



Annual General Meeting Minutes

Sunday 27 April 2014, Madrid

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

Present MPE members and correspondent delegates	Apologies
Amen Israeli Myeloma Patient Foundation Varda shoham Ron Dalumi Yacob Yacobovitch	Foundation for the Advancement of Bone Marrow Transplantation Switzerland (SFK)
Society for Assistance to Patients with Oncohaematological Diseases Oksana Chirun	MyMu Wallonie-Bruxelles (MyMu)
Association of myeloma patients of Serbia (AMPS) Maja Milisavljevic	Contactgroep Myeloom en Waldenström Patiënten Vlaanderen vzw (CMP vzw)
Cancer and Stemcell Organization - Coordination Association (KOKDER) Sarper Diler	Asociación Española de Afectados por Linfoma, Mieloma y Leucemia (AEAL)
Udruga Za Podršku Oboljelima Od Multiplog Mijeloma (Mijelom CRO) Mira Armour & Ana Tudor	Društvo bolnikov z limfomom (DBL)
Myeloma UK Eric Low	Myelom Kontaktgruppe Schweiz (MKGS)
Leukaemihilfe RHEIN-MAIN e.V. (LHRM) Christa Kolbe-Geipert	Individual member Philip Bloom
Myeloma Euronet Romania (MER) Viorica Cursaru Mihaela Despa	Myelom Deutschland E.v

Hematon Hans Scheurer (HS)	Deutsche Leukämie- & Lymphom-Hilfe e.V. (DLH)
Slovak Myeloma Society (SMYS-KP) Miroslav Hrianka Michal Miroslav Hrianka	Društvo bolnikov z limfomom (DBL)
Suomen syöpäpotilaat-myelooma potilasverkosto Mika Peltovara	Ege Uni tip fak
Centro de Histocompatibilidade do Norte (CHN) Helena Alves	Multiples Myelom Selbsthilfe Oesterreich (MMSOe)
Carita-Living with Myeloma Wieslawa Adamiec Emilia Demczur	Slovensko Združenje Bolnikov Z Limfomom In Levkemijo L&L
Associação Portuguesa Leucemias e Linfomas (APLL) Isabel Leal	Klub pacientů mnohočetný myelom (KPMM)

Special guest (Non-MPE member)
Hungarian group Ibolya Keri Márta Lukács (Celgene)

Present MPE Staff
Ananda Plate (AP)

Summary of actions

Agenda Item	Action	Who
2.	A canvas would be sent to all to fill in within an agreed time. It would form a basis for a business plan for the next 2 years.	EL
5.	diversify sources of sponsorship and to gradually include non-pharma sponsors.	Board
8.	Send draft of amended constitution to all members	AP
8.	Give feedback and input to the draft constitution	ALL
8.	Set date for teleconference for members to approve the amended constitution	AP
8.	Take part in member teleconference to approve the amended constitution	ALL

10.	A business plan would follow shortly.	EL
10.	Members were asked for their active contributions to these communication tools	All
10.	Shorter MPE member updates were requested by member	AP
12.	Send proposal for course in leadership leading to an accredited Diploma in Leadership.	EL

Agenda Item	Minutes	Actions
1.	<p>SD officially opened the AGM. He stated the value of meeting in person and interacting.</p> <p>All present members were welcomed and apologies were received from PL, BB and GG.</p>	none
2	<p>EL gave an overview of the Masterclass.</p> <p>MPE would help develop strategic capability of its members by creating a business plan. The Masterclass included a session on Business Canvas – A canvas would be sent to all to fill in within an agreed time. It would form a basis for a business plan for the next 2 years.</p> <p>It was suggested by members to incorporate members' business plans into MPEs business plan.</p>	EL
3.	<p>Members were informed about MPE's accounts and financial situation.</p> <p>A brief summary was given of the problems experienced with BB as a Treasurer, in order to explain the reason why the financial report was not ready for the AGM. Members were informed that the Financial Summary presented was not accurate.</p> <p>BB had sent very limited amount of information the evening before the AGM, despite having been asked for this information by the Board, AP and the accountants for several months.</p> <p>5000 € or the prospective amount needed for 6 months operations would be put into a reserve account, in order to ensure MPE's sustainability. Approximately 200,000€ would</p>	none

	be spent on programmes and services. A proportion of this expenditure would be allocated to the 2nd employee to reduce the fixed costs.	
4.	It was explained that BB would be removed as bank account signatory as soon as possible once the new Board was in place. The new signatories would be the new Treasurer and AP.	none
5.	The 2014 budget was approved unanimously. It was expected to have 7 sponsors for 2014 to 2015. The Board had decided to diversify sources of sponsorship and to gradually include non-pharma sponsors. The Board would consider allocating a proportion of the budget for members to access training courses and conferences in advocacy Members were informed that the AGM and Masterclass had an approximate cost of 20.000-30 000 €.	None Board
6.	The AGM was informed that professional accountants had been appointed in order to revise the accounts from the previous years and ensure accurate accounts and timely reports in the future. This could be reconsidered in the future.	none
7.	The appointment of an auditor (Michel Weber) was approved by the AGM.	none
8.	The amendments to the MPE Constitution, proposed by the Board, were presented to the AGM by EL. Some corrections to the proposed changes were made and agreed. The draft of the amended Constitution would be sent to all members within 30 days. Members would have two weeks to give input to the amended text. It was agreed that a face-to-face meeting was not necessary to approve the new Constitution. The amended text would be approved by members via teleconference. A teleconference would be scheduled at the most convenient time/date for the majority of members. The date and time would be communicated at least two weeks in advance of the teleconference. The Founders were limited to 3 from each of Me and EMP when the two merged. It was not practical to include all the members. VC requested that all members at the time	AP ALL AP

	<p>of the merger should be included as founder members. SD and EL stated that this was the advice of Lawyers at the time.</p> <p>EL explained the changes to Board Structure are to make it more transparent and sustainable. MPE needs to preserve organisational memory, keep the core expertise and knowledge.</p>	
9.	<p>The activity report of 2013 was presented and discussed. The most important one was the MPE Report on Myeloma Patient Perspectives, which was disseminated and had a very good response.</p> <p>The summary of the Masterclass 2013 would be uploaded as soon as the new website was launched.</p> <p>An overview of all planned activities and projects for 2014 was given.</p>	None
10	<p>The Strategic Plan Summary for 2013 – 2018 was presented. A business plan would follow shortly.</p> <p>Regular bulletins with Board news, summaries of conferences and Breaking News would be sent once the second worker was hired. Members were asked for their active contributions to these communication tools.</p> <p>Shorter MPE member updates were requested by member.</p>	<p>EL</p> <p>All</p> <p>AP</p>
11	<p>The most recent MPE member (Carita from Poland) was welcomed by the Board and all present delegates.</p> <p>Carita's membership was ratified.</p> <p>A presentation was given by delegates of Carita to explain who they are and what their main activities are.</p> <p>They are very keen to contribute to MPE activities.</p>	none
12	<p>EL proposed a course in leadership which would give an accredited Diploma in Leadership.</p>	EL
13	<p>A short presentation on personal background and objectives was given by candidates standing for elections to the MPE Board:</p> <p>Sarper Diler Eric Low Mira Armour Christa Kolbe-Geipert Mika Peltovaara Viorica Cursaru Yacob Yacobovitch</p>	none
13.	<p>All seven members were elected by the AGM unanimously.</p> <p>The newly elected Board members decided among themselves their specific roles on the Board. The newly elected Board is formed by:</p>	none

	<ul style="list-style-type: none"> • Sarper Diler: President • Eric Low: Vice-President • Mira Armour: Treasurer • Christa Kolbe-Geipert: Secretary • Mika Peltovaara • Viorica Cursaru • Yacob Yacobovitch <p>The new Management Team is formed by:</p> <ul style="list-style-type: none"> • Sarper Diler: President • Eric Low: Vice-President • Mira Armour: Treasurer • Christa Kolbe-Geipert: Secretary 	
14.	<p>The new MPE website was presented to all attending members, who were able to see the new sections and design.</p> <p>General feedback was very good.</p> <p>It was mentioned that the colours of the website could have been a little more matching to the MPE colours.</p> <p>It was explained that the website would soon be finalised and with sufficient content to go live.</p> <p>Additional content would be added in the months following the launch.</p>	none
15.	No AOB	none
16.	AGM was closed at 1pm.	none

Signed.....

Date.....