



Annual General Meeting Minutes

Sunday 14 April 2013, Madrid

Present Board Members	Apologies
Sarper Diler (SD)	Eric Low (EL)
Yacob Yacobovitch (YY)	Philip Bloom (PB)
Begona Barragan (BB)	Greetje Goossens (GG)
Peter Lens (PL)	

Present MPE members and correspondent delegates	Received Apologies
Amen Israeli Myeloma Patient Foundation Paula Asulay (PA) & Yacob Yacobovitch (YY)	Udruga Za Podršku Oboljelima Od Multiplog Mijeloma (Mijelom CRO)
Asociación Española de Afectados por Linfoma, Mieloma y Leucemia (AEAL) Begona Barragan (BB) & Belen Gutierrez (BG)	Society for Assistance to Patients with Oncohaematological Diseases
Association of myeloma patients of Serbia (AMPS) Maja Milisavljevic (MM)	Foundation for the Advancement of Bone Marrow Transplantation Switzerland (SFK)
Cancer and Stemcell Organization - Coordination Association (KOKDER) Sarper Diler (SD)	Myeloma UK
Contactgroep Myeloom en Waldenström Patiënten Vlaanderen vzw (CMP vzw) Tanguy Pansaerts (TP)	Suomen syöpäpotilaat-myelooma potilasverkosto
Društvo bolnikov z limfomom (DBL) Blaž Kondža (BK)	MyMu Wallonie-Bruxelles (MyMu)

Leukaemihilfe RHEIN-MAIN e.V. (LHRM) Anita Waldmann (AW)	Myeloma UK
Myeloma Euronet Romania (MER) Viorica Cursaru (VC) & Mihaela Despa (MD)	
Contactgroep Myeloom en Waldenström Patiënten (CMWP) Peter Lens (PL)	
Slovak Myeloma Society (SMYS-KP) Rudolf Hanuljak (RH)	

Present MPE Staff
Ananda Plate (AP)

Summary of actions

Agenda Item	Action	Who
4.	Discuss about reducing the number of Masterclasses from two to one a year and inform members of the final decision.	Board
4.	Send an evaluation questionnaire to members in order to gather input for improving MPE events and increasing member's participation.	AP
8.	Discuss options for resource allocation/investment.	Board
14.	Discuss about how to coordinate and professionalise the MPE board.	Board
15.	Include in the Strategic Plan the provision of education for "board members and other members appointed by the board" instead of only "board members".	Board
17.	Translate Strategy Plan into a management/ business plan.	Board
20.	Prepare summaries of the member organisations in their own language in a standard format and a link to the member organisation's website on the MPE website.	Board
21.	Ask the board for permission to represent MPE at conferences.	All

25.	Represent MPE at ECCO (27 September-2October) with a booth freely offered by ECCO PAC and take part of the patient advocacy session.	Board & AP
27.	Volunteer for translating MPE documents in other languages.	All
27.	Permit the translation of MPE documents into other languages	All
28.	Discuss whether/what MPE material (posters, flyers, etc.) can be provided to members for them to print out and promote MPE.	Board

Agenda Item	Minutes	Actions
1.	SD officially opened the AGM. All present members were welcomed and apologies were received from EL, GG & PB	none
2.	SD acknowledged GG for her hard work during the last months for organising and resolving all problems related to the appointment of MPE's Operations Manager. This was appreciated by all.	none
3.	The 2012 Activity Report was presented by SD and discussed addressing all questions of members.	none
4.	<p>Members were informed that the board was thinking about reducing the number of annual Masterclasses due to low participation. The board would discuss this possibility in detail and inform members of their final decision.</p> <p>It was suggested by some delegates that, in order to increase participation, the agenda should be sent earlier and invitations should be more personal. Also, that it would help if the invitation were extended to other representatives of that organisation (e.g. sometimes the contact person of the organisation was busy and therefore a substitute could be sent, etc.)</p> <p>The board informed that a questionnaire would be sent out soon in order to gather input and ideas for a better event in the future.</p>	<p>Board</p> <p>AP</p>

5.	<p>With regards to the development of the report, the European spirit of report was questioned by one member since it had been developed by a small group not taking into account the opinion of all members.</p> <p>All present delegates were informed by the board that the report was MPE's first important piece of research, which required the development of a reduced advisory group specialised in the field in order to assure the high quality of its content. Members were also informed that the report had indeed a very European perspective although there had been difficulties in gathering data from some European (non EU) countries.</p>	none
6.	<p>The finances of 2012 were presented by BB, who clarified that there were figures missing and that this was the reason for which no expenses for 2012 were reflected on the 2012 budget (e.g. expenses had been covered by MUK or Myeloma Euronet in 2012 because MPE had difficulties with the Belgian bank account).</p>	none
7.	<p>Further to a member's request, it was explained by the board that the reason for which activities and administration costs had similar percentages, was that MPE is in a start-up mode, which means that most of the costs go into administration/staff as a necessary initial investment and that this would change over time, with the expected increase in sponsors etc.</p>	none
8.	<p>It was suggested by one delegate that MPE could search for an investment advisor in order to wisely keep/invest/allocate the money.</p> <p>This was generally perceived as a good suggestion and it was stated that the board would talk about this possibility.</p>	none Board
9.	<p>Also, in order to protect MPE's resources, it was suggested by one delegate to have two parallel bank accounts in order to protect one of them against misuse, hackers, etc.</p>	none

10.	The budget for 2013 was presented by BB, by whom it was clarified that the income in 2013 was not yet reflected on this budget.	none
11.	It was asked, on behalf of the Austrian organisation, whether it would be possible to get financial support from MPE for member organisations (e.g. to pay the flights of speakers to attend a patient's day, etc.). It was stated that in order to reply with a letter a formal request should be received from the Austrian group. The Romanian group proposed to facilitate access to education/training to any PAE member who is interested, and worthy of such investment. Delegates were informed by the board that the mission of the umbrella organisation was not to give financial support to individual members and member organisations. MPE member organisation would get support through displaying the MPE logo or other logistic support where possible.	none
12.	The finances of 2012 and budget for 2013 were approved: motion (AW), seconded (BK), no one against, approved.	none
13.	The final draft of MPE's 5 year Strategic Plan was presented by PL and feedback was gathered from members. Printed copies of the Strategic Plan were distributed to all present delegates.	none
14.	Other main issues discussed focused on the need for a more coordinated and professional board in the sense of better defining roles of the board. The board stated it would talk about this in the nearer future.	Board
15.	Following the request of one delegate, it was discussed whether education should be provided only to board members or also to all other members. It was explained by the board that this education need refers to the MPE board members since they represent MPE to the exterior and it is important they are informed about the subjects being discussed there. However, the board agreed that it would be possible to include in the Strategic Plan that "board members and other members appointed by the board" would	Board

	receive this education instead of only "board members".	
16.	Also, the importance of including Healthcare and research in the Strategic Plan and the relation of MPE/national organisations with drug pricing authorities/pharma was raised by some delegates.	none
17.	It was further clarified that the next step would be the translation of this Strategy Plan into a management/business plan.	Board
18.	Copies of the MPE Clinical Trial Charter were distributed to all present members.	none
19.	Two copies of the MPE Patients' Perspectives Report were circulated among all present members.	none
20.	Regarding the MPE website, it was asked by the delegates whether it was planned to have a fundraising option on the website and country sections with flags/links to the member webs in order for interested people to get information in their own language. Delegates were informed that the board decided of putting summaries of the member organisations on MPE finalised website and a link to the member organisation's website.	Board
21.	It was offered by AW to represent MPE at conferences. It was suggested by some delegates that she should be a good will ambassador for MPE. It was acknowledged by the board that visibility is important and that any of the delegates could ask the board for permission to represent MPE at conferences. Also material, such as flyers, etc. would be given to that person if the board approves the request. Requests will be evaluated case by case by board	none All Board
22.	It was discussed by all present delegates and the board that it is important to use the momentum and that 2013 would be a crucial year for MPE.	none

23.	The 2013 Activity Plan was presented and discussed among all present delegates and the board. Printed copies of this document were distributed to all present delegates.	none
24.	The delegates were informed that the September Masterclass might be skipped and that they would be informed in time about how the board has decided on this issue.	Board
25.	Delegates were informed about MPE being represented at ECCO (27 September-2October) and that once more MPE would take part of the patient advocacy session.	Board & AP
26.	It was indicated by the board that the board meeting scheduled for October may be rescheduled for September, during the ECCO meeting.	Board
27.	The importance of translating all MPE documents in national languages was stressed by some of the present delegates. Delegates were reminded that AP was looking for volunteers to translate these documents into all possible languages. VC offered herself as a volunteer to translate into Romanian language and this was accepted.	none All VC
28.	It was asked by VC whether she could have MPE material (posters, flyers, etc) to promote MPE on events. This idea was welcomed by the board and it was decided that this possibility would be further discussed among the board.	Board

Additional Information	<p>The AGM ended early (12:30am) due to the sudden death of a family member of one of the delegates. Besides, several members had to leave early afternoon for their flights.</p> <p>It was decided that the country updates that were planned for the afternoon would be skipped. Instead, members would have the possibility to submit their presentations for the next country update E-newsletter. These contributions would have to be submitted in written to AP before the end of April 2013.</p>	none
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Signed..... Date.....

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