

Genetic Frontotemporal Dementia Initiative

<https://www.neurodegenerationresearch.eu/cohort/genetic-frontotemporal-dementia-initiative/>

Cohort Acronym

GENFI

Cohort type

Neurodegenerative disease-specific cohort

Disease

Frontotemporal dementia, Motor neurone disease

Participant type

At-risk diagnosis

Profile

Recruitment Period 2015-20

Sample size at start or planned sample size if still recruiting 500

Estimated Current Sample Size 0 to 4,999

Age at Recruitment >18

Gender Male and Female

Abstract

GENFI is a five year longitudinal biomarker cohort study of genetic Frontotemporal Dementia and its associated disorders (including MND/ALS) investigating members of families with a known mutation in GRN or MAPT or an expansion in C9orf72 (including those affected with the disorder as well as at-risk members of families). Non-carrier first-degree relatives will serve as a control group.

All GENFI participants will be assessed longitudinally (annually) with a set of clinical, neuropsychiatric, cognitive, imaging and biosample protocols.

Last update – 25/01/2017

Country United Kingdom

Contact details

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Funders (Core support) UK Medical Research Council

The Bluefield Project

Variables Collected

Brain related measures:

Behaviour, Cognitive function, Neurological

Functional rating:

N/A

Anthropometric:

N/A

Physical:

N/A

Biological samples:

Blood, Cerebral spinal fluid (CSF)

Genotyping:

Gene screening

Brain imaging:

Magnetic resonance imaging (MRI)

Brain banking:

N/A

Lifestyle:

Alcohol, Smoking

Socio-economic:

Education, Ethnic group, Occupation and employment

Health service utilisation:

N/A