

DUCHENNE

PATIENT ACADEMY

Agenda

Athens Masterclass 6-8 December, 2019

Royal Olympic Hotel - Athanasiou Diakou 28, Athens, Greece 117 43

ARM1 – Next Generation - New Patient Advocates - Meeting Room TEMPLAR'S

ARM2 – Patient Organization Leaders - Experienced Patient Advocates - Meeting Room ABBEY

Joined sessions – ARM1, ARM2 - Meeting Room TEMPLAR'S

Friday 6th of December

Vision-DMD Working Group (Invitation only) - Meeting Room Abbey

14:00 – 15:30 **Vision-DMD**

Laurie Conklin, Reveragen, Nefeli Panousis, MDA Hellas, Dimitrios Athanasiou, WDO

This part of the meeting is directed to DMD Patient Organizations and Advocates

15:00 - 16:00 **Coffee and Registration at the Meeting Room TEMPLAR'S**

JOINED ARM1 & ARM2

16:00 – 16:15 **Welcome**

Elizabeth Vroom, DPP NL & WDO Chair

16:15 – 16:45 **Session A1.1 - Session A2.1** - Introductions and Update on WDO and DDF Activities

Elizabeth Vroom, DPP NL & WDO Chair, George Paliouras, DDF Chair

ARM1

16:45 – 17:30 **Session A1.2** - 10 Fundraising Ideas for starting up

Nicoletta Madia, Community Manager WDO

17:30 – 18:00 **Coffee Break**

18:00 – 18:45 **Session A1.3** - EMA interactions and Managing Conflict of Interest (CoI)

Dimitrios Athanasiou, MDA Hellas, Board Member WDO

ARM2

16:45 – 17:30 **Session A2.2** - Advocacy with national stakeholder

Kostas Aligiannis, Policy Officer European Patient Forum (EPF)

17:30 – 18:00 **Coffee Break**

18:00 – 18:45 **Session A2.3** - 10 Fundraising Ideas for POs

Elizabeth Vroom, DPP NL & WDO Chair, Nicoletta Madia, Community Manager WDO

JOINED ARM1 and ARM2

18:45 – 19:30 **Session A1.4 & Session A2.4** Duchenne Map Pilot – *please bring your laptop*

Suzie-Ann Bakker, Communications Coordinator, Nicoletta Madia, Community Manager WDO

20:00 – Evening **SOCIAL DINNER** at 'Diavlos', Adrianou 1, Athina 105 55, Greece

DUCHENNE

PATIENT ACADEMY

Saturday 7th of December

This part of the meeting is directed to DMD Patient Organizations and Advocates

8:30 - 9:00 Welcome, coffee at the **Meeting Room TEMPLAR'S**

ARM1

09:00 – 09:45 **Session A1.5** - Advocacy 101

Pat Furlong, PPMD Chair, Board Member WDO

09:45 – 10:30 **Session A1.6** - Clinical Trials 101 and the role of the CRO

Dr. Martine Dehlinger-Kremer, VP Pediatric Development, Synteract & EUCROF President

10:30 – 11:00 **Coffee Break**

11:00 – 11:45 **Session A1.7** - What is HTA and what do they look for

Maria Jose Vicente Edo, Researcher Officer Aragon Health Science Institute

ARM2

09:00 – 09:45 **Session A2.5** – Advanced Policy & Lobbying Techniques

Kostas Aligiannis, Policy Officer European Patient Forum

09:45 – 10:30 **Session A2.6** - How to interact with you HTA

Maria Jose Vicente Edo, Researcher Officer Aragon Health Science Institute

10:30 – 11:00 **Coffee Break**

11:00 – 11:45 **Session A2.7** - Clinical Trials readiness and the role of patient organization

Dr. Martine Dehlinger-Kremer, VP Pediatric Development, Synteract & EUCROF President

JOINED ARM1 and ARM2

11:45 – 12:30 **Session A1.8 & A2.8** - How and where to look for EU Finding

Daria Julkowska, PhD, Assistant Director Thematic Institute GGB EJP RD Coordinator

12:30 – 13:15 **Session A1.9 & A2.9** - EU Project readiness

Daria Julkowska, PhD, Assistant Director Thematic Institute GGB EJP RD Coordinator

This part of the meeting is directed to DMD Patient Organizations and Industry Partners

13:15 – 14:15 **NETWORKING LUNCH at the Ioannis Roof Garden**

14:15 – 14:45 **Session A1.10 & A2.10** - Duchenne Data Initiatives

Elizabeth Vroom, DPP NL & WDO Chair

14:45 – 16:15 **Joined Session AB1.1** Evolving Standards of Care

Pat Furlong, Elizabeth Vroom, Dr. Imelda de Groot

16:15 – 17:00 **Coffee Break**

17:00 – 18:30 **Joined Session AB1.2** - Between mouse and man, hype and hope

Pat Furlong, PPMD Chair, Board Member WDO

Dr. Annemieke Aartsma-Rus, Leiden University Medical Center

18:30 – 19:15 **Panel Discussion Session AB1.3** - Pipeline challenges both for Industry and PO

Co-Chairs: Elizabeth Vroom, Pat Furlong, Industry Partners

20:00 – Evening **SOCIAL DINNER** at 'Abibayio', Iraklidon 3, Athina 118 51, Greece

DUCHENNE

PATIENT ACADEMY

Sunday 8th of December

This part of the meeting is directed to DMD Patient Organizations

8:30 - 9:00 Welcome, coffee at the **Meeting Room TEMPLAR'S**

ARM1

09:00 – 09:45 **Session A1.11** – Capacity Building

Bettina Ryll, MD/PhD, President Melanoma Patient Network Europe

09:45 – 10:30 **Session A1.12** – Dealing with Pseudoscience, how to read Scientific Papers

Bettina Ryll, MD/PhD, President Melanoma Patient Network Europe

ARM2

09:00 – 09:45 **Session A2.11** - Patient Organization preparedness to attract, use and deliver on Governmental/Institutional funded project

Lea Robič Mohar, business director PROFUTURUS

09:45 – 10:30 **Session A2.12** - Strategic partnerships through Corporate Engagement, Venture Philanthropy and Impact Investing.

Eleni Theodorou, Ms in International Affairs, CSR and VP expert

This part of the meeting is directed to Industry Partners

09:30 – 10:30 **Duchenne Map Break out Session - Meeting Room ALEXANDER**

George Paliouras, DDF Chair, Suzie-Ann Bakker, Communications Coordinator WDO

10:30 – 11:00 Coffee Break

This part of the meeting is directed to DMD Patient Organizations and Industry Partners

11:00 – 12:30 **Joined Session AB 1.3** - Managing Patient Burden to CT the participants - cross border CTs
Panel Discussion *Co-Chairs: Elizabeth Vroom, Pat Furlong, Industry Partners*

12:30 – 12:45 Wrap-Up, Next Steps

12:45 – 14:00 NETWORKING LUNCH at the **Ioannis Roof Garden**

END OF THE DMD MASTERCLASS

Psychosocial project working group (Invitation only) - Meeting Room TEMPLAR'S

14:00 – 17:00 Psychosocial project with companies and working group

Core Dataset for Registries meeting (Invitation only) - Meeting Room ABBEY

14:00 – 17:00 Core dataset for Duchenne registries