Early biomarker changes in frontotemporal dementia

https://neurodegenerationresearch.eu/survey/early-biomarker-changes-in-frontotemporal-dementia/

Title of study

Early biomarker changes in frontotemporal dementia

Acronym for cohort

FTD-RisC

Name of Principal Investigator - Title

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Funding source

Memorabel

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

Motor neurone diseases| Alzheimer's disease and other dementias

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

Aim to find early disease-related differences and biomarkers in MRI, blood, cerebrospinal fluid and neuropsychological assessment in presymptomatic familial frontotemporal dementia

Q2b. What distinguishes this case-control study from other studies?

This is the first and the largest single-center longitudinal cohort study of presymptomatic familial frontotemporal dementia

Q3a. i) Number of publications that involve use of your cohort to date

6

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

Dopper et al., 2014 – Structural and functional brain connectivity in presymptomatic familial frontotemporal dementia - Neurology Rohrer et al., 2015 – Presymptomatic cognitive and neuroanatomical changes in genetic frontotemporal dementia in the Genetic Frontotemporal dementia Initiative (GENFI) study: a cross-sectional analysis – Lancet Neurology Dopper et al., 2016 – Cerebral blood flow in presymptomatic MAPT and GRN mutation carriers: A longitudinal arterial spin labeling study – NeuroImage Clinical Jiskoot et al., 2016 – Presymptomatic cognitive decline in familial frontotemporal dementia: A longitudinal study – Neurology Meeter et al., 2016 – Neurofilament light chain: a biomarker for genetic frontotemporal dementia – Annals of Clinical and Translational Neurology Meeter et al., 2016 – Progranulin levels in plasma and cerebrospinal fluid in granulin mutation carriers – Dementia and Geriatric Cognitive disorders Extra

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:

18

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

until death

Q4b. Study criteria: what are the inclusion criteria?

Subjects are 50% at risk for familial frontotemporal dementia by a first-degree relative with a known pathogenic familial FTD mutation

Q4c. Study criteria: what are the exclusion criteria?

Previous stroke or other neurological conditions that may affect cognitive functions

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

MRI, DNA, RNA, plasma, serum, CSF, NPA, skin biopsy

Q6b. Are there additional measures for participants with the clinical disorder?

No

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

Age| Sex

Q9a. Does your study includes a specialised subset of control participants?

Yes

Q9b. If your study includes a specialised subset of control participants please describe

Control participants are 50% at-risk subjects, without carrying the gene mutation

Q10a. Is data collection for this study

Data collection ongoing| Data analysis 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

Only through study

Q12. Is there a system in place to enable re-contact with patients for future studies?

No

Q13a. Please give information on data stored in a database (1)

Data summarised in database

% Available

100

Q13a. Please give information on data stored in a database (2)

Database is web-based

% Available

90

Q13a. Please give information on data stored in a database (3)

Database on spreadsheet (e.g. excel)

% Available

100

Q13a. Please give information on data stored in a database (4)

Database on paper

% Available
Q13a. Please give information on data stored in a database (5)

No

% Available
Please specify language used
% Available

100

Q13b. Please give information on how data is held as individual records

Data is web-based

% Available

90

Q14a. Are data available to other groups?

Yes

Q14b. If data is available to other groups what is the access policy/mechanisms for access?

Apply to PI or co-ordinator at resource| Access through collaboration with PI only| Local/ regional access| National access| International access| Access for pilot studies permitted| Resource has own ethics approval so usually no need for separate external ethics approval

Q15. What data sharing policy is specified as a condition of use?

No policy exists

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

Yes

Q16b i) If yes, please describe below

Living donors: blood| Living donors: blood derivatives| Living donors: DNA| Living donors: cerebro-spinal fluid| Living donors: other (Skin biopsy)

Q16b. ii) In what form are tissues/samples/DNA supplied?

Primary Samples: Stabilised samples (frozen or fixed)| Secondary samples:(derivatives of primary samples)| Secondary samples: plasma| Secondary samples: DNA| Secondary samples: RNA

Q16b iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data (Q14 above)?

Yes

Q17. Is information on biological characteristics available to other groups?

Yes, for all the cohort

Types:

Case Control Studies

Member States:
Netherlands

Diseases:
Alzheimer's disease & other dementias, Motor neurone diseases

Years:
2016

Database Categories:
N/A

Database Tags:
N/A