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
### 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**
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