Cohort – ALS

https://neurodegenerationresearch.eu/survey/cohort-als/

Title of the cohort

Cohort – ALS

Acronym for cohort

Name of Principal Investigator

Title	Adjunct Prof
First name	Pentti
Last name	Tienari

Address of institution where award is held

Institution	Univ Helsinki, Mol Neurol programme
Street Address	Haartmaninkatu 8
City	Helsinki
Postcode	FIN-00290

Country

- Finland

Website

http://www.biomedicum.com/index.php?page=279&lang=2

Contact email

pentti.tienari@hus.fi

Funding source

Multiple

1. The cohort includes, or expects to include, incidence of the following conditions

- Motor neurone diseases

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

- Already possible

2a. Stated aim of the cohort

Genetic analysis of Finnish ALS

2b. Features distinguishing this cohort from other population cohorts

3a. i) Number of publications that involve use of cohort to date

1

3a. ii) Up to three examples of studies to date (PI, Institution, Title of Study)

1. Name of PIPentti Tienari, Univ Helsinki, Finnish ALS-GWAS

3b. Publication list/link to where data or publications are accessible (if available)

Laaksovirta H*, Peuralinna T*, Schymick JC*, Scholz SW, Lai SL, Myllykangas L, Sulkava R, Hernandez DG, Gibbs JR, Tienari PJ*,Traynor BJ*. Chromosome 9p21 in amyotrophic lateral sclerosis in Finland: a genome-wide association study.. Lancet Neurol 2010; Oct;9(10):978-85.

3c. Information (i.e. research findings) expected to be gained from the population cohort

4a. Study criteria: age range of participants at recruitment

Age in years from: 30

To ('until death' if applicable): until death

4b. Study criteria: inclusion criteria

Diagnosis of motor neuron disease

4c. Study criteria: exclusion criteria

Unwilling to participate

5. Size of the cohort (i.e. number of participants enrolled)

- 1,000 – 5,000 participants

6a. Measures used to characterise participants

GWAS data, exome sequencing of a few individuals, clinical characteristics.

6b. Additional measures for participants with a clinical disorder

6c. Are there defined primary and secondary endpoints (e.g. defined health parameters)

- No

7. Study design

- Retrospective cohort

8. Cases matched by

- Other health assessment (specify) / N/A
- ALS diagnosis

9a. Does the study include a specialised subset of control participants

- Yes

9b. If yes, description of specialised subset of control participants

Population controls, non-ALS..

10a. i) Data collection start date

01-01-1995

10a. ii) Data collection end date

31-12-2015

10a iii) Data collection for this study is

- Data analysis ongoing

10b. Plans to continue the cohort study beyond the current projected end date

- Yes – intend to apply for funding

11. Data collected

- Through links to medical records

12. System in place to enable re-contact with patients for future studies

- No

13a. Format and availability of data stored in a database

	Yes/No	% available
Data summarised in database		
Database is web-based		
Database on spreadsheet	yes	100
Database is on paper		
Other (specify)		

Language used:

Finnish

13b. Format and availability of data held as individual records
Language used:

Finnish

13b. Format and availability of data held as individual records

	Yes/No	% available
Data held as individual records		
Data is web-based		
Data held on computer based records	Yes	100
Data held on cards		

Other (specify)

Language used:

Finnish

14a. Are data available to other groups

No

14b. Access policy/mechanisms for access if data are available to other groups

15. Data sharing policy specified as a condition of use

- Data made publicly available after a specified time point

16a. Are tissues/samples/DNA available to other groups

Yes

16b. i) Description of available tissues/samples/DNA

- Living donors:blood
- Living donors: DNA
- Living donors: other, please specify below
- Post-mortem donors: brain
- Post-mortem donors: spinal cord

16b. ii) Form available tissues/samples/DNA are supplied in

- Primary Samples: Stabilised samples (frozen or fixed)
- Secondary samples: DNA
- Secondary samples: RNA
- Secondary samples: protein extracts
- Secondary samples: cell lines derived from primary samples

16b. iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data

17. Is information on biological characteristics available to other groups

- If available for a subset please specify number of patients and % of total cohort
- 1%