

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

ORGANIZED BY

DUCHENNE

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IN COOPERATION WITH



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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

TOPIC 2

15:45 – 17:00

17:00 – 17:10

18:20 – 18:30

SATURDAY

DECEMBER 13

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COMPANY UPDATES

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

Break

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

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

15:00 – 15:10

Welcome

- Welcome
Nicoletta Madia, World Duchenne Organization

TOPIC 3 COMMUNITY

15:10 – 15:30

Presentations

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

TOPIC 4 NETWORK BUILDING

15:30 – 16:20

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

TOPIC 5

16:20 – 17:20

SUNDAY

DECEMBER 14

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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
Ilker 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