FTD DISORDERS REGISTRY
STRATEGIC PLAN

2020-2022

THANK YOU

The FTD Disorders Registry LLC would like to acknowledge our founders, **The Association for Frontotemporal Degeneration** and the **Bluefield Project to Cure Frontotemporal Dementia**. Together they nurtured the vision of a person-centric registry and cultivated input from the FTD community to guide our design and implementation. They continue to be strong partners in driving our mission.

The **Rainwater Charitable Foundation, Tau Consortium** has also been instrumental in supporting the Registry from its earliest days to the present.

Additional sponsors, known and anonymous, have contributed to our sustainability.

We are also appreciative of our relationships with allied patient advocacy groups, such as **CurePSP** and clinical research collaborators, including the **ARTFL-LEFFTDS Longitudinal Frontotemporal Lobar Degeneration** (ALLFTD) multisite research consortium.

The Registry extends our deepest appreciation to persons diagnosed with FTD, their family members, and caregivers for sharing their stories.

We thank you all for your support and partnership!

WELCOME

from Registry Director
Dianna Wheaton, M.S., Ph.D., CHES

December 1, 2020

The FTD Disorders Registry LLC is a powerful tool to help us increase our understanding of these neurodegenerative disorders. 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.

We designed the FTDDR to be the 'go to' place for person's diagnosed and their families to access information about FTD research as well as participate in studies. This vision was nurtured by patient advocacy groups, research scientists, clinicians, and most importantly, by those affected by FTD.

Joining the Registry is an act of self-advocacy and enables direct participation in research with few barriers. Registry research is focused on collaboratively capturing the lived experience of FTD.

Research advances in FTD are driving the impetus from natural history studies and symptom-reducing agents toward clinical trials to investigate interventions targeted to root causes. This shift brings a welcome increase of pharma-based researchers to augment and accelerate efforts.

The Registry will play a valuable role in facilitating and advancing these efforts to find treatments and cures for FTD. We will partner throughout the FTD community to be a key resource in supporting research and sharing data.

The pages that follow outline the FTDDR Strategic Plan for 2020 – 2022. Nearly all of our Goals, Strategies, and Tactics have a basis in collaboration and partnering. The four pillars of the plan are ***Infrastructure, Growth, Partnering & Collaboration,*** and ***Sustainability***.

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

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

Dianna Wheaton

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WHO WE ARE

OUR VISION

The FTD Disorders Registry LLC envisions a world in which research on frontotemporal degeneration (FTD) is a robust, collaborative, and effective enterprise among researchers, persons diagnosed, care partners, and those at risk.

OUR MISSION

The Registry's mission is to facilitate and advance research into the spectrum of FTD disorders and to accelerate the development of treatments by providing tools and resources that:

- Promote and support research participation
- Enable access and sharing of data with researchers
- Amplify the voice of the patients' and families' lived experiences

OUR VALUES

AUTONOMY

We honor and respect each individual's right to represent themselves.

KNOWLEDGE

We seek to gain and share information.

INCLUSION

We seek to represent all members of the FTD community, regardless of race, ethnicity, or socioeconomic status.

ACCESS

We seek to ensure that all individuals impacted by FTD have the opportunity to participate in the research process.

COLLABORATION

We work together as, and for the benefit of, a community.

INTEGRITY

We will adhere to the highest ethical and moral standards, both in interactions with our community and as guardians of their data.

STAKEHOLDERS

What value does the FTD Registry bring to participants and partners?

For participants (persons diagnosed, caregivers, family members, friends), joining the Registry offers:

- inclusion in an understanding community
- a shared experience that reduces isolation
- an opportunity to be informed and educated about potential treatment options
- the ability to contribute to a better future, giving purpose to their journey
- hope

For researchers (clinicians and academic investigators), collaborating with the Registry offers:

- the ability to reach a larger audience from which to recruit research participants
- access to an efficient remote data collection mechanism
- access to de-identified data

For pharmaceutical colleagues, including trial sponsors, working with the Registry offers:

- help with participant recruitment and retention to maximize the likelihood a study is completed on time and on budget
- expertise in designing studies that reflect patient and caregiver perspectives
- communication mechanisms that engage the community

For physicians, working with the Registry offers:

- free educational and engagement tools to empower patients and their care partners
- research opportunities for patients, families, and those at risk

For government entities, working with the Registry offers:

- the assurance that patient voices are included in research through an independent, partnership-driven, nonprofit registry

For FTD Patient Advocacy Groups and other nonprofits, partnering with the Registry offers:

- the ability to achieve economies of scale
- the opportunity to advance patient-centered research and empower the community

WHAT WE DO

The FTD Disorders Registry (FTDDR) is designed to bring together the FTD community. This means persons diagnosed, their family members, caregivers, and friends as well as clinicians, scientists, patient advocacy groups, and the pharma/biotech industry.

Our overarching goal is to advance the science and assist in moving faster toward finding treatments and cures for the spectrum of disorders, including:

- behavioral variant FTD (bvFTD)
- any of the primary progressive aphasias (PPA)
- progressive supranuclear palsy (PSP)
- corticobasal degeneration (CBD)/corticobasal syndrome (CBS)
- FTD with motor neuron disease (also called FTD-ALS)

The Registry was created to be a resource for FTD-diagnosed persons, their families and caregivers. It provides one location to collect and share de-identified data, promote research studies, and notify potentially eligible study candidates.

The FTDDR is both a Contact Registry and a Research Registry.

Contact Registry — Registrants in the Contact Registry receive emails about FTD and the Registry, including news and general research updates. The Contact Registry is open to U.S. and international enrollment for persons 18 years old or older.

Research Registry — In addition to receiving emails about FTD, these registrants are sent study notices and can complete surveys to help researchers better understand FTD. Participant data is kept confidential, and identifiable information is never shared. Research Registry enrollment requires participants to be:

- at least 18 years of age
- a resident of the United States or Canada
- able to actively participate in answering survey questions, even with the help of a care partner

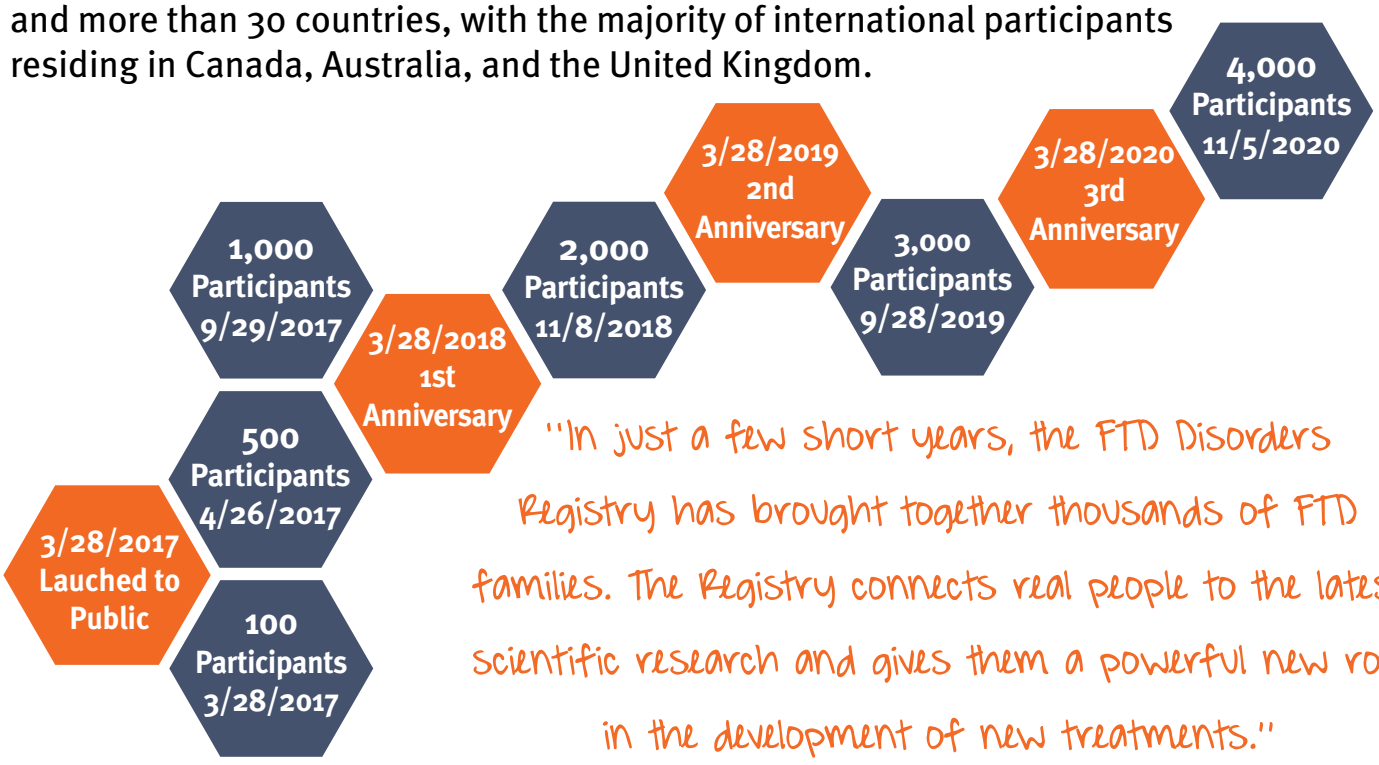
Join the Registry. Tell your story. Advance the science.

HISTORY OF GROWTH

The FTD Registry was co-founded as an independent entity in March 2015 by The Association for Frontotemporal Degeneration (AFTD) and the Bluefield Project to Cure Frontotemporal Dementia. We received nonprofit 501(c)(3) status in March 2016 and then launched for public enrollment in March 2017, giving birth to a shared vision to create a patient registry for the frontotemporal disorders (FTD) community.

When the Registry opened for enrollment on March 28, 2017, we exceeded our two-week goal of 100 registrants in less than 24 hours. Since that day, we have continued to surpass enrollment goals for each anniversary for the first three years.

Through these years, the Registry has grown to include persons 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.



"In just a few short years, the FTD Disorders Registry has brought together thousands of FTD families. The Registry connects real people to the latest scientific research and gives them a powerful new role in the development of new treatments."

Patrick Brannelly, Managing Director, Tau Consortium

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GOAL #1

INFRASTRUCTURE

Ensure a robust online Registry platform that creates value for our stakeholders

STRATEGIES

1. Ensure compliance, regulatory, and security best-practices for current and planned activities
    - Upgrade web content management system
    - Investigate regulatory and compliance impediments for additional international research enrollment
2. Improve direct engagement with registrants and researchers
    - Build and implement registrant and researcher portals/dashboards by expanding functionality within the current platform
    - Create a core de-identified dataset with basic Registry demographics
3. Develop, build, or transfer to a long-term platform that will allow implementation of genetic data collection and expanded international research enrollment
    - Identify format and design of expanded or new platform
    - Implement by building or transferirng
4. Evaluate functional and services expansion to continually improve value-add for stakeholders
    - Query internal and external stakeholders through feedback mechanisms and quantifiable tools
    - Leverage funding opportunities to drive expansion

OUTCOMES

- **Registrants and researchers are able to interact directly with the data.**
- **The Registry has the capacity to store genetic data.**
- **The Registry is expanded to include additional international research participants.**

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GOAL #2

GROWTH

Cultivate and grow our community of Registry participants through outreach and engagement activities

STRATEGIES

1. Actively recruit to increase the number of registrants
    - Optimize domestic and international recruitment through marketing strategies that include grassroots resources to promote enrollment of diverse populations
    - Plan and execute campaigns to encourage contact-to-research conversion

2. Ensure the Registry website is accessible, informative, and engaging
    - Promote equitable access, usability, and comprehension while working to reduce barriers
    - Develop and execute strategies to improve minority engagement
    - Develop and implement an interactive participant dashboard
    - Develop and activate a searchable FIND A STUDY page

3. Create outreach, engagement, and retention activities via digital and face-to-face opportunities
    - Inform and engage registrants with robust, regular communications
    - Create and curate an educational series focused on research, clinical trials, and genetics
    - Cultivate caregiver event attendance and speaker opportunities
    - Disseminate research study and clinical trial notices to general and targeted populations

4. Collect, analyze, and disseminate Registry data
    - Collect and curate Registry research data through surveys using existing and new tools
    - Disseminate Registry research data through lay and professional channels

5. Evaluate the Registry as a host to facilitate genetic testing to the FTD community

OUTCOMES

- **Registry enrollment doubles by end-of-year 2022.**
    - Domestic and international enrollment increases
    - Proportion of registrants participating in research increases
    - Recruitment of minority and underserved populations increases
- **Engagement with registrants is reflected by high participation rates in data collection and Registry content.**

GOAL #3

PARTNERING & COLLABORATION

Establish the Registry as a primary resource for researchers to promote clinical studies, collect data, and provide access to a broad data pool

STRATEGIES

1. Partner with researchers to accelerate research and enhance the voice of the patient
    - Cultivate an understanding of researcher and pharma needs
    - Articulate opportunities for clinical research and pharma to advance programs through Registry resources and patient-centered activities

2. Provide an efficient mechanism for researchers and pharma to communicate with and collect data on the FTD community
    - Develop and execute collaborative interactions with the research community to
        1. promote research study and clinical trial enrollment
        2. promote data collection and de-identified data sharing
    - Provide and optimize an efficient Project Proposal Submission Program to review collaboration requests
    - Create and maintain an interactive data engagement tool for researchers (i.e., researcher portal)

3. Engage in strategies that promote and support effective partnerships with academia, industry, government, and patient advocacy groups
    - Engage in active business development through targeted outreach
    - Foster grassroots relationships with patient advocacy groups, national nonprofits' local affiliates, and community-based organizations
    - Support collaborative alliances by using the Alternative Registration Pathway (ARP). The ALLFTD natural history study is our first collaborative client.

OUTCOMES

- **The Registry offers a menu of value-add resources for researchers and pharma.**
- **An interactive portal for researchers is implemented.**

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GOAL #4

SUSTAINABILITY

Develop a business plan and long-term funding strategy that includes multiple types of funding streams

STRATEGIES

1. Develop a formal business and financing plan
    - Benchmark operations and financing approaches of other rare disease registries
    - Draft and approve mechanisms and policies to accomplish multi-stream funding
    - Create an actionable business development plan that drives program support and generates new revenue

2. Develop and refine policies for business development and partnering
    - Draft and enact Data Use Agreement
    - Draft and enact Publication Policy
    - Draft and enact Contracting Template
    - Refine the Scientific Advisory Board policies and procedures to promote efficiency and engagement

OUTCOMES

- **The Registry has a written roadmap for sustainability.**
    - Financing plan includes multiple funding streams via grants, sponsorships, and fee-for-service
    - Business plan includes partnerships across multiple sectors: researchers, pharma, government, and nonprofits
- **The Scientific Advisory Board engages robustly and smoothly, with broad participation from the expert community.**
- **Clear policies and procedures are in place for partnerships and access to Registry data.**
- **The Registry has clear and timely processes to deliver on partners' needs.**

Join the Registry.
Tell your story.
Advance the science.

FTD DISORDERS REGISTRY LLC

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

www.FTDregistry.org