

The FTD Registry was created as a shared vision between the [Association for Frontotemporal Degeneration](#) (AFTD) and the [Bluefield Project to Cure Frontotemporal Dementia](#). FTDDR was founded in 2015 and launched to the public in 2017.

In addition to funding from the AFTD and the Bluefield Project, the FTDDR is supported by the [Rainwater Charitable Foundation's Tau Consortium](#) program. The Registry has received generous annual grants from the Tau Consortium since its inception in 2015.



FTDDR BY THE NUMBERS

DAY 1 - MARCH 28, 2017

- 14 Diagnosed
- 50 Biological Family Members
- 72 Caregivers, Spouses, Friends
- **136 TOTAL**
- 54 Contact Registry only
- 4 Contact Registry - International
- 78 Research Registry
- **136 TOTAL**

MONTH 1 - APRIL 28, 2017

- 46 Diagnosed
- 159 Biological Family Members
- 213 Caregivers, Spouses, Friends
- **418 TOTAL**
- 174 Contact Registry only
- 31 Contact Registry - International
- 213 Research Registry
- **418 TOTAL**

YEAR 1 - MARCH 28, 2018

- 190 Diagnosed
- 469 Biological Family Members
- 556 Caregivers, Spouses, Friends
- **1,215 TOTAL**

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YEAR 1 - MARCH 28, 2018 (continue)

- 521 Contact Registry only
- 99 Contact Registry - International
- 596 Research Registry
- **1,215 TOTAL**

YEAR 2 - MARCH 28, 2019

- 432 Diagnosed
- 961 Biological Family Members
- 1,005 Caregivers, Spouses, Friends
- **2,398 TOTAL**
- 1,265 Contact Registry only
- 172 Contact Registry - International
- 1,133 Research Registry
- **2,398 TOTAL**

YEAR 3 - MARCH 28, 2019

- 669 Diagnosed
- 1,447 Biological Family Members
- 1,414 Caregivers, Spouses, Friends
- **3,530 TOTAL**
- 1,923 Contact Registry only
- 241 Contact Registry - International
- 1,607 Research Registry
- **3,530 TOTAL**

REGISTRY TEAM MEMBERS

- Registry Director: Dianna Wheaton
- Registry Manager: Lakecia Vincent
- Communications Manager: Sherry Harlass
- ALLFTD Study Liaison: Sweatha Reddy
- IT System Administrator: Kevin Wheaton
- Special Projects Manager: Lauren Youngborg

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

"Together, we can make a difference!"

TIMELINE

- March 2015 - Founded by the AFTD & Bluefield Project for the Cure (to Cure Frontotemporal Dementia)
- January 2016 - Dr. Dianna Wheaton named first Registry Director
- March 2016 - Granted nonprofit 501(c)(3) status
- April 2016 - Launched Facebook account
- May 2016 - Launched Twitter account
- May 2016 - Presented at first caregiver conference - 2016 AFTD Education Conference, Minneapolis, MN
- August 2016 - Attended and hosted booth at first scientific conference - ICFTD 2016, Munich, Germany
- September 2016 - Presented at first scientific conference - CurePSP 2016 International Research Symposium, Jersey City, NJ
- March 28, 2017 - Launched to public with website and emails to more than 10,000; reached more than 100 registrants first day
- September 2017 - Added Registry Manager (Kristin Shelby)
- **March 28, 2018 - 1st Enrollment Anniversary**
- August 2018 - Added IT System Administrator (Kevin Wheaton)
- September 2018 - Logo given registered approval
- Fall 2018 - Presented at first international conferences:
 - Scientific conference - London, England, UK (October 2018)
 - Scientific conference - Sydney, Australia (ICFTD - November 2018)
 - Caregiver conference - Sydney, Australia (ICFTD Carers Day - Nov 2018)
- January 2019 - Added Communications Coordinator (Sherry Harlass)
- March 2019 - Launched YouTube channel
- **March 28, 2019 - 2nd Enrollment Anniversary**
- July 2019 - Launched LinkedIn account
- November 2019 - Added Special Projects Manager (Lauren Youngborg)
- January 2020 - Added new Registry Manager (Lakecia Vincent)
- January 2020 - Added ALLFTD Study Liaison (Sweatha Reddy)
- **March 28, 2020 - 3rd Enrollment Anniversary**

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