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Thursday

The New Zealand Genetic Frontotemporal Dementia Study (FTDGeNZ): study protocol, and baseline demographic and clinical characteristics

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State of the art: Natural history studies of genetic FTD cohorts provide a unique opportunity to identify biomarkers of pre-symptomatic dementia, as carriers can be identified and studied decades before expected symptom onset.
Methodology: The New Zealand Genetic Frontotemporal Dementia Study (FTDGeNZ) is a longitudinal study of a large New Zealand pedigree with genetic FTD. FTDGeNZ was established in 2016 with the aim of identifying the earliest pre-symptomatic biomarkers of FTD, in collaboration with international multi-centre cohorts.
Results: We enrolled 25 participants from a single family between April 2016 and August 2018. Participants were genotyped to determine whether they were pre-symptomatic carriers of the mutation (MAPT IVS 10+16 C>T), or non-carrier controls. Participants have undergone clinical assessments including neuropsychological and mood assessment; olfactory testing; assessment of social cognition; and blood collection for analyses of microRNA and protein fluid biomarkers annually. We have also performed structural and functional MRI of the brain and assessment of autobiographical memory biennially, and retinal imaging at baseline. Here, we describe the full study protocol and the baseline demographic and clinical characteristics of the FTDGeNZ cohort.
Conclusion: FTDGeNZ is an emerging longitudinal study that is well-placed to contribute to the international search for pre-symptomatic biomarkers of FTD. These biomarkers are critical to the success of future clinical trials aimed at preventing or treating FTD.

Conflicts of interest

N/A