

# Biomarkers, environmental and lifestyle risk factors for amyotrophic lateral sclerosis

<https://www.neurodegenerationresearch.eu/survey/biomarkers-environmental-and-lifestyle-risk-factors-for-amyotrophic-lateral-sclerosis/>

## **Title of study**

Biomarkers, environmental and lifestyle risk factors for amyotrophic lateral sclerosis

## **Acronym for cohort**

ALSrisc

## **Name of Principal Investigator - Title**

Dr

## **Name of Principal Investigator - First name**

Fang

## **Name of Principal Investigator - Last name**

Fang

## **Address of institution -Institution**

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

Nobelsväg 12A

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## **Country**

Sweden

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## **Funding source**

Swedish Research Council, Karolinska Institutet, Ulla-Carin Lindqvist Foundation

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

Motor neurone diseases

**Q2a. In a single sentence what is the stated aim of the study? (Maximum 30 words)**

To identify potential biomarkers as well as genetic and non-genetic risk factors for ALS

**Q2b. What distinguishes this case-control study from other studies?**

Population-based design, multiple control groups, rich biosamples

**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**

We aim to understand the impact of environmental and lifestyle risk factors on ALS risk, the interactions between these risk factors and ALS genes, as well as the impact of these risk factors on ALS prognosis.

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

20

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

until death

**Q4b. Study criteria: what are the inclusion criteria?**

Newly diagnosed ALS patients in the Stockholm area, during 2016-2018

**Q4c. Study criteria: what are the exclusion criteria?**

Non-Swedish speaking

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

1-1,000

**Q5b. What is the expected number of control participants?**

200-500

**Q6a. Please describe what measures are used to characterise participants**

Questionnaire data, clinical medical records, and biosamples

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

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

Yes

**If YES please specify**

Death

**Q7. What is the study design?**

Prospective cohort| population-based case-control study

**Q8. Are your cases matched by**

Age| Sex|

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

Yes

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

We include sibling and spouse controls

**Q10a. Is data collection for this study**

Data collection ongoing

**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**

Only through the study| Through links to medical records| Through links to other records or registers(Swedish National Health Registers)

**Q12. Is there a system in place to enable re-contact with patients for future studies?**

No

**Q13a. Please give information on data stored in a database (1)**

Data summarised in database

**% Available**

100

**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)**

Yes

**% Available**

100

**Please specify language used**

SAS/ACCESS

**% Available**

100

**Q13b. Please give information on how data is held as individual records**

**% Available**

**Q14a. Are data available to other groups?**

Yes

**Q14b. If data is available to other groups what is the access policy/mechanisms for access?**

Apply to PI or co-ordinator at resource| Access Committee mechanism| Local/ regional access| Local/ regional access| Local/ regional access| Access for pilot studies permitted| Access restricted to peer-reviewed work| Applicant needs to provide separate external ethics approval

**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?**

Yes

**Q16b i) If yes, please describe below**

Living donors: blood| Living donors: blood derivatives| Living donors: DNA| Living donors: cerebro-spinal fluid| Living donors: other (saliva, fecal, hair, and nail samples)

**Q16b. ii) In what form are tissues/samples/DNA supplied?**

Primary samples: Supplied fresh| Secondary samples: plasma| Secondary samples: DNA

**Q16b iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data (Q14 above)?**

Yes

**Q17. Is information on biological characteristics available to other groups?**

No

**Types:**

Case Control Studies

**Member States:**

Sweden

**Diseases:**

Motor neurone diseases

**Years:**

2016

**Database Categories:**

N/A

**Database Tags:**

N/A