Adults with SMA

Over the course of two connected symposia, please join our pair of neuromuscular experts as they discuss, through the use of patient cases, the latest evidence and their perspectives on what this means for treating adults with SMA.

Episode One
To treat or not to treat?
Saturday 19 June 2021 | 16:15–16:45
Central European Summer Time

Faculty
Chamindra Konersman, MD
University of California San Diego (UCSD) and Rady Children’s Hospital, San Diego, CA, USA

Anna Kostera-Pruszczyk, MD, PhD
Medical University of Warsaw, Warsaw, Poland

Monday 21 June 2021 | 16:15–16:45
Central European Summer Time

How to define treatment response?

Faculty
Chamindra Konersman, MD
University of California San Diego (UCSD) and Rady Children’s Hospital, San Diego, CA, USA

Anna Kostera-Pruszczyk, MD, PhD
Medical University of Warsaw, Warsaw, Poland

Sunday 20 June 2021 | 13:15–13:45
Central European Summer Time

Genetic ALS: epidemiology and testing

Faculty
Ammar Al-Chalabi, MB, ChB, PhD
Institute of Psychiatry, Psychology & Neuroscience (IoPPN)
King’s College London, London, UK

About the Artists
Phil L. Herold is an internationally recognized artist who describes himself as a “cyberspace expressionist of the 21st century”. Born in Munich in April 1980, and diagnosed with Spinal Muscular Atrophy (SMA) type 2 in early childhood, today Phil designs his large format works of art on a PC, using a small joystick on his wheelchair. Thus, through only the minimal movement that he is left with, he continues to create, inspire, delight and challenge us.

Sarah Ezekiel is one of the world leading eyegaze artists. Sarah studied art and history of art, but when, at the age of 34, she was diagnosed with motor neuron disease (MND), she believed that she would never create anything again. In fact, she continues to work using assistive devices, offering inspiration, support and a positive outlook to families in a similar situation.