

WDAD2022 ONLINE EVENT: WOMEN AND DUCHENNE

Wednesday 7 September, 3pm Central European Summer Time

Elizabeth Vroom (Netherlands) & Nicoletta Madia (Italy)

Welcome, introduction, why this year's theme

Maria Bernabeu, mother of Alma Navarro (Spain)

Interview with a mother of a young girl with Duchenne

Prof Alessandra Ferlini (Italy)

Why women can also be affected by DMD, insights from ENMC workshop on female carriers

Prof Annemieke Aartsma-Rus (Netherlands)

Drug development in female DMD and why girls are often excluded from clinical trials

Lizanne Schreur (Netherlands)

Interview with a woman living with Duchenne

Prof. Linda Cripe (United States)

Why cardiac care is so important for DMD carriers, what carriers can do to take care of their heart

Josefina Garcia Huibrodo (Chile)

What it means being a Duchenne mother

Prof Eugenio Mercuri (Italy)

Experience of seeing 25+ years of Duchenne mothers in clinic

Dr Lakshmi Rahman (India)

Overcoming challenges regarding Duchenne mothers and carriers in India

Prof Daniela Chieffo (Italy)

How to support and empower mothers and women in Duchenne

Aida Adra (Lebanon)

Lessons learnt from setting up a support network of women in the Middle East

Doug and Lauren Robins (Australia)

What it is like being Duchenne spouse

Hazel Weaver (United Kingdom)

Being a sibling to a person with Duchenne, setting up a sibling network

Nicoletta Madia (Italy)

Reflecting on Women and Duchenne from interviews with the community

Graciela Mendez (Mexico)

Setting up an organization in LATAM as a Duchenne aunt

Pat Furlong (United States) & Elizabeth Vroom (Netherlands)

Sharing 30+ years of working as a patient advocate in Duchenne

Scolar Muthamia (Kenya)

Working to set up and support women and Duchenne families in Kenya and Africa

WORLDDUCHENNE.ORG