

Amyotrophic Lateral Sclerosis Online Genetics Database (ALSOD)

<https://neurodegenerationresearch.eu/survey/amyotrophic-lateral-sclerosis-online-genetics-database-alsod/>

Title of the register

Amyotrophic Lateral Sclerosis Online Genetics Database (ALSOD)

Name of Principal Investigator - Title

Prof

Name of Principal Investigator - First name

Peter

Name of Principal Investigator - Last name

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

Motor neurone diseases|Prion disease

Q2. In a single sentence, what is the stated aim of your register?

register of patients with any type of ALS/prion disease that has donated a blood sample to our molecular and genetic studies into the causes of ALS

Q2b. What distinguishes this register from other disease registers?

it is unique designed to fit the needs of the ALS research group at UmU

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

>180

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?

please see web of science, PubMed. Search terms are my name and prof. Stefan L. Marklund

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 register

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

0

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

until death

Q4b. Study criteria: what are the inclusion criteria?

EFNS criteria for ALS/MND

Q4c. Study criteria: what are the exclusion criteria?

standard exclusion criteria for ALS/MND

Q5. What is the size of the register (i.e. how many patients have been enrolled)?

More than 10,000 clinical cases

Q6a. Please describe what measures are used to characterise participants

standard clinical EFNS criteria plus genetic screening criteria

Q6b. Are there defined primary and secondary endpoints (e.g. defined health parameters)?

No

If YES, please describe

Q7a. i) Is the register of fixed duration?

No

Q7a. ii) Please enter the data collection start date

01/10/1992

Q7a. iii) Please enter the data collection end date

Q7b. Could you provide some information about the data collection for this register?

Data collection ongoing|Data analysis ongoing

Q8. Funding of the register - How is the register funded?

KAW, Hjärnfonden, VR, Söderberg stiftelse etc.

Q8. Funding of the register - Is this funding expected to continue

Yes

Q8. Funding of the register - If so, for how long (months)?

Many years

Q9. Could you provide information about data sweeping? - How many data sweeps have taken place?

many since the first in 1995

Q9. Could you provide information about data sweeping? - When was the most recent data sweep?

01/09/2016

Q9. Could you provide information about data sweeping? - When is the next data sweep?

Q9. Could you provide information about data sweeping? - How many more data sweeps are planned on current funding? e.g 0,1,2.....

Q9. Could you provide information about data sweeping? -How many more data sweeps are planned in total (with funding and with funding yet to be secured) e.g. 0,1,2...

Q10. Is the clinical (phenotypic) information that is held in the register from patients and other participants such as family members:

Routinely collected as medical records

Q11. Is there a limit on the number of studies that can be based on this set of patients?

Yes

If YES, please give details

the limit is what is permitted by the consent from the patients/relatives enrolled and the Ethical Review Board

Q12a. Please give information on the format and availability of data stored in a database (1)

Data summarised in database

% Available

95

Q12a. Please give information on the format and availability of data stored in a database (2)

No

% Available

Q12a. Please give information on the format and availability of data stored in a database (3)

No

% Available

Q12a. Please give information on the format and availability of data stored in a database (4)

Database on paper

% Available

5

Q12a. Please give information on the format and availability of data stored in a database (5)

No

% Available

Please specify language used

Swedish and English

Q12b. Please give information on how data is held as individual records (1)

Data is held as individual records

% Available

5

Q12b. Please give information on how data is held as individual records (2)

No

% Available

Q12b. Please give information on how data is held as individual records (3)

Data held on computer based records

% Available

95

Q12b. Please give information on how data is held as individual records (4)

No

% Available

Please specify language used

Swedish and English

Q13a. Is data available to other groups?

No

Q13b. If data is available to other groups what is the access policy/mechanisms for access?

Q14. What data sharing policy is specified as a condition of use?

No policy exists

Q15a. Are tissues/samples/DNA available to other groups?

Yes

Q15b. i) If yes, please describe below:

Living donors: blood|Living donors: blood derivatives|Living donors: DNA|Living donors: cerebro-spinal fluid|Post-mortem donors: brain|Post-mortem donors: spinal cord|Post-mortem internal organs; cell lines

Q15b. ii) In what form are tissues/samples/DNA supplied?

Secondary samples: plasma|Secondary samples: DNA|Secondary samples: protein extracts|Secondary samples: cell lines derived from primary samples

Q15b. iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data (Q13b above)?

No

Q16a. Is information on biological characteristics available to other groups?

If available for a subset please specify number of patients and % of total cohort

Number of patients

% of total cohort

Q16b. If yes, is the access policy/mechanism for obtaining samples the same as that for obtaining data (Q13b above)?

Yes

Types:

Disease Registers

Member States:

Sweden

Diseases:

Motor neurone diseases, Prion disease

Years:

2016

Database Categories:

N/A

Database Tags:

N/A