

Dec 13 – 14, 2025  
duchennepatientacademy.org

# DUCHENNE PATIENT

Connecting DMD/BMD patient advocates  
of the future



WORLD  
DUCHENNE  
ORGANIZATION  
UPPMD

DUCHENNE  
DATA FOUNDATION

# ACADEMY

DUCHENNE  
PATIENT ACADEMY

# PROGRAM

## DAY 1 SATURDAY DECEMBER 13

14:00 – 18:30 CET

*Welcome & introduction*  
*Advocacy by patient organizations*  
*Standard of Care and Care Guidelines*  
*Updates on drug development*

## DAY 2 SUNDAY DECEMBER 14

15:00 – 17:30 CET

*Welcome*  
*How to start a patient organization*  
*Improving advocacy*  
*How and why involve young people in drug development*  
*Networking, why and how*  
*Why data are important to patients and patient organizations*  
*Importance of Accredited Duchenne Care Centers to patients*  
*Thirty years of keeping hope in the Duchenne Community*  
*Conclusion*

**DUCHENNE**  
PATIENT ACADEMY

ORGANIZED BY

**DUCHENNE**  
DATA FOUNDATION

IN COOPERATION WITH



**WORLD  
DUCHENNE  
ORGANIZATION**  
UPPMD

SUPPORTED BY



**BIOMARIN**



**DUCHENNE**  
PATIENT ACADEMY

# SATURDAY

DECEMBER 13

*Times are shown in Central European Time*

14:00 – 14:05

## Welcome

- Welcome  
*Elizabeth Vroom, World Duchenne Organization*

## TOPIC 1

# ADVOCACY & CARE

14:05 – 15:35

## Presentations

- Advocacy by patient organizations  
*Elizabeth Vroom, World Duchenne Organization*
- Standards of Care and Care Guidelines  
*Dr Karolina Podolska, World Duchenne Organization*
- Drug Development in the Duchenne field  
*Prof Annemieke Aartsma-Rus, Leiden University Medical Center*
- Questions and answers, moderated  
*Elizabeth Vroom, World Duchenne Organization*

15:35 – 15:45

Break

# SATURDAY

DECEMBER 13

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## TOPIC 2

# COMPANY UPDATES

15:45 – 17:00

## Company updates

- Introduction to the session  
*Dr Karolina Podolska, World Duchenne Organization*
- Session 1: Presentations by companies  
*Prof Eugenio Mercuri, Gemelli Hospital*  
*Various companies and speakers*
- Questions and discussion, moderated  
*Dr Karolina Podolska, World Duchenne Organization*

17:00 – 17:10

Break

- Session 2: Presentations by companies  
*Various companies and speakers*
- Questions and discussion, moderated  
*Dr Karolina Podolska, World Duchenne Organization*

18:20 – 18:30

## Wrap-up

- Take home messages  
*Dr Karolina Podolska, World Duchenne Organization*
- Wrap-up & Agenda for next day  
*Elizabeth Vroom, World Duchenne Organization*

# SUNDAY

DECEMBER 14

*Times are shown in Central European Time*

## Welcome

- Welcome  
*Nicoletta Madia, World Duchenne Organization*

15:00 – 15:10

## TOPIC 3

15:10 – 15:30

## TOPIC 4

15:30 – 16:20

## COMMUNITY

### Presentations

- Opening session on community  
*Nicoletta Madia, World Duchenne Organization*
- How to start a patient organization  
*Nana Zomen, Seven Seas*

## NETWORK BUILDING

### Presentations

- Opening session on advocacy  
*Elizabeth Vroom, World Duchenne Organization*
- How and why involve young people in drug development  
*Dr Anneliene Jonker, Duchenne Parent Project Netherlands*
- Networking: Why and how  
*Dimitrios Athanasiou, World Duchenne Organization*

# SUNDAY

DECEMBER 14

*Times are shown in Central European Time*

## TOPIC 5

16:20 – 17:20

17:20 – 17:30

## EMPOWERMENT

### Presentations

- Why data are important to patients and patient organizations  
*Dr George Paliouras, Duchenne Data Foundation*
- Why Accredited Duchenne Care Centers are important to patients  
*İlker Karci, DMD Aileleri*
- Thirty years of keeping hope in the Duchenne Community  
*Pat Furlong, PPMD USA*

### Wrap-up

- Take home messages  
*Dr Karolina Podolska, World Duchenne Organization*
- Conclusion  
*Elizabeth Vroom, World Duchenne Organization*