

The VOICE of FTD

FALL 2021

RARE Revolution Magazine:

October 2021 Digital Spotlight on FTD, the Registry, and More

RARE Revolution Magazine focused on frontotemporal degeneration (FTD), the FTD Disorders Registry, and educational content about this disease for its October 2021 Digital Spotlight. There are seven articles that are part of this featured topic.

Registry Director Dianna Wheaton, M.S., Ph.D., CHES, discussed the importance of registries and, in particular, the benefits of joining the FTD Registry not only for persons diagnosed with FTD, but also their spouses, biological family members, caregivers, and friends.

Additionally, the article notes how the Registry partners with researchers to support their studies as well as collects data from participants to report on the disease. The digital publication used the Registry's [Disease Impact of FTD poster](#) as an example of aggregate data gathered from survey responses.

RARE Revolution is a free, quarterly digital magazine for the rare disease community and those wishing to learn more and be inspired by their stories. It is published by NRG Collective.

The magazine partnered with Prevail Therapeutics to share this educational content on frontotemporal dementia. Interviews and editorial writing were handled by the magazine.



[Read the article about the FTD Disorders Registry.](#)

Additional articles that are part of this magazine's Digital Spotlight on FTD include:

- [An overview of FTD variants, symptomology, and disease progression from neurologist Dr. Ahmed](#)
- [The Association for Frontotemporal Degeneration \(AFTD\): providing reliable information, essential resources, and vital support for the FTD community](#)
- [Caregivers – understanding the impact of an FTD diagnosis on carers and families](#)
- [The significance of FTD genetic confirmation and the considerations needed before knowing your genetic status](#)
- [The genetic testing dilemma – understanding inheritance risk and what that means for individual family members](#)
- [Gene therapy research for frontotemporal dementia: understanding the science and clinical trial considerations](#)

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