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Data from the FRONTotemporal dementia Incidence European Research Study'

Background: Defining numbers of individuals with Frontotemporal Lobar Degeneration (FTLD) in large multinational studies is urgent in light of new therapies.

To address this issue, the FRONTotemporal dementia Incidence European Research Study (FRONTIERS) was established to assess FTLD epidemiology across Europe.

Methods: This retrospective study was conducted from June 1st, 2018 to May 31st, 2019 in 13 European centres across 9 countries with a combined catchment population of about 12,000,000 inhabitants. During the study period, all new FTLD cases (incident FTLD) were counted and all patients' records were reviewed. Random intercept Poisson models were used to obtain estimates of the European FTLD incidence rate taking into account the geographic heterogeneity.

Findings: Based on more than 250 identified cases, the estimated annual incidence rate for FTLD in Europe was between 2 and 3 per 100,000 person-years. There was a progressive increase in FTLD incidence across age, with higher among men than among women. Behavioural variant frontotemporal dementia was the most common phenotype (40 %), followed by language (29%) and extrapyramidal phenotypes (26%). Frontotemporal dementia with amyotrophic lateral sclerosis was the rarest phenotype. About one third FTLD patients presented a family history of dementia. The estimated projection number of new FTLD cases in Europe, 28 members, is more than 10000 per year.

Interpretation: FTLD is more common than previously recognized, with a risk spanning a wide age range and incidence peak in the seventies. Improved knowledge of FTLD epidemiology based on population-based collection of cases, may contribute to improve health and care planning, for patients in Europe and may help in the design of future clinical trials of innovative drugs.

