

**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 MPE members – tbd

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 tbc*

**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 Shohom, 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?
- 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 tbc*

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 tbc*

**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*

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*

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**15 – 17 March 2019, Munich (Germany)**

- 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 communication with patients and stakeholders**  
Room: Sapporo  
*Speaker: Ana Vallejo, Myeloma Patients Europe*
  - **Fundraising for patient groups**  
Room: Harrare  
*Speaker, e.g. EPF, so. from Find a cure, tbd*
  - **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*
- Psychosocial issues for patients (supportive care, emotional care etc)  
*Speaker: Fatima Castaño conf.*
  - Communicating with patients  
*Speaker: Diego Villalón, Fundación MÁS QUE IDEAS conf.*
- 19:30 – 22:00    **Offsite dinner in Munich**

### **Sunday, 17 March**

**ONLY FULL MEMBERS ALLOWED** - Room: Sapporo/Harrare

- 8:30 – 10:45    **General Assembly**
- 11:15 – 11:45    **Coffee break**
- 11:45 – 13:00    **General Assembly**
- 13:00 – 14:00    **Farewell lunch**