

PROGRAM

Tuesday Nov 30, 18:00 – 20:30 CET

Care

Challenges and opportunities in improving DMD/BMD care
Patients' and carers' experience of medical care for their rare disease
What patient organizations can do to improve care

Wednesday Dec 1, 18:00 – 20:30 CET

Capacity & Policy

Mindsets and strategies for negotiation success
Professional communication
Navigating global policy

Thursday Dec 2, 18:00 – 20:30 CET

Therapy Development

Why we aren't having gene and stem cell therapy yet
The importance of publishing negative results
Improving the patient voice in therapy development

Friday Dec 3, 18:00 – 20:30 CET

Data & Scientific Information

Contributing to collecting and connecting health data
Available tools to collect and connect health data
Organizing individual data return from clinical trials
Finding, following and understanding scientific information

Saturday Dec 4, 15:00 – 19:00 CET

Project updates

Various presentations

Returning individual clinical trial results back to patients

Patient preference on returning individual clinical trial data
The role of CRO's in returning individual clinical trial data
Which tools are available to facilitate this?

Company updates to the community

Presentations and panel discussion

Closing ceremony