

# DZNE Alzheimer Disease Family Study

<https://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](http://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