

Attendees: see list added

1. Welcome and opening remarks were performed by Saper Diler, actual chair of MPe. All board members were present.

2. Financial Report 2014, Budget 2015

Treasurer Mira Armour apologizes not having distributed 2013 and 2014 balances prior to the AGM. They were not available yet. Members will get them with the AGM-minutes.

Despite some difficulties with the former MPe-treasurer balance sheet is healthy. The expected income for 2015 is about 255.000€ .

3. 2014 Activity Report and 2015 Activity Plan

Ananda Plate and Alfonso Aguarón, Mpe staff, presented the report and the plan.

Several master classes, workshops and webinars were organised by Mpe in 2014, and were followed by 10 to 30 attendees. The documentation and reports published on Mpe website may be used by members for their regional purposes.

A new website had been launched in late 2014. Mpe had been present at all important hematological congresses like EHA, ECCO and ASH. Reports may be seen on the website. Within social media MPe is represented as well.

Most important project running is the “European Atlas on Access to Treatment”. It already had been presented in different occasions gaining great attention and respect. It will be completed during 2015. Besides the Atlas several tool kits for members are going to be performed like fact sheets or flyers as well as a position paper. Due to hiring Alfonso as a project manager an excellent IT support is available within MPe.

Members who want to have a translated version of the MPe-guide should translate it by themselves. An update is ongoing, so it could be efficient to

wait for it.

4. Amendments to MPE constitution

Amendments were announced already at 2014 AGM, but not performed and distributed yet. Board members will make suggestions within next months and distribute both versions (original and amended) in time before next AGM.

5. Welcome of new MPE members

Saper and the board welcomed new members representing Myeloma and Lymphoma groups from **Estonia, Hungary, France, Norway and Portugal.**

Their reports and presentations about how they are performing patients groups in their countries had been highly appreciated by all attendees. Here are some shortly reported highlights (complete reports are available).

Estonia, Mait Raava

The myeloma group was founded in Oct.2012, counting 19 actual members. The number of newly diagnosed patients per year is about 60. The group emphasizes on information and communication with the patients as well as with the public media. In 2015 a study about the support of family doctors is planned.

Hungary , Ibolya Kévi

The MOHA organisation for haematological diseases was founded in 2012. Ibolya and her three board members are advocating, educating and supporting patients in encouraging them and mental help. 400 patients are newly diagnosed per year. In contrary there are decreasing medical professionals.

France, Catherine Filliol

The French organisation's name is AF3M and was founded in Sept.2007. It is divided into 24 regional groups and counts 9 board members. The organisation is providing information for the patients in different forms, like

newsletters, website, regional patient days, booths at medical congresses and they are earning a great publicity, even within overseas regions. Financing is with membership fees as well as pharma's sponsoring. As very important AF3M gives value to patients' education about new drugs.

Norway, Tone Hansen and Barbo Hardersen

The norwegian organisation for blood cancer patients derives from 1951, reorganized in 2013. It is supported by the Norwegian government and is fund raising as well. The treatment options in Norway are very good, so that the patients organisation is able to focus on advisory, psychological support, peer support and collaboration with different advisory boards and haematological departments of hospitals as well.

They have about 900 members, a board with 5 members, organising a big patients day once a year and myeloma related seminars. Newest project is patient support in going through treatment and hospital.

Portugal, Sofia Sá Cardoso

The organisation APCL exists since 2002 with actually about 1400 members. They run a big stem cell donors' register, third worldwide. Members are supported in different ways: information, education, psychologically, social and even financial support (up to 3 months). There are 4 councils and 200 associates. Financing is done by fund raising, which is very successful grace to intensive public relationship. Besides financial support for families, a save house was founded for giving accommodation to family members while patients are hospitalised.

Bosnia, Amira Mrdjanovic

A new individual member with her Hasband Ibrahim. Sadly Ibrahim has passed away in March. Bosnian patients are struggling with access and a very complicated canton system of health care they have had since the war. Patient Advocacy and involvement are not accepted so patients struggle to get information or to take part in any decisions about their treatment. Amira is intending to set up a group with some of the fellow patients and carers. This was presented by Mira Armour, Mijeloma CRO, who has given them support.

6. AGM proposal 2016

A lot of proposals were made by members. Ananda registered them for

being evaluated later by the board.

7. AOB

Mira reported about her experiences with a Bosnian patient and his family. The patient, only 46 years, was diagnosed in 10/2014 with IgG lamda and died in lack of treatment and drugs in Bosnia in 3/2015. Before, his family spent their whole money for buying different drugs in the exterior on their own risk.

It was suggested to give to the widow a kind of prize like “patient of the year”. Another idea was told to give to the Bosnian government a reward for the worst treatment in Europe. The idea of support by money had not been agreed. No decision had been made.

Finally members were asked to give a feedback on a distributed sheet.

Minutes by Christa Kolbe-Geipert, Secretary