

Title: The National Swedish ALS quality registry

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Abstract

Sweden is a small but elongated country with about 10 million inhabitants. The country consists of mixed demography including both urban and rural populations, of which the rural areas include both coastal, cultivated and forest areas. Despite this fact, ALS affects people all over Sweden with about the same incidence and prevalence rates. Although a more detailed classification of specific phenotypes of ALS in Sweden has never been investigated. Several University Hospitals care for ALS-patients by forming special ALS-teams. Although some of the clinics only have a handful of patients, and the diagnostic criteria and treatment guidelines are not updated to European standard (MALS). The research activity among the ALS-teams can be absent and the patients from smaller towns are therefore not included in research projects taking place at the larger hospitals. Our primary aim was to construct a national quality registry for ALS patients in Sweden, which will assure high quality health care in an easy accessible way. Our secondary aim is to create a research base and prospectively follow the entire ALS community in Sweden to investigate among other: phenotypic variation, biomarkers of disease and progression, life quality and treatments. To involve the patients in their own care, we have created a patient own reporting portal (PER). It enables patients to answer questions about their health and life status via the Internet before meeting with their care provider at the clinic. By using PER, the patients are given the opportunity to view a visual report of their status (their own reports) in real time, which has proven highly appreciated. The Swedish ALS registry is voluntary but easily accessible via Internet, and aims to aid the ALS clinicians as a decision-making tool and thus facilitates the clinical visit both for clinicians and ALS patients. To date 70% of the Swedish ALS population is registered and monitored.

Biography

Caroline Ingre started her internship in neurology in 2006 at Karolinska University Hospital and finished her specialization in 2013. In 2013 she also finished her PhD and defended her thesis On the aetiology of ALS: A comprehensive genetic study at the Department of Clinical Neuroscience in Umeå University, Sweden. Dr Ingre was later that year awarded with the Ulla-Carin Lindquist foundation prize. She now works as a specialist in neuromuscular diseases, with a special interest in ALS at Karolinska University Hospital. Dr Ingre is also a post doc at the Department for Clinical Neuroscience at Karolinska Institute. In 2014 Dr Ingre created a national quality registry for ALS in Sweden and in 2015 she was appointed head of ALS section at Karolinska University Hospital. She has received a scholarship from the Swedish Society for Medical research for 2 years and is a member of the advisory committee for the Board of Neuro Association in Sweden. Her research interests are about ALS in the areas of genetics, epidemiology, riskfactor and biomarker research as well as imaging, phenotyping and clinical treatments.