

Duchenne Care Conference 2025

Monday May 26

Times are shown in Central European Summer Time (CEST)

Welcome

- 15:00 Welcome and introduction**
Elizabeth Vroom – Chair of the World Duchenne Organization (NL)

Speakers & Topics

- 15:05 Communication in science**
Prof Annemieke Aartsma-Rus – Professor of Translational Genetics at Leiden University Medical Center (NL)
- 15:25 Givinostat: A clinical overview**
Prof Annemieke Aartsma-Rus – Professor of Translational Genetics at Leiden University Medical Center (NL)
- 15:45 Adrenal insufficiency with vamorolone**
Dr David Weber – Pediatric Neurologist at Children's Hospital of Philadelphia (USA)
- 16:05 Predictors of cardiac disease in Duchenne MD**
Prof Karim Wahbi – Cardiologist at Cochin Hospital & Institute of Myology, Assistance Publique – Hôpitaux de Paris (FR)
- 16:25 Management of Becker Muscular Dystrophy**
Prof Luca Bello – Neurologist at University of Padua (IT)

- 16:45 Palliative care in Duchenne MD**
Prof Derek Willis – Medical Director at Severn Hospice in Shrewsbury (UK)

- 17:05 Regional diversity in DMD Care**
Dr Rasha El Sherif – Assistant Professor at New Giza University (EG)

- 17:25 Duchenne MD and sleep**
Dr Murat Türk – Pulmonologist-somnologist at Erasmus Medical Center (NL)

Wrap-up

- 18:05 Wrap-up, agenda for tomorrow**
Elizabeth Vroom

Duchenne Care Conference 2025

Tuesday May 27

Times are shown in Central European Summer Time (CEST)

Welcome

15:00 Welcome and introduction

Dr Karolína Podolská – Board member at World Duchenne Organization, Coordinator of Centre for adult patients with DMD, Prague (CZ)

Speakers & Topics

15:05 Role of patient organisations in improving care in Duchenne MD

Dr Karolína Podolská – Board member at World Duchenne Organization, Coordinator of Centre for adult patients with DMD, Prague (CZ)

15:25 Transition into adult life in Duchenne MD

Prof Ros Quinlivan – Professor of Neuromuscular Disease at University College London (UK)

15:45 Pubertal induction in Duchenne MD

Dr Claire Wood – Pediatric Endocrinologist at Newcastle University (UK)

16:05 Sexuality and fertility in Duchenne MD

Dr Nora Renthal – Pediatric Endocrinologist at Boston Children's Hospital / Harvard University (USA)

16:25 When to consider foot surgery in perspective of the future

Prof Imelda de Groot – Retired rehabilitation specialist, Program Lead at the Accredited Duchenne Centers Program (NL)

16:45 What clinicians should know about gene therapy

Prof Eugenio Mercuri – Pediatric Neurologist at Fondazione Policlinico Universitario Agostino Gemelli (IT)

17:05 Role of HCPs in education of patients with DMD and their families

James Jones – DMD Hub Advanced Nurse Practitioner, part of the Neuromuscular Team at RJAH (UK)

17:25 Orofacial issues in Duchenne MD

Elizabeth Vroom – Chair of the World Duchenne Organization (NL)

Wrap-up

18:05 Closing

Elizabeth Vroom and Dr Karolína Podolská