

RIMS Grant Application 2019 Winner

Anne Christin Rahn

Abteilung "Internationale Versorgungsforschung", Department für Versorgungsforschung, Fakultät VI Medizin und Gesundheitswissenschaften, Carl von Ossietzky Universität Oldenburg

RiGra project NIPS: Needs of people with primary progressive multiple sclerosis.

SUMMARY

For people with primary progressive multiple sclerosis (pwPPMS) very limited immunotherapeutic and evaluated management options do exist. This mirrors a substantial psychological and physical burden for pwPPMS. Within the NIPS (Needs of people with primary progressive multiple sclerosis) project, a scoping review on the needs and knowledge of pwPPMS will be performed. Based on the available evidence, an interview guide will be developed. A qualitative interview study with pwPPMS and health professionals (HPs) will be performed in 6 participating European countries. Based on data synthesis, a survey with HPs will be developed and conducted in the participating countries. This could serve as a basis for a larger survey study to verify the hypothesis on unmet needs and patient information gaps in PPMS and to set up an intervention development agenda.

The NIPS project started in 2020. So far, we have performed the scoping review, gained ethical approvals from the participating countries, and developed the interview guide for pwPPMS and HPs. At the moment, the interviews are being conducted in the participating countries and will be analysed until June 2022.

PROJECT PARTNERS

Dr. Andrea Giordano (co-applicant)

Unit of Neuroepidemiology, Fondazione IRCCS Istituto Neurologico C. Besta, Milan

Dr. Alessandra Solari

Head, Unit of Neuroepidemiology, Scientific Directorate, Fondazione IRCCS Istituto Neurologico Carlo Besta (FINCB), Milan

Dr. Sinéad Hynes, BSc, PhD, PgCert

(co-applicant)

School of Health Sciences | Áras Moyola, NUI Galway

Dr Eli Silber

Consultant neurologist, Department of neurology, Kings College Hospital, London, UK

Miguel Ángel Robles Sánchez

Neurology-Neuroimmunology Department & Neurorehabilitation Unit Multiple Sclerosis Centre of Catalonia (Cemcat), Vall Hebron Barcelona Hospital Campus

Edwin Roger Meza Murillo

Neurology-Neuroimmunology Department & Neurorehabilitation Unit Multiple Sclerosis Centre of Catalonia (Cemcat), Vall Hebron Barcelona Hospital Campus

Ingrid Galan

Neurology-Neuroimmunology Department & Neurorehabilitation Unit Multiple Sclerosis Centre of Catalonia (Cemcat), Vall Hebron Barcelona Hospital Campus

Dr. Klara Novotna

MS centre, Department of Neurology and Center of Clinical Neuroscience, First Faculty of Medicine, Charles University and General University Hospital in Prague

Prof. Dr. phil. Sascha Köpke

Full Professor for Clinical Nursing Science, University of Cologne, Faculty of Medicine and University Hospital Cologne, Institute of Nursing Science

Prof. Dr. Christoph Heesen

Institute for Neuroimmunology and Multiple Sclerosis, Universitätsklinikum Hamburg-Eppendorf (UKE)

Patient representatives:

Dutch Nationaal MS Fonds: Yvonne Hetteema & Rianne Wisgerhof-van Dijk