

# The VOICE of FTD

SUMMER 2022

## Registry Launches Quick Questions

*The FTD Disorders Registry invites you to answer our monthly survey*

The FTD Disorders Registry kicked off its Quick Questions polling campaign in June 2022.

More than 850 people answered the first question using the anonymous form. The Registry also somewhat unexpectedly received replies to the question via our website chat tool, emails, and replies on social media.

“We were incredibly excited by the number of responses that we received in such a short time,” said Registry Director Dianna Wheaton, MS, Ph.D., CHES.

Each month we will post a research-related question that, if it applies to you, we would like you to answer. Some questions will be directed to persons diagnosed with frontotemporal degeneration (FTD) and/or their biological family members. Other times the question may be directed to caregivers or all family members.

In addition to the question of the month, survey participants are asked to answer two additional questions about gender and relationship to an FTD-diagnosed person.

The Quick Questions survey uses the same secure platform that the Registry uses for our registration process. Answers are anonymous.

“The FTD Disorders Registry is gathering great input from everyone in the FTD community,” Dr. Wheaton

said. “We welcome all to answer the questions whether or not they are a participant in the Registry.”

A new question will be posted each month on our Facebook and Twitter pages. Persons who have joined the FTD Registry and given us permission to send them our emails will also receive an eBlast with the question and a link to the form.

Highlights of the results will be posted on social media along with the next month’s question. A full summary of the results will be posted on our website that can be accessed either from the Thank You page for the next month’s question or the NEWS summary page.

“Completing our Quick Questions poll allows you to provide feedback in bite-size pieces on various research topics that teaches us more about FTD,” Dr. Wheaton said.

“Your input is valuable and will help us learn more about the thoughts, feelings, and experiences of those directly affected by FTD,” she added. “Providing your unique perspective not only increases our understanding of these diseases, but drives person-centered research.”

[Read June 2022 Results - Have you tried to get genetic testing for FTD over the last 3 years?](#)

[Read July 2022 Results - Have you participated in an FTD research study?](#)

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