FTLD Cohort

Title of study

FTLD Cohort

Acronym for cohort
Name of Principal Investigator - Title

Prof

Name of Principal Investigator - First name

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Name of Principal Investigator - Last name

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Funding source

Q1a. Please indicate below if your cohort includes or expects to include, incidence of the following conditions?

Alzheimer's disease and other dementias

Q2a. In a single sentence what is the stated aim of the study? (Maximum 30 words)

To observe appearance and progression of FTLD

Q2b. What distinguishes this case-control study from other studies?
Q3a. i) Number of publications that involve use of your cohort to date

0

Q3a. ii) Please give up to three examples of studies to date (PI, Institution, Title of Study)
Q3b. If data on research outputs are already available please paste the publication list/other data or provide a link to where these data are publicly available
Q3c. If no research has been done as yet, please explain in a few sentences what information (i.e. research findings) you expect will be gained from the case-control study
Q4a. Study criteria: what is the age range of participants at recruitment? Age in years From:

not specified

Q4a. Study criteria: what is the age range of participants at recruitment? To:

until death

Q4b. Study criteria: what are the inclusion criteria?

clinical phenotype consistend with a FTLD spectrum disorder

Q4c. Study criteria: what are the exclusion criteria?

Other neurodegenerative diseases

Q5a. What is the size of the cohort (i.e. how many participants have enrolled)?

1-1,000

Q5b. What is the expected number of control participants?

200-500

Q6a. Please describe what measures are used to characterise participants

Behavioural assessment battery; FBI; NPI; AES-C; GDS-15; CRS; E60F; ZBI-12; FTLD

Q6b. Are there additional measures for participants with the clinical disorder?
Q6c. Are there defined primary and secondary endpoints (e.g. defined health parameters)?

No

If YES please specify
Q7. What is the study design?

Prospective cohort

Q8. Are your cases matched by
Q9a. Does your study includes a specialised subset of control participants?

No

Q9b. If your study includes a specialised subset of control participants please describe
Q10a. Is data collection for this study

Data collection ongoing

Q10b. If data collection is ongoing, are there plans to continue the cohort study beyond the current projected end date?

Yes - intend to apply for funding

Q11. Are data collected
Q12. Is there a system in place to enable re-contact with patients for future studies?
Q13a. Please give information on data stored in a database (1)
% Available
Q13a. Please give information on data stored in a database (2)
% Available
Q13a. Please give information on data stored in a database (3)
% Available
Q13a. Please give information on data stored in a database (4)
% Available
Q13a. Please give information on data stored in a database (5)
% Available
Please specify language used
% Available
Q13b. Please give information on how data is held as individual records
% Available
Q14a. Are data available to other groups?

Yes

Q14b. If data is available to other groups what is the access policy/mechanisms for access?
Q15. What data sharing policy is specified as a condition of use?

Data made publicly available after a specified time point

Q16a. Are tissues/samples/DNA available to other groups?

Yes

Q16b i) If yes, please describe below
Q16b. ii) In what form are tissues/samples/DNA supplied?
Q16b iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data (Q14 above)?
Q17. Is information on biological characteristics available to other groups?

Yes, for all the cohort

Types:
Case Control Studies

Member States:
Germany

Diseases:
Alzheimer's disease & other dementias

Years:
2016

Database Categories:
N/A

Database Tags:
N/A