

Saturday

Nothing about us without us: giving voice to persons with a diagnosis, family members and care partners through research participation

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STATE OF THE ART

Opportunities for patients, caregivers, and research participants to become advocates are critically important to promote research participation, develop person-centered research protocols and define clinically meaningful outcomes. Despite this importance, multiple barriers exist for patient engagement due to challenges related to cognitive impairment and communication difficulties.

METHODOLOGY

The ALLFTD study was established as a multicenter collaborative project to further research in the frontotemporal degenerations (FTD). The ALLFTD Participant and Family Engagement Board (Board) was created as a platform to advise principal investigators and study staff on participant and family priorities.

RESULTS

The Board was launched in February of 2021 with the development of a charter and call for nominations from ALLFTD sites. Current board members include two individuals living with a diagnosis of FTD, two care partners, and one member of a family impacted by an inherited (genetic) form of FTD. Initial board meetings yielded contributions to an educational flyer and a recruitment email. To support the participation of members living with an FTD diagnosis, preparatory and follow up meetings were conducted, transcriptions and recordings were compiled for offline review, and speech language pathologists were present at meetings to provide communication support.

CONCLUSION

To acknowledge personhood and dignity of research participants in FTD-related research, we must offer platforms that allow for the amplification of the patient voice. Accommodations for individuals with communication challenges and cognitive impairment takes additional planning and resources to yield full participation but can succeed.

Conflicts of interest

Wave Life Sciences, Presenter, I presented a talk on the lived experience of caring for a loved one with Frontotemporal Dementia in honor of Rare Disease Day. The purpose of the talk was to share my personal experience caring for my late husband throughout his journey living with behavioral variant Frontotemporal Dementia.