

RARE DISEASES: HERO PROFILES

HERO 1: Dr Henna Jonsson

Helsinki University Central Hospital, Finland

Henna works as a paediatric neurologist in the Epilepsy Unit of the HUS Helsinki University Hospital. She made the initial epilepsy diagnosis of a 4-year-old boy and needed help from European colleagues to determine the right treatment in his case. “With these rare diseases, where very few doctors have enough experience to tackle the case, the more information you can gather, the better. In this sense, EpiCARE is more than helpful.” EpiCARE is a European Reference Network of specialists working on rare and complex epilepsies. The network brings together healthcare specialists from across Europe.

HERO 2: Professor J. Helen Cross

Great Ormond Street Hospital for Children, United Kingdom

Helen coordinates EpiCARE, a European Reference Network on rare and complex cases of epilepsy. The network comprises 28 medical centres in 13 countries and aims to improve diagnoses and treatments for people with rare epilepsies. “The most important thing for me is the constant ability to discover things and make a difference to patients,” says Helen. She is renowned in the field of childhood epilepsy and an Honorary Consultant in Paediatric Neurology at the Great Ormond Street Hospital for Children. She also works at Young Epilepsy, a national charity supporting children and young people with epilepsy up to the age of 25.

HERO 3: Professor Bertil Rydenhag

University of Gothenburg, Sweden

Bertil is a Professor of Neurosurgery in the University of Gothenburg’s Department of Clinical Neuroscience. As a member of the European Reference Network for epilepsy, EpiCARE, Bertil specialises in epilepsy surgery. He has worked in this field for more than 30 years, treating both adults and children. “Some diseases are very rare so the accumulation of experience is very useful; in sharing knowledge and experience you can treat the patients better, either at home or in another centre”.

HERO 4: Alexis Arzimanoglou

Greek/French, University Hospitals of Lyon, France

Alexis is the director of the Paediatric Clinical Epileptology, Sleep disorders and Neurophysiology department of the University Hospitals of Lyon. He also works as a consultant for the Epilepsy unit of the SJD Barcelona Children's Hospital. Over the past years, he has been working to develop new anti-epileptic drugs. Alexis has also conducted research on surgical procedures for childhood epilepsies as well as on the cognitive development and emotional disorders in children experiencing focal seizures. Alexis is a member of the EpiCARE steering committee, the European Reference Network for epilepsy, and coordinator of the Lyon EpiCARE team.