

The VOICE of FTD

SUMMER 2022

FTD Registry Reports FTD Data at AAIC 22

The FTD Disorders Registry presented frontotemporal degeneration (FTD) findings this summer at the 2022 Alzheimer's Association International Conference (AAIC).

Registry Director Dianna Wheaton, MS, Ph.D., CHES, shared information from the FTDDR Research Readiness Survey during a poster presentation, and she gave a separate 10-minute talk using data from a portion of the FTD Insights Survey. Registry staff members also were co-authors on a second poster presentation that highlighted the experiences of African Americans diagnosed with FTD.

"We were incredibly excited that Registry data was afforded the opportunity to be represented in three different sessions during this key conference," Dr. Wheaton said.

AAIC is the largest and most influential international meeting dedicated to advancing dementia science. Each year scientists, researchers, investigators, clinicians, and the care research community share discoveries that may lead to methods of prevention, treatment, and improvements in the diagnosis of Alzheimer's disease and related dementia.

There were more than 3,000 poster presentations and over 650 podium presentations on basic science, new

research, the latest practice techniques, imaging, technology, and more.

The Registry was involved with three presentations at this year's hybrid conference event, which was held from July 31- August 4, 2022, in San Diego, California. More than 9,500 attendees came from around the world to learn about the latest advances in dementia research.

"This conference offers great educational opportunities and encourages networking among the thousands of dementia researchers," Dr. Wheaton said. "For many, this meeting represented the first opportunity in more than a year to interact with colleagues and share scientific information in person."

FTDDR Research Readiness Survey Poster

A poster presentation based on the Registry's Research Readiness Survey offered an understanding of people's perceptions about FTD research. The title of this poster was "Assessing Awareness and Attitudes Towards Participation in Research."

"We are thankful for those who have joined the Registry, signed up for research, and completed our surveys," Dr. Wheaton said. "This poster presentation

AAIC22 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



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



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



bit.ly/YouTubeFTDRegistry

AAIC22 continued from Page 1

is one way the Registry shares our participants' de-identified information to inform the science and guide future research.”

The Research Readiness Survey was designed to assess the FTD lay community to determine their:

- knowledge of basic research principles
- perceptions of the value of research studies and clinical trials
- willingness to participate
- barriers to participation

The 23-question survey used a multiple-choice and True/False-style format. It was administered online to FTDDR participants residing in the United States and Canada. The survey collected 750 responses between March 2017 and January 2022.

The survey showed that FTDDR members have a positive perception of research and are somewhat knowledgeable about basic rules of participation. However, there is a strong desire for more information and education. Additionally, emotional, financial, and logistical barriers could hinder participation even if people have a positive attitude toward research studies.

“The results also showed that research study enrollment may increase by understanding and addressing perceived barriers,” Dr. Wheaton said. “Additional participation may be gained by creating person-centric studies that have an emphasis on participant-facing educational materials.”

Authors for this poster included Sweatha Reddy, BS, Sherry Harlass, BA, Lakecia Vincent, MPH, MCHES, and Dr. Wheaton.

[View the Research Readiness Poster](#)

[Watch the Research Readiness Presentation](#)



FTD Research Topic Presentation

In a separate oral presentation session, Dr. Wheaton discussed findings from the FTD Insights Survey which was created to understand the lived experience of FTD from the perspectives of individuals diagnosed with FTD, biological family members, and care partners. It covered the diagnostic journey, symptoms experienced, and disease and treatment impact.

“This was the first opportunity to give an extended talk on frontotemporal degeneration and the data resulting from the FTD Insights Survey,” Dr. Wheaton said. “The AAIC meeting allowed us to share this information with a wider audience of professionals in the dementia field.”

The 10-minute presentation was titled “Chronicling the Diagnostic Journey, Symptom Experiences, and Disease Impact in Frontotemporal Degeneration (FTD).” It focused on the experiences of 656 people in the early to mid stages of the disease. Of these, 219 were FTD-diagnosed persons and 437 were care partners.

The survey showed that the diagnostic journey for those diagnosed with FTD and their families is often complicated. About half of all respondents reported seeing three or more doctors before an FTD diagnosis was made.

AAIC22 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



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



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



bit.ly/YouTubeFTDregistry

AAIC22 continued from Page 2

Symptoms experienced were in line with the type of FTD, whether behavioral FTD (bvFTD), primary progressive aphasia (PPA), or progressive supranuclear palsy/corticobasal syndrome (PSP/CBS). However, there was major overlap in symptoms across these types.

Additionally, symptom distress, reduced quality of life, and loss of independence both inside and outside of the home are significant elements of the disease impact of FTD.

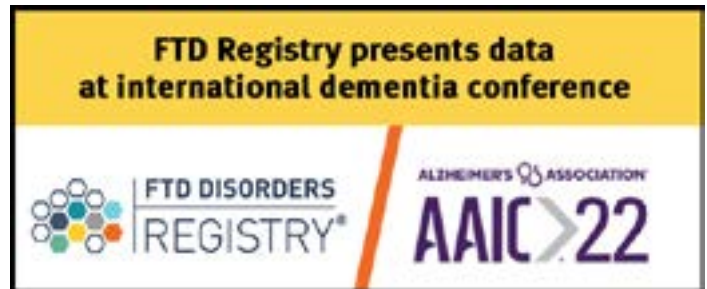
The survey data reflects that the perspectives of those living with FTD should guide research design, care options, and development of treatments to improve quality of life.

The FTD Insights Survey was developed with guidance from the AFTD and FTDDR with input from experts in the field of FTD. A total of 1,796 people completed it anonymously from October 2020 through March 2021.

“There was great enthusiasm for this data, including anticipation for the future publication of a full-length paper,” Dr. Wheaton said. “Because this was a subset of the full survey data, next steps, such as additional analyses and data-sharing, were also of high interest.”

Abstract authors included Megan S. Barker, PhD, Jillian L. Joyce, BSc, and Stephanie Cosentino, PhD, from Columbia University Medical Center; Shana G. Dodge, PhD, Debra Niehoff, PhD, Penny Dacks, PhD, Sharon S. Denny, MA, Susan Dickenson, MSGC, from the AFTD; and Dacks and Wheaton from the FTD Disorders Registry.

[Watch the Disease Impact Presentation](#)



African American Experience: A Subset of the FTD Insights Survey Poster

Another poster presented at AAIC on which Registry staff members were co-authors was the “African American experience of FTD: A sub-cohort assessment of the FTD Insights Survey.” The data used for this poster was a different subset than the oral presentation.

Shana Dodge, Ph.D., MA, Director of Research Engagement with The Association for Frontotemporal Degeneration (AFTD), presented the poster at AAIC on Monday, August 1, 2022.

“Though a small sample size, we found that it took African American respondents on the FTD Insights Survey longer to receive an FTD diagnosis than the overall respondent pool,” Dr. Dodge said. “They were also more likely to initially receive a different diagnosis and reported some differences in what symptoms initially presented and what symptoms they found most distressing.”

While efforts are underway to better understand different aspects of FTD, most research participation has been dominated by persons of European descent. A better understanding of the breadth of the FTD experience is critical to providing optimal healthcare and conducting research that produces more generalizable results.

AAIC22 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

AAIC22 continued from Page 3

In preparation for an Externally Led Patient-Focused Drug Development (PFDD) meeting, the AFTD and FTD Registry collaborated to develop the FTD Insights Survey. The online survey queried aspects of the lived experience of FTD from the patient/family/carer perspective.

The African American experience reported on this Survey represents a small sample size of individuals with greater than average levels of education. Many (76%) indicated they had an Associate's degree or higher.

In addition, the experiences they reported overlap with those of other respondents, but with key differences including greater difficulty getting a timely diagnosis. More information is needed on the lived experience of FTD across people of different cultural, social, and economic backgrounds.

"AAIC was a wonderful opportunity to present and discuss some of the findings from the FTD Insights Survey with the larger Alzheimer's and Related Dementia stakeholder community," Dr. Dodge said. "Several researchers and clinicians indicated that they suspect there are differences in access to FTD diagnoses across racial, ethnic, and socioeconomic groups and were pleased to see that The Association for Frontotemporal Degeneration and the FTD Disorders Registry are examining these issues."

In addition to Dr. Dodge, FTD Registry Manager Lakecia Vincent, MPH, MCHES, and Dr. Wheaton were co-authors along with Dr. Dacks, Senior Director of Scientific Initiatives at AFTD and President of FTDDR.

[View the African American Experience Poster](#)

[Watch the African American Experience Presentation](#)



**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



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



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



bit.ly/YouTubeFTDregistry