

Friday, 15 March

13:00 – 15:00 **Check-in and registration/Lunch**

15:00 – 15:10 **Welcome & Introductions** – Room: Sapporo/Harrare
Hans Scheurer – President of Myeloma Patients Europe
Ananda Plate – CEO of Myeloma Patients Europe

15:10 – 16.10 **Myeloma Treatment Updates** – Room: Sapporo/Harrare

- Treatment of newly diagnosed myeloma
- Role of maintenance treatment
- New and upcoming treatments for NDMM
- Updates on treatment of relapsed myeloma
- New and upcoming treatments for relapsed MM
- Update on related conditions (myeloma, AL amyloidosis etc)

Speaker: Prof. Heinz Ludwig, Wilhelminen Cancer Research Institute, Austria tbc

16:10 – 17:00 **Spotlight on MPE scholarship programme** – Room: Sapporo/Harrare
Chair: Kate Morgan, MPE & Ana Vallejo, MPE

5-Minute presentations from 5 MPE members

- Myeloma UK (UK) - Research Capacity Building Workshops, Jayne Galinsky
- Blodkreftforeningen (Norway) - Workshop on patient involvement in myeloma research, Jacob Hygen
- Kraujas (Lithuania) - Myeloma infoday and the book "Sexuality and oncological diseases", TBC
- Blodcancerförbundet Sweden (Sweden) – Workshop on combination therapy in myeloma, TBC
- Borka (Macedonia) – Myeloma campaign "Let's make changes", Biba Dodeva

17:00 – 17:15 **Coffee break**

17:15 – 19:00 **Plenary Workshop AL Amyloidosis** – Room: Sapporo/Harrare
Chair: Ananda Plate and Hans Scheurer, MPE
Introduction to AL amyloidosis (20 min)
Speaker: Dr Moshe Gatt, Israel

AL amyloidosis from a patient advocates view (10 min.)
Speaker: Daniel Drimer, Amyloidosis Israel

Challenges of diagnosing myeloma from the patient advocates view (10 min.)
Speaker: Kate Morgan, Myeloma UK and Varda Shoham, Myeloma Israel (TBC)

Workshop (40 min. team work in small groups and 20 min. discussion/feedback)

- How can the AL amyloidosis and myeloma community collaborate to help build a stronger AL amyloidosis community in Europe?
- What does the picture of diagnosing AL amyloidosis and myeloma look like in your country?

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- How can we tackle the issue of late diagnosis of AL amyloidosis and myeloma at national level?
- What can MPE do to tackle the issue of late diagnosis of AL amyloidosis and myeloma at a Europe level?

20:00 – 22:00 **Dinner (Hotel restaurant)**

Saturday, 16 March

9:00 – 10:00 **The role of CAR-T** – Room: Sapporo/Harrare

- What is CAR-T?
- How does it work?
- How is it being looked at in myeloma?
- Companies involved in this
- Application in AL amyloidosis?
- Regulatory challenges faced (e.g. cost, hospital provision etc)
- Role of advocacy in trying to make this available for patients

Dr. Michael Hudecek, University of Wuerzburg, Germany

10:00 – 10:15 **Coffee break**

10:15 – 11:15

AL amyloidosis clinical session Updates in treatment of AL amyloidosis

- Diagnostics
- Link between myeloma and AL amyloidosis
- Treatment of newly diagnosed AL amyloidosis (and updates from ASH)
- Treatment of relapse AL amyloidosis (and updates from ASH)
- Coordinated care in AL amyloidosis
- Upcoming treatments and clinical trials

Room: Sapporo/Harrare
Speaker: Dr Moshe Gatt, Israel

Myeloma clinical session Treatment challenges in myeloma

- Riskstratification: High-risk vs. intermediate/low risk
- Treating frailer, elderly patients
- Treating younger patients with myeloma
- Personalised forms of medicine

Room: Cincinnatti
Speaker: Heinz Ludwig, AT tbc

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- 11:15 – 11:30 **Coffee break**
- 11:30 – 12:30 **Breakout Session Advocacy
“Surrogate end-points and
biomarkers in myeloma and AL
amyloidosis”**
- Minimal residual disease in myeloma and AL amyloidosis
 - Biomarkers in myeloma and AL amyloidosis
 - Regulatory challenges associated with these and getting new medicines approved
- Room: Sapporo/Harrare
Speaker: Dr. Moshe Gatt, Israel
- Breakout Session Advocacy
“Measuring and utilising quality of life”**
- PROMS, PREMS, PRO, QoL measures and patient
 - Preference studies
 - Examples in myeloma
 - Examples in AL amyloidosis
 - How they can be used in practice?
 - Can they improve survival?
- Room: Cincinnatti
Speaker: Jayne Gallinsky and Kate Morgan, Myeloma UK
- 12:30 – 14:00 **Lunch**
- 14:00 – 16:15 **ROTATING WORKSHOP SESSIONS
(45 minutes each – Choose 2 out of 3, 15 min for rotation)**
- **Internal and external communications. How to create communications strategy.**
Room: Sapporo
Speaker: Ana Vallejo, Myeloma Patients Europe
 - **Fundraising for patient groups**
Room: Harrare
Speaker, TBC
 - **Compliance and legal agreements (WECAN legal framework)**
Room: Cincinnatti
Speaker: Ananda Plate, MPE/Jan Geissler, CML Advocates Network
- 16:15 – 16:45 **Coffee Break**
- 16:45 – 17:30 **Supportive and psychosocial issues for myeloma and AL amyloidosis**
Room: Sapporo/Harrare
Chair: Ibolya Keri, MOHA, Hungary (TBC)
- Psychosocial issues for patients (supportive care, emotional care etc)
Speaker: Fatima Castaño, Psycho-oncologist
 - Communicating with patients
Speaker: Diego Villalón, social worker, Fundación MÁS QUE IDEAS
- 19:30 – 22:00 **Offsite dinner in Munich**

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Sunday, 17 March

ONLY FULL MEMBERS ALLOWED - Room: Sapporo/Harrare

9:00 – 11:00 **General Assembly**

11:00 – 11:30 **Coffee break**

11:30 – 13:00 **General Assembly**

13:00 – 14:00 **Farewell lunch**