

DZNE Alzheimer Disease Family Study

<https://www.neurodegenerationresearch.eu/survey/dzne-alzheimer-disease-family-study/>

Title of study

DZNE Alzheimer Disease Family Study

Acronym for cohort

DAFS

Name of Principal Investigator - Title

Dr

Name of Principal Investigator - First name

Annike

Name of Principal Investigator - Last name

Spottke

Address of institution -Institution

German center of neurodegenerative diseases

Address of institution - Street address

Sigmund-Freud-Str. 25

Address of institution - City

Bonn

Address of institution - Postcode

53105

Country

Germany

Website

www.dzne.de

Contact email

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 build up a cohort of healthy probands who are at increased risk to develop Alzheimer disease

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:

70

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

until death

Q4b. Study criteria: what are the inclusion criteria?

First degree relative of a patient with clinically proven Alzheimer disease

Q4c. Study criteria: what are the exclusion criteria?

Cognitive impairment, known mutation causing Alzheimer disease

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

1-1000

Q5b. What is the expected number of control participants?

200-500

Q6a. Please describe what measures are used to characterise participants

Neuropsychology, MRI, amyloid-PET, CSF

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

Q6c. Are there defined primary and secondary endpoints (e.g. defined health parameters)?

If YES please specify

Manifestation of dementia

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?

No

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

Q10a. Is data collection for this study

At the planning stage

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?

No

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?

No requirement to make data publicly available

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

No

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?

No

Types:

Case Control Studies

Member States:

Germany

Diseases:

Alzheimer's disease & other dementias

Years:

2016

Database Categories:

N/A

Database Tags:

N/A