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GENFI Network

The Genetic Frontotemporal dementia (FTD) Initiative (GENFI) is the largest familial FTD cohort study worldwide and over its initial ten years has created a network of more than 30 research centres across Europe and Canada, and a cohort of over 1000 participants. GENFI was established to develop robust biomarkers that could be used as stratification and outcome measures in clinical trials. A harmonised platform for the study of the clinical, cognitive, imaging and fluid biomarkers of familial FTD was created. Particular highlights of the study include: the validation of clinical rating scales; the development of a cognitive composite that reduces sample sizes required for trials; the validation of magnetic resonance imaging markers that are being used as outcome measures in current trials; the development and/or validation of several fluid biomarkers that are now being used in therapeutic studies including plasma neurofilament light chain, plasma glial fibrillary acidic protein, plasma progranulin and CSF poly(GP) dipeptide repeat proteins; and insights into the intermediate mechanisms of human disease resulting from FTD-causing mutations. When the GENFI study started there were no clinical trials in genetic FTD, but multiple trials are now underway or in the planning stages. GENFI has developed and validated a number of biomarkers that are now being implemented in these clinical trials. Future studies in GENFI will help to refine these even further, with a focus on worldwide collaboration with other familial FTD cohorts through the FTD Prevention Initiative or FPI.

