

The EUROSCA Natural History Study

<https://neurodegenerationresearch.eu/cohort/the-euroasca-natural-history-study/>

Cohort Acronym

EUROSCA

Cohort type

Neurodegenerative disease-specific cohort

Disease

Spinocerebellar ataxia (SCA)

Participant type

Condition diagnosed

Profile

Recruitment Period Ongoing

Sample size at start or planned sample size if still recruiting 730

Estimated Current Sample Size 0 to 4,999

Age at Recruitment >18

Gender Male and Female

Abstract

The key goal of EUROSCA-NHS is to determine and compare the rate of disease progression in SCA1, SCA2, SCA3 and SCA6. To this end, a newly developed and validated ataxia scale (Scale for the Assessment and Rating of Ataxia, SARA) will be used. EUROSCA-NHS has a number of secondary aims including determination of the order and occurrence of non-ataxia symptoms, assessment of activities of daily living (ADL) and quality of life (QoL), and identification of predictors of disease progression and survival.

Patients are first seen at a baseline visit, followed by annual visits for 3 years scheduled ? 3 months around the specified time point. After the initial 3 year observation period, visits are done at irregular intervals each time they went to hospital.

Last update – 12/08/2017

Country Austria, Belgium, France, Germany, Hungary, Italy, Netherlands, Spain, United Kingdom

Contact details

Institution name Dept. of Neurology, University Hospital Bonn

Website <http://www.ataxia-study-group.net/html/studies/euroasca>

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Contact phone number

Funders (Core support) Ataxia Study Group

Variables Collected

Brain related measures:

N/A

Functional rating:

Caregiver, Individual physiological, Individual psychological

Anthropometric:

Height, Weight

Physical:

N/A

Biological samples:

Blood, Urine

Genotyping:

Gene screening

Brain imaging:

Magnetic resonance imaging (MRI)

Brain banking:

N/A

Lifestyle:

Alcohol, Physical activity, Smoking

Socio-economic:

Housing and accommodation

Health service utilisation:

N/A