

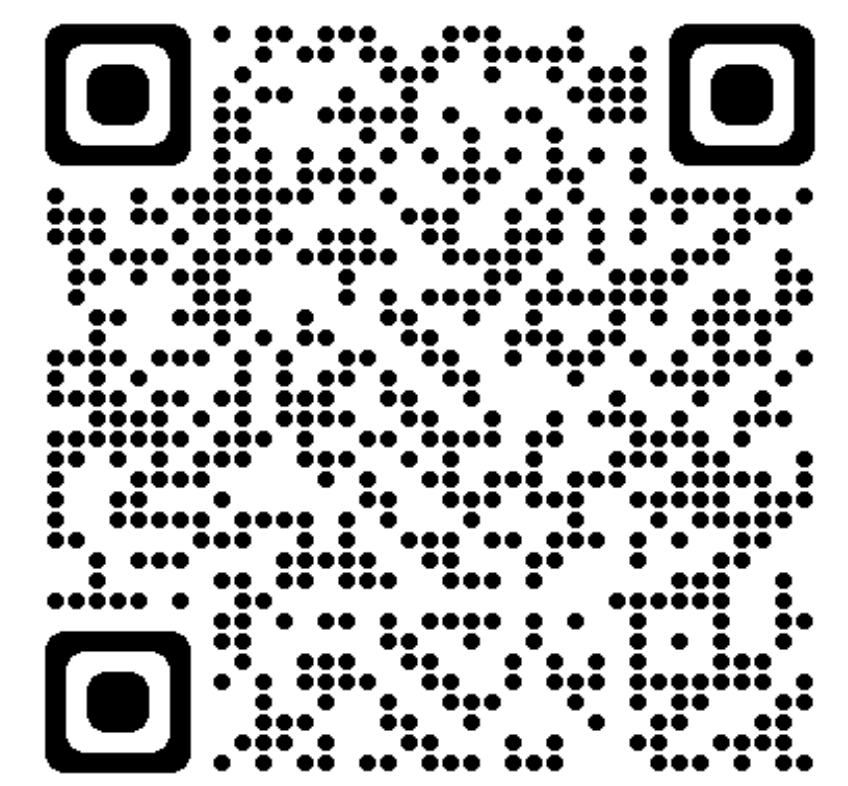


Integrating Patient Perspectives To Accelerate Therapeutic

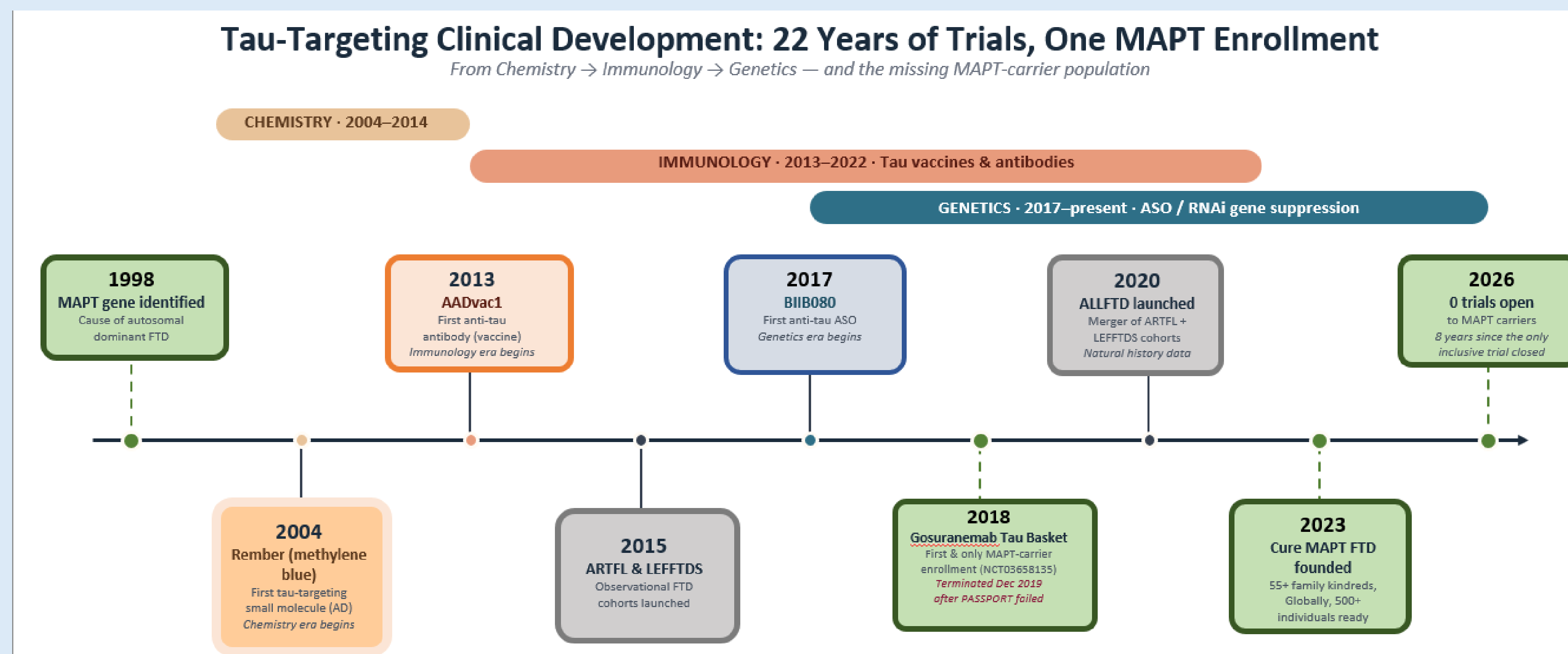
Development For MAPT Frontotemporal Dementia

Authors: Linde Jacobs, RN, Swetha Mohan, PhD, Cure MAPT FTD

hello@curemaptftd.org | www.CureMAPTFTD.org



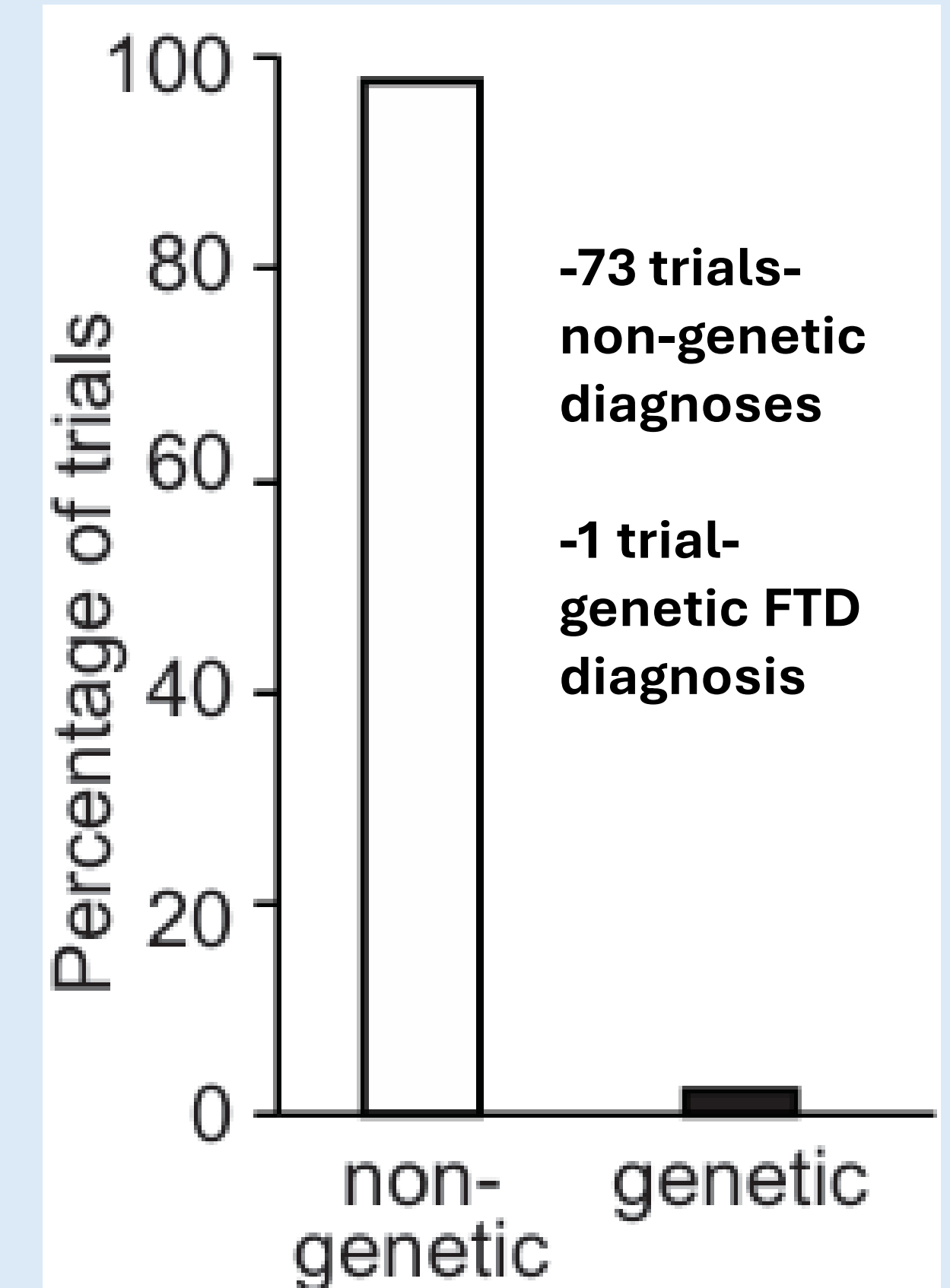
MAPT TIMELINE



WHY NOT MAPT FTD?

- ***Pure tau pathology** – Only human population with known tau pathology
- ***Tau is cause, not consequence** – pathogenic MAPT variants act directly on the drug's target
- ***Predictable trajectory** – Onset and progression documented in longitudinal studies (ALLFTD)
- ***Identifiable pre-symptomatically** – genetic test confirms carriers before symptom onset
- ***Regulatory precedent** – FDA approved genetic ASO's on a biomarker (Tofersen)

74 Tau Trials Since 2004

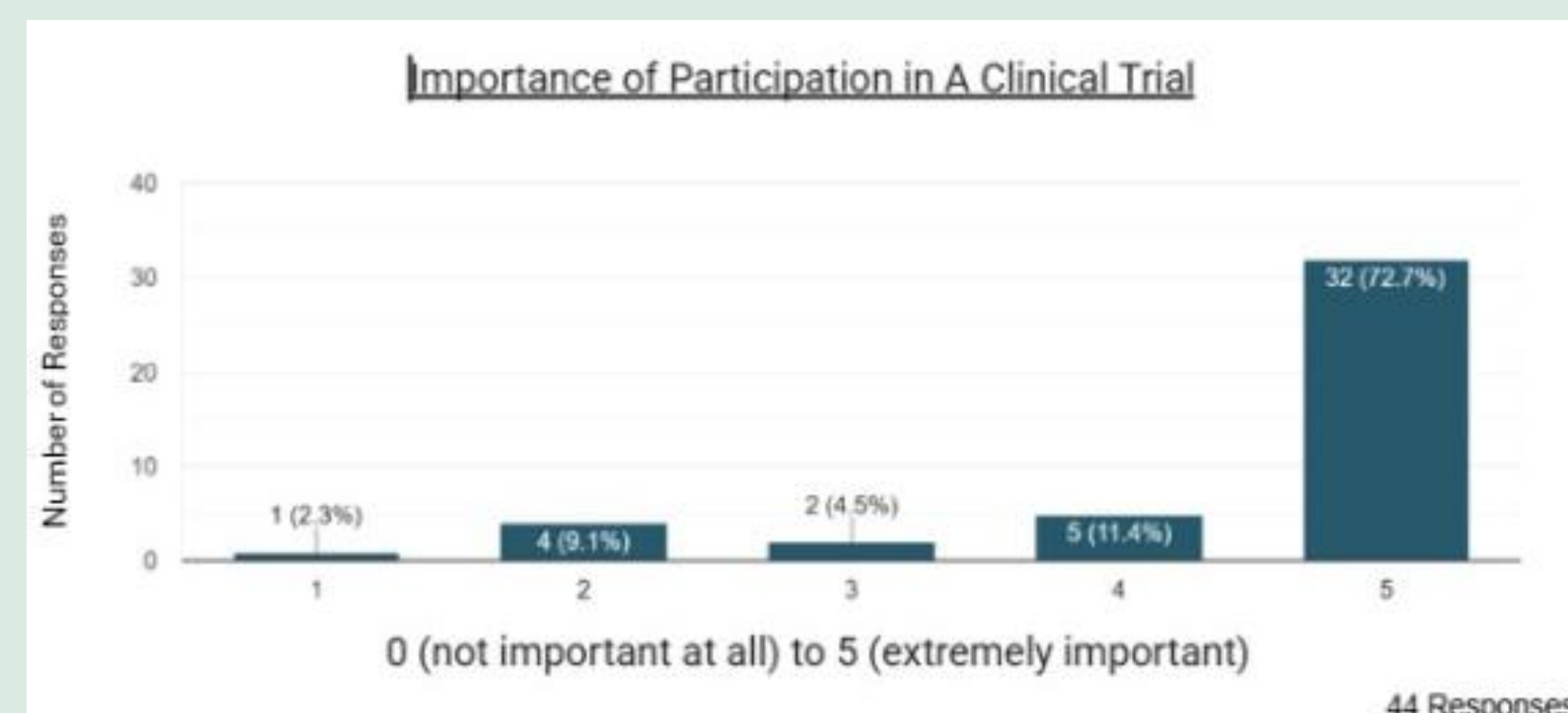


33 tau-targeting drugs · 74 clinical trials · 22 years

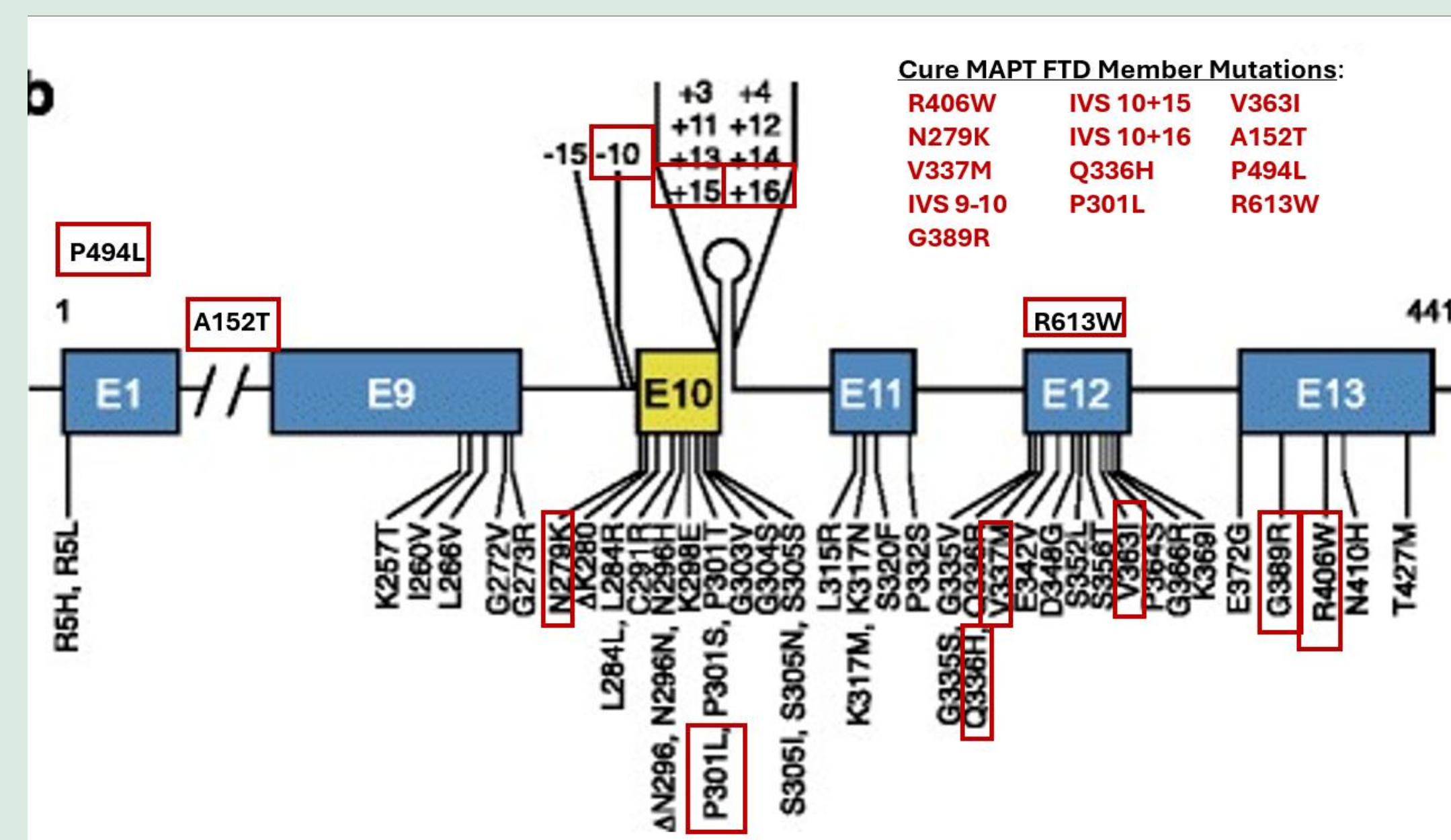
1 trial included MAPT mutation carriers

ABOUT CURE MAPT FTD

Cure MAPT FTD is a nonprofit organization created by impacted family members to mobilize and raise awareness of the MAPT genetic mutations causing Frontotemporal Dementia (FTD), assisting a global network of families, and advocating for clinical trials with the goal of finding a cure. The organization created a centralized space for researchers, clinicians, other non-profit partners, and industry to locate families impacted by MAPT mutations and to work in a proactive approach to lead further development of therapeutic potential and clinical trial readiness through our three main pillars: advocacy, awareness and connection.



MEMBER MUTATION CODES



Goedert, Michel & Spillantini, Maria Grazia. (2017). Propagation of Tau aggregates. Molecular Brain. 10. 10.1186/s13041-017-0298-7.

FDA LISTENING SESSION

To ensure clinical trial readiness, Cure MAPT FTD participated in an FDA Patient Listening Session where speakers with lived experience voiced the needs of the MAPT FTD community. A survey was sent out to our families to ensure that the plea of the community was heard through themes of all the testimonies and ultimately landing on these 7 recommendations:

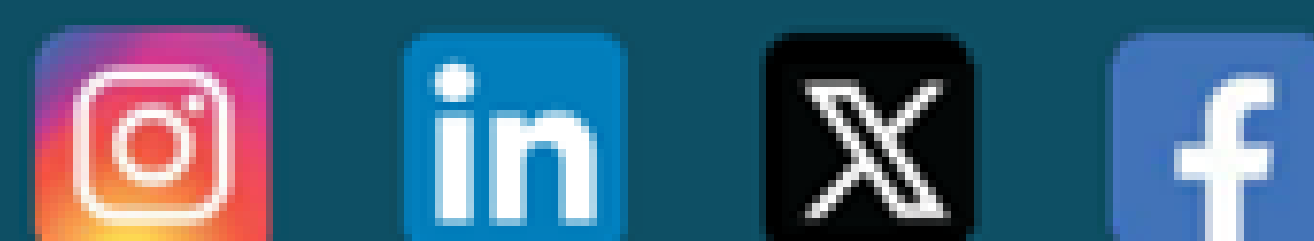
1. Expand indication labeling for Tau-Based therapies.
2. Include care partners in the clinical trial process
3. Expand clinical trial access to include MAPT FTD patients
4. Use natural history data to replace control groups in trials
5. Include asymptomatic mutation carriers in clinical trials.
6. Families are willing to assume moderate to high levels of risk for clinical trial participation.
7. Highly targeted symptoms in the absence of disease-modifying therapies

FDA LISTENING SESSION SUMMARY

FORMAL PUBLICATION COMING SOON IN NPJ DEMENTIA- JULY 2026



Connect with us!



hello@curemaptftd.org