



# Duchenne Care Conference 2023

Wednesday June 7

Times are shown in Central European Summer Time (CEST)

## Welcome

### 15:00 Welcome and introduction

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

## Females with Dystrophinopathies

### 15:05 Care for females with dystrophinopathies

Prof Ros Quinlivan – *Professor of Neuromuscular Disease at the Department of Neuromuscular Diseases of University College London (UK)*

### 15:25 Girls with dystrophinopathies

Dr Saskia Houwen – *Pediatric rehabilitation doctor at Radboud University Medical Center (NL)*

### 15:40 Duchenne mothers: Healthcare & Selfcare compliance

Dr Karolína Podolská – *Care Coordinator at Parent Project Czech Republic (CZ)*

### 15:55 Questions & Answers

Moderated by Elizabeth Vroom

### 16:05 Break

## Cardiology

### 16:15 Cardiac care for females with dystrophinopathies

Prof Linda Cripe, MD – *Pediatric Cardiologist Professor of Pediatrics at Nationwide Children's Hospital, Columbus Ohio (USA)*

### 16:35 Current insights in cardiac care for Duchenne muscular dystrophy

Prof Karim Wahbi – *Cardiologist at the Institute of Myology and Cochin Hospital, Professor at The Assistance Publique Hopitaux de Paris (FR)*

### 16:55 Questions & Answers

Moderated by Elizabeth Vroom

## Endocrinology in DMD

### 17:05 Revisiting the approach to osteoporosis management in DMD

Dr Jarod Wong – *Pediatric endocrinologist and senior research fellow at The Royal Hospital for Sick Children Glasgow (SC)*

### 17:25 Puberty and sexual health in DMD

Dr Claire Wood – *Academic Clinical Lecturer in Pediatric Endocrinology at Newcastle University (UK)*

### 17:40 Nutrition and weight gain

Dr Natassja Billich – *Accredited Practising Dietician at Murdoch Children's Research Institute and University of Queensland (AUS)*

### 17:55 Questions & Answers

Moderated by Elizabeth Vroom

## Wrap-up

### 18:05 Wrap-up, agenda for tomorrow

Elizabeth Vroom



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## Welcome

### 15:00 Welcome and introduction

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

## Newborn Screening (NBS)

### 15:05 Newborn screening, current situation and policies

Prof Martina Cornel – *Professor of community genetics and public health genomics at Amsterdam University Medical Center (NL)*

### 15:20 Screen4Care: innovative research approach to accelerate RD diagnosis

Prof Alessandra Ferlini – *Professor in medical genetics, director of the Medical Genetics section at the University of Ferrara (IT)*

### 15:35 NBS for Duchenne: the New York pilot

Niki Armstrong – *Associate VP, Community Research and Genetic Services PPMD (USA)*  
Norma Tavakoli – *Research Scientist, Wadsworth Center, NY State Dept of Health (USA)*

### 15:55 Questions & Answers

Moderated by Elizabeth Vroom

### 16:10 Break

## Emergencies

### 16:20 Emergency Care in Duchenne muscular dystrophy

Prof Eugenio Mercuri – *Professor, Head of the Pediatric Neurology and Psychiatry Unit of the Gemelli Hospital Catholic University (IT)*

### 16:40 Questions & Answers

Moderated by Elizabeth Vroom

## Neuropsychology in DMD

### 16:55 Neuropsychology in Duchenne: the Big Ten

Dr Jos Hendriksen – *Clinical (neuro)psychologist, Kempenhaeghe (NL)*

### 17:15 The use of psychopharmaca in Duchenne muscular dystrophy

Dr Philippe Collin – *Child and Adolescent Psychiatrist, Kempenhaeghe (NL)*

### 17:30 Questions & Answers

Moderated by Elizabeth Vroom

## Wrap-up

### 17:45 Wrap-up

Elizabeth Vroom