

European Spinocerebellar Ataxia Natural History Study

<https://neurodegenerationresearch.eu/survey/european-spinocerebellar-ataxia-natural-history-study/>

Title of cohort

European Spinocerebellar Ataxia Natural History Study

Acronym for cohort

EUROSCA-NHS

Name of Principal Investigator - Title

Prof

Name of Principal Investigator - First name

Thomas

Name of Principal Investigator - Last name

Klockgether

Address of institution -Institution

University of Bonn

Address of institution - Street address

Sigmund-Freud-Str. 25

Address of institution - City

Bonn

Address of institution - Postcode

53105

Country

Germany

Website

<http://www.ataxia-study-group.net>

Contact email

Funding source

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

Spinocerebellar ataxia (SCA)

Q1b. When are studies on the above condition(s) expected to become possible?

Q2a. In a single sentence what is the stated aim of the cohort?

Q2b. What distinguishes this cohort from other population cohorts?

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 (Principal Investigator, 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 population

Q4a. Study criteria: what is the age range of participants at recruitment? Age in years From:

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

Until death

Q4b. Study criteria: what are the inclusion criteria?

Q4c. Study criteria: what are the exclusion criteria?

Q5. What is the size of the cohort (i.e. how many participants have enrolled)?

1,000-5,000 participants

Q6a. Please describe what measures are used to characterise participants

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

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

If yes please specify

Q7. What is the study design (select all that apply)?

Prospective cohort

Q8. Are your cases matched by

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

No

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

Q10a. i) Please enter the data collection start date

Q10a. ii) Please enter the data collection end date

Q10a. iii) Is data collection for this study

Closed to new patients

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. Is data collected

Other please specify here

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

Q13a. Please give information on the format and availability of data stored in a database (1)

% available

Q13a. Please give information on the format and availability of data stored in a database (2)

% available

Q13a. Please give information on the format and availability of data stored in a database (3)

% available

Q13a. Please give information on the format and availability of data stored in a database (4)

% available

Other (please specify)

% available

Q13b. Please give information on the format and availability of data held as individual records (1)

% available

Q13b. Please give information on the format and availability of data held as individual records (2)

% available

Q13b. Please give information on the format and availability of data held as individual records (3)

% available

Q13b. Please give information on the format and availability of data held as individual records (4)

% available

Please specify language used

Q14a. Is 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?

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

Number of Patients

% of total cohort

Types:

Population Cohorts

Member States:

Germany

Diseases:

Spinocerebellar ataxia (SCA)

Years:

2016

Database Categories:

N/A

Database Tags:

N/A