

# 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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Institutionen för farmakologi och klinisk neurovetenskap, Umeå universitet

## **Address of institution - Street address**

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Umeå

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901 85

## **Country**

Sweden

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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