The EUROSCA Natural History Study

https://www.neurodegenerationresearch.eu/cohort/the-eurosca-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
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Principal Investiator (PI) Prof. Thomas Klockgether
Contact email Email: PI email:
Contact phone number
Funders (Core support) Ataxia Study Group

Variables Collected

Brain related measures:

N/A
Funtional 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