

General Assembly 11 April 2024

MINUTES OF THE MEETING

In attendance:

Attendee	Organisation
Liselott Eriksson (Chair)	MPE president
Riikka-Leena Manninen	MPE (former) board member
Reidar Nordby	MPE board member + representative of Norwegian Blood Cancer Association (vote)
Zvi Zilberman	MPE board member + up for re-election for the board (no voting rights)
Barbara Leonardi	MPE board member + up for re-election for the board (no voting rights)
Diane Loening Martens	MPE board member + up for re-election for the board (no voting rights)
Katie Joyner	MPE (staff)
Kate Morgan	MPE (staff)
Solène Clavreul	MPE (staff)
Ellidh Duncan	MPE (staff)
Ana Vallejo	MPE (staff)
Valentina Christodoulidou	MPE (staff, minuting)
Linda Christopher	MPE (staff)
Patricia Matamoros	MPE (staff)
Monica Racovita	MPE (staff)
Vincent Claus	Candidate for the board (no voting rights)
Kristina Modic	Slovensko Združenje Bolnikov Z Limfomom In Levkemijo L&L + candidate for the board (no voting rights)
Dražen Vincek	HULL Croatia - Croatian Leukemia and Lymphoma Society (vote)
Snezana Doder	Udruženje obolelih od multiplog mijeloma Serbia, candidate for board + no voting rights
Cvetka Flajs Cotic	Association of Patients with Blood Diseases Slovenia / Društvo bolnikov s krvnimi boleznimi Slovenije (Društvo BKB Slovenija) (vote)
Jürgen Martens	AMM Online Germany (vote)
Gay Corinne Charles	MyMu Wallonie-Bruxelles Belgium (vote)
Ric-Paul Hammink	Amyloidosis Foundation Netherlands (vote)
Ronald Meint Jacob Voorthuis	Stichting Hematon Netherlands (vote)
Jenni Tamminen-Sirkia	Suomen Syöpäpotilaat Finland (vote)
Dražen Vincek	HULL Croatia (vote)
Dr. Otmar Pfaff	LHRM / MM-RHEIN-MAIN (vote)
Łukasz Rokicki	CARITA Foundation Poland (vote)
Rafi Amit	Âmyloidosis Israel (vote)
Viorica Cursaru	Myeloma Euronet Romania (MER) (vote)
Milica Kuzmanovaska	Hema Macedonia (vote)
Lidija Pecova	Hema Macedonia (no voting right)
Varda Shoham	AMEN Israel (vote)
Svetlana Marinkovic	Udruženje obolelih od multiplog mijeloma Serbia (vote)
Nitu Lucica	SOS Mielom Romania (vote)
Fionnuala Duffy	Multiple Myeloma Ireland (vote)
Mary Kelly	Multiple Myeloma Ireland (no voting rights)
Mira Armour	Mijelom CRO (vote)
Brina Žagar	Slovensko Združenje Bolnikov Z Limfomom In Levkemijo (L&L) (vote)
Florin Rupper	MPS Myelom Patienten Schweiz (vote)

Apologies:

Attendee	Organisation
Yervand Hakobyan	AHA - Armenian Hematology Association (vote)
Elena Palma	AELCLES Spain (vote)
Julia Dmitrieva	Dzivibas koks Latvia (vote)
Kristin Einarsdottir	Perluvinir Iceland (vote)
Isabel Barbosa	Associação Portuguesa Leucemias e Linfomas (vote)

Minutes of the Meeting:

08:50 – 09:00	Technical Support for Virtual AGM Members joined the call. Valentina Christodoulidou and Ana Vallejo provided technical support to ensure all attendees were able to fully participate in the meeting as required.	
09:00 – 09:10	Welcome President Liselott Eriksson welcomed all attendees to the meeting. A minute of silence was observed for all patients lost this year. Liselott resumed and talked through the agenda for the meeting.	
	Attendance and Apologies As noted above	
09:10-09:20	Approval of the 2023-AGM minutes (vote) Riikka-Leena Manninen who was stepping down at this AGM presented the minutes of 2023 General Assembly as her last day as secretary of the board. The minutes were presented, and members were asked to indicate if they had comments or objections page by page. Riikka-Leena also reminded members that they received the minutes 4 weeks prior of the AGM. No comments from members. Minutes are approved by the majority (50% + 1): 15 of 21 votes. (6 abstentions from attending members).	Ref. 1
09:20 – 10:10	Financial Year Report (vote) <u>Closure of Financial Year 2023</u> Barbara Leonardi provided an overview of the Financial Year 2023. Barbara explained that the year ended with positive results. She broke down the expenses of the year and that the reserve is sufficient for MPE to operate with no other funding for approximately six months. Barbara then presented a breakdown of the 2023 income and the largest sponsors, and the funding allocation per programme. She then explained MPE's accounting practices and the deferred income practice. Barbara also explained the difference in actual spending and budget allocated for the year 2023, including hiring at a later date than expected, less attendance to conferences and lower costs for Masterclass and ADP. Barbara also presented the financial statement for 2023. Member Mira Armour asked whether the financial statement was provided beforehand. Barbara and Valentina confirmed that it was part of the pack sent a month prior (annex 1). Member Mira also wanted to confirm the allocation of funding from specific industry sponsors, to which Barbara provided the breakdown again.	Ref. 2

	<p>There were no other questions or comments from members. Valentina asked members to vote for the financial year 2023.</p> <p>Vote: Approved by 15 out of 21 (50%+1). (6 abstentions by those present)</p> <p><u>Budget 2024</u></p> <p>Barbara then proceeded to present the budget for 2024. She first started with the general overview for the income and cost for the year. In terms of costs, she then explained that it will differ per workstream. She also presented the comparison of the 2023 and the 2024 budget as well as a history overview of the MPE funding from 2020 onwards. On the income by programme Barbara presented the sponsor and programme funding breakdown as of February 2024 and what is expected for the rest of the year. Barbara congratulated the management and team for securing such a large amount so early in the year.</p> <p>In terms of expenses Barbara explained that it will be higher than last year as the inflation around Europe pushes costs higher than usual. The staff costs will be increased as the team is growing. Costs connected to projects will also be higher and provided the reasons for each project (including delays, bigger number of participation, travel costs, investing in website infrastructure). Barbara also explained that there will be some cost decreases to specific programmes due to doing more in-housework and less outsourcing.</p> <p>Barbara then opened the floor to questions from members.</p> <p>Member Fionnuala Duffy asked about industry funding allocated to core funding and the local feedback about industry not providing core funding but rather having specific project funding only. Co-CEO Katie Joyner explained that this is a big challenge on a local level but not as big of a problem on a European level. Katie mentioned that MPE is interested to engage in discussions on how they can best help national organisations tackle this issue.</p> <p>Member Mira Armour expressed agreement with Fionnuala's enquiry and expressed interested in MPE organising a session on how this barrier can be overcome and what the best route for support is. Mira also enquired whether MM Ireland and MPE has any experience with sponsorships from industry to which Katie replied that MPE tends to do more grants over sponsorships.</p> <p>President Liselott Eriksson also agreed that such a session on the topic of industry funding on a local level vs a European level and how MPE can support organisations would be very beneficial and agreed that there have been similar experiences in Sweden in terms of core funding.</p> <p>Member Snezana Doder also mentioned similar experiences in Serbia and issues on both lack of access to medicine and funding. Member Lidija from Macedonia agreed with Snezana and said the same situation and worse is happening in Macedonia. Member Reidar Nordby from Norway also mentioned that a key issue for the national organisation must not be under the control of the sponsorships.</p> <p>Member Mary Kelly asked about the difference in the level of funding from each sponsor and whether MPE has a set amount they request from each company to which Katie Joyner explained that no, it just varies in terms of what each company can support. She also explained the process she follows to request funding, which includes multiple calls with each company to understand what to expect in the coming year.</p> <p>There were no other questions or comments from members. Valentina asked members to vote for the budget 2024.</p> <p>Vote: Approved by 16 out of 21 (50%+1). (4 abstentions by those present)</p> <p>Barbara also explained that MPE has decided to implement annual contractual audits and that from 2025 the outcome of the audit will be presented at the AGM.</p>	
10:10 – 10:50	MPE Internal Rules amendment (vote) <p>Valentina thanked Barbara and moved on to the internal rules amendments topic. She</p>	Ref 3

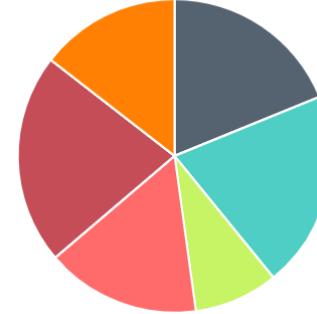
<p>explained to members the purpose for the internal rules' amendments and what the process of voting will be (voting per amendment).</p> <p>Amendment on section 1.3 Board's responsibilities, bullet point no.2 Vote: Approved by 15 out of 21 (50%+1). (6 abstentions by those present)</p> <p>Amendment on section 1.6 Board's operations, board meetings, bullet point no.1 Vote: Approved by 15 out of 21 (50%+1). (6 abstentions by those present)</p> <p>Amendment on section 2.3 Governance, adding a bullet point Vote: Approved by 14 out of 21 (50%+1). (7 abstentions by those present)</p> <p>Amendment on section 2.8 CEO compensation, bullet point 1&2. <i>Members raised questions about the phrasing of the paragraph and the ambiguity it raises. Members requested to have this section reviewed once more by the board and rephrased and then brought for voting in AGM 2025.</i> Vote: 13 out of 21 (50%+1) voted in favour of removing this amendment from the vote/agenda. (8 abstentions by those present)</p> <p>Amendment on section 3 Standing Committees and working groups, bullet point updates. Vote: Approved by 17 out of 21 (50%+1). (4 abstentions by those present)</p> <p>Amendment on section 3 Standing Committees and working groups, bullet point no.4 Vote: Approved by 19 out of 21 (50%+1). (2 abstentions by those present)</p> <p>Amendment on section 3 Standing Committees and working groups, bullet point no.5 <i>As this amendment was linked to amendment 2.8 members confirmed it would align to also vote on not voting for this during the current AGM.</i> Vote: 14 out of 21 (50%+1) voted in favour of removing this amendment from the vote/agenda. (7 abstentions by those present)</p> <p>Amendment on section 3 Standing Committees and working groups, bullet point no.8 Vote: Approved by 17 out of 21 (50%+1). (4 abstentions by those present)</p> <p>Amendment on Section 4.3 Profile of ideal board member, last sentence before bullet points Vote: Approved by 15 out of 21 (50%+1). (6 abstentions by those present)</p> <p>Section 4.4 Election procedure, bullet points 3&4 Vote: Approved by 17 out of 21 (50%+1). (4 abstentions by those present)</p> <p>Section 4.3 (2) The Voting Procedure, bullet points 1-6 Vote: Approved by 14 out of 21 (50%+1). (7 abstentions by those present)</p> <p>Section 5 (5.1) Financial reporting and budgeting, bullet points 3,5, 7 Vote: Approved by 16 out of 21 (50%+1). (5 abstentions by those present)</p> <p>Section 5.2 Monitoring financial operations, bullet point 1 Vote: Approved by 15 out of 21 (50%+1).</p>	
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<p>(6 abstentions by those present)</p> <p>Section 5.5 MPE's credit and other bank cards, bullet point no.2 Vote: Approved by 17 out of 21 (50%+1). (4 abstentions by those present)</p> <p>Section 5.3 Annual reserve, bullet point 1 Vote: Approved by 15 out of 21 (50%+1). (6 abstentions by those present)</p> <p>Section 5.6 Policy on general expenditure – MPE programmes and activities Vote: Approved by 15 out of 21 (50%+1). (6 abstentions by those present)</p> <p>Section 5.7 “The following rules shall apply”, bullet points 2 & 4 Vote: Approved by 15 out of 21 (50%+1). (6 abstentions by those present)</p> <p>Section 5.7 “The following principles apply for travel:” Vote: Approved by 17 out of 21 (50%+1). (4 abstentions by those present)</p> <p>Section 5.7MPE Staff and board members Vote: Approved by 16 out of 21 (50%+1). (5 abstentions by those present)</p> <p>Section 5.7 Small items of expenditure – up to 250 Euro per transaction, bullet point 1 Vote: Approved by 16 out of 21 (50%+1). (5 abstentions by those present)</p> <p>Section 6.3 Funding: guiding principles, last bullet point Vote: Approved by 16 out of 21 (50%+1). (5 abstentions by those present)</p> <p>Section 7. MPE Conflict of interest policy, 7.1. bullet point 2 Vote: Approved by 17 out of 21 (50%+1). (4 abstentions by those present)</p>	<p>MPE Constitution amendment (vote)</p> <p>Valentina explained that by updating the internal rules then MPE also needs to update the date that references the internal rules latest version within the MPE Constitution. She also explained that since MPE is legally registered in Belgium in the French speaking register, any changes in the constitution need to be prepared in French for publication in the official Belgian Gazette.</p> <p>Therefore, article 12 to be modified is presented here below in French for the vote. Valentina explained that members would find the English translation directly below the French version.</p> <p>Updating the date of latest version of the internal regulations in the MPE statutes:</p> <p>The General Assembly of 11 April 2024 is invited to approve to modify the article 12 of its statutes, formerly worded as follows:</p> <p>“Article 12: Règlement intérieur Le conseil d’administration est chargée d’élaborer et de mettre à jour le règlement intérieur qui précisera ces statuts et leurs applications. Le règlement intérieur sera suivi à titre provisoire sous réserve de sa ratification au cours de la prochaine AG. Le règlement intérieur sera révisé chaque année par le conseil d’administration.</p> <p>La dernière version approuvée de règlement intérieur est datée du 29 mars 2022.”,</p>
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	<p>by a new article 12 worded as follows:</p> <p>“Article 12: Règlement intérieur Le conseil d’administration est chargée d’élaborer et de mettre à jour le règlement intérieur qui précisera ces statuts et leurs applications. Le règlement intérieur sera suivi à titre provisoire sous réserve de sa ratification au cours de la prochaine AG. Le règlement intérieur sera révisé chaque année par le conseil d’administration.</p> <p>La dernière version approuvée de règlement intérieur est datée du 11 avril 2024.”</p> <p>Vote: the modification was approved by 17 out of 21 votes (50%+1) (4 abstentions by those present)</p> <p>Vote : la modification est approuvée par 17 voix sur 21 (50%+1) (4 abstentions des membres présents)</p>	
10:50- 11:00	Coffee Break	
11:00 – 11:35	<p>MPE Annual Activity Report</p> <p>Co-CEO Kate Morgan began the presentation on the activity section, by providing an overview of MPE workstreams and staff and introduced Monica Racovita, MPE’s Access and Policy Manager who joined the team in January of 2024. Kate then moved on the Access and Policy workstreams and presented the main achievements in 2023 for the Atlas Access</p> <p>She then moved on to CEE Workgroup and the Ukrainian Workstream and explained that MPE has not been receiving any requests for help or support on the Ukrainian workstream for some time now so that project is slowly closing but MPE will always respond to any enquiries on an adhoc basis. On the Policy and Regulatory Kate went over MPE’s active involvement in EMA feedback. On the public-funded project ASCERTAIN, Kate explained that this is a project relevant to Access and is led by the University of Erasmus and MPE is one of the Consortium Members who is providing the patient perspective. As there were no questions from members, Kate gave the floor to Solène Clavreul, Head of Medical Education and Scientific Engagement to present the department’s achievements in 2023.</p> <p>Solène presented the European Myeloma and AL Amyloidosis Trial Navigator and announced that it would be launched this year (2024). She also explained that last year MPE recruited colleague Thisari Dharmapriya to help work on the navigator. On the AL Amyloidosis Workstream Solène explained that in 2023, among other publications, the research project to better understand patient perspectives on quality of life was also published. For the Medical Advisory Committee, she explained that there are currently 20 members, different medical experts who participate in many MPE events such as webinars and seminars as well as Masterclass and also provide feedback on topics that concern Myeloma and AL Amyloidosis.</p> <p>Member Rafi Amit asked where the various QnA and other guides are published to which Solène explained that everything is available on the MPE website but encouraged members to also contact her directly if they are looking for any report and she can provide it to them.</p> <p>On the public-funded projects, Solène announced that two projects (IMI Harmony and Horizon CARAMBA) ended and then presented the CERTAINTY project which started in 2023 and is focused CAR-T and its side-effects.</p> <p>Member Mira Armour wanted to ask about the public funded projects (Harmony and CARAMB) and how national organisations can be involved in them. Solène explained that it depends on the projects, level of involvement and what tasks they have been allocated. She further gave an example of involving patients in the CERTAINTY project. Mira also asked whether MPE – when recruiting patients for projects – sends this request to all member organisations and whether that can be done in the future.</p> <p>As there were no more questions from members, Solène gave the floor to Eilidh Duncan, Head of Patient Evidence, to present her department’s accomplishments in 2023.</p>	Ref. 4

	<p>Eilidh explained that the MRD project was published in 2023 and the results were presented at the IMS congress in Athens. She also moved on to the Needs of working age patients project which was also completed and was presented at Masterclass, journal articles and other conferences. On the shared decision-making project she explained that phase 1 was completed in collaboration with KU Leuven University. The treatment administration project was launched in 2023 as well and is nearing completion.</p> <p>On the public-funded project IMI SISAQOL, Eilidh explained how in 2023 MPE with the involvement of WECAN reviewed on recommendation statements, delivered a workshop at the WECAN Academy and disseminated a newsletter among other things. Eilidh explained that the current end date for this project is June 2025.</p> <p>Katie then presented Member and Patient Community Programmes which are led by Katie and Linda Christopher. Katie first presented the ADP programme accomplishments for 2023 and showcased the programme's success and attendance at EHA 2023. She also mentioned that this year the ADP programme received the highest number of applicants to date (15). On the Scholarship and Capacity Building Programme she explained that last year 10 scholarships were awarded on various topics and the grant recipients are presented at newsletters and quarterly meetings.</p> <p>For Masterclass 2023 Katie mentioned the event's success in Dubrovnik, with several videos posted on the MPE website which summarise the seminars. Feedback was provided after Masterclass which was taken into account when organising the 2024 event. Katie mentioned that MPE is looking forward to seeing everyone at Masterclass 2024 and announced that plans for Masterclass 2025 are already underway. On the member support workstream Katie then explained that two new projects were undertaken in 2023 for the support of patients in ways MPE had not been doing before. These were the quarterly meetings with members where experiences, best practices and dialogue between members are shared. The other programme was the European Young Myeloma Patients Support group which was spearheaded by ADP participants who wanted to support patients under 55 and have unaddressed needs.</p> <p>On European Myeloma Day, Katie mentioned that the event in September was successful with particular focus on early diagnosis and disseminating the early diagnosis pathway. Katie mentioned that new translations will be uploaded on the website. Member Dr. Otmar Pfaff wanted to express his appreciation for the work MPE is doing as it really helps patients and organisations across Europe.</p> <p>Lastly, Head of Communications Ana Vallejo presented the department updates, including the launch of the new MPE website in 2023 and the filming of conference speaker interviews on treatment updates and seminar summaries, MPE events and the support the department provides to all other departments by creating and publishing MPE materials for the website and social media.</p> <p>Member Snezana Doder asked how come MPE has no Instagram account. Ana explained that although many organisations have Instagram accounts, but as many patients are older, they are easier to access on other platforms (such as Facebook) but that MPE will create one if there is a need for it.</p> <p>With no further questions or comments from members, Ana closed the activity report section and gave the floor to Valentina.</p> <p><i>At 11:15 member Florin Rupper (MPS Myelom Patienten Schweiz) left the meeting.</i> <i>At 11:35 member Rick-Paul Hammik (Amyloidosis Foundation Netherlands) left the meeting.</i> <i>The meeting proceeded with the rest of the attendees, including 19 members with voting rights.</i></p>	
11:35– 12:10	Elections to MPE Board (election buddy vote) Valentina presented the elections to the MPE Board. She also gave a brief explanation of how the board works and the election process according to the constitution and explained	Ref. 5

<p>how the voting platform works. President Liselott thanked Riikka-Leena Manninen and Ananda Plate for their contribution to the board and their support.</p> <p>Valentina mentioned that this year:</p> <ul style="list-style-type: none"> two board members, Ananda Plate and Riikka-Leena Manninen are resigning from the board. Riikka-Leena Manninen has reached the maximum amount of terms as per the constitution, and Ananda Plate is stepping down voluntarily for personal reasons; and Barbara Leonardi, Diane Loening-Martens and Zvi Zilberman due to end of their first mandate. All three are running for re-election. <p>Then Valentina moved on to present the candidates this year, which included the three current board members who were standing for re-election for their second term, and three new candidates.</p> <p><u>The following candidates stood for election:</u></p> <ul style="list-style-type: none"> Barbara Leonardi, MPE board member and Carita Poland member, standing for re-election for her second term; Diane Loening-Martens, MPE board member and AMM Online Germany member, standing for re-election for her second term; Zvi Zilberman, MPE board member and AMEN Israel member, standing for re-election for his second term; Vincent Claus, Belgian MM patient and part of the core team of MPE's European Young Myeloma Patients Support Group; Snezana Doder, member of Udruženje obolelih od multiplog mijeloma Serbia; and Kristina Modic, member of Slovensko Združenje Bolnikov Z Limfomom In Levkemijo, L&L, Slovenia. <p>There were no questions or comments from members. The candidates were given a few minutes to present themselves and then the members were asked to use the link provided and access codes and proceed to the online ballot.</p> <p><u>Once the voting closed, Valentina presented the results:</u></p> <p>Barbara Leonardi: 13 out of 19 votes Diane Loening-Martens: 14 out of 19 votes Zvi Zilberman: 6 out of 19 votes: Vincent Claus: 11 out of 19 votes Snezana Doder: 15 out of 19 votes: Kristina Modic: 10 out of 19 votes</p> <p>All candidates have been elected to the Board of Directors as they successfully received at least 25% of the votes of members present or represented by proxy as per the constitution guidelines.</p> <p>The voting results were displayed to members as below:</p>		
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	<table border="1"> <tbody> <tr><td>Barbara Leonardi</td><td>13.00 votes</td></tr> <tr><td>Diane Loening-Martens</td><td>14.00 votes</td></tr> <tr><td>Zvi Zilberman</td><td>6.00 votes</td></tr> <tr><td>Vincent Claus</td><td>11.00 votes</td></tr> <tr><td>Snezana Doder</td><td>15.00 votes</td></tr> <tr><td>Kristina Modic</td><td>10.00 votes</td></tr> <tr><td colspan="2">Snezana Doder, Diane Loening-Martens, Barbara Leonardi, Vincent Claus, Kristina Modic, and Zvi Zilberman win.</td></tr> </tbody> </table> <p>   </p>	Barbara Leonardi	13.00 votes	Diane Loening-Martens	14.00 votes	Zvi Zilberman	6.00 votes	Vincent Claus	11.00 votes	Snezana Doder	15.00 votes	Kristina Modic	10.00 votes	Snezana Doder, Diane Loening-Martens, Barbara Leonardi, Vincent Claus, Kristina Modic, and Zvi Zilberman win.		
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12:10 – 12:30	<p>MPE Membership applications (vote)</p> <p>Katie Joyner moved on to the last topic on the agenda and explained the types of memberships at MPE and the criteria for application as well as the rights for full members and associate members.</p> <p>She then presented the first membership application of Kierunek Zdrowie, Poland and gave a brief overview of the organisation, including their activities, goals, founding year and number of members. Kate explained that Kierunek Zdrowie applied for full membership. There were no questions or comments from members. Valentina asked members to vote on the membership.</p> <p>Full Membership approved with 13 out of 21 votes (8 abstention from an attending members)</p> <p>Katie then proceeded to present the second application MPE received, Blodcancerforum (BCF), Sweden and also gave an overview of the organisation's goals, activities, founding year and member count. BCF also applied for full membership. Valentina then proceeded to ask members to vote:</p> <p>Full Membership approved with 14 out of 21 votes (7 abstentions from an attending members)</p> <p>The floor was then given to Kate Morgan who proceeded to present the third application MPE received, Italiana Pazienti Mieloma Multiplo, Italy and gave an overview of the organisation's details. This organisation applied for associate membership. Valentina then proceeded to ask members to vote:</p> <p>Associate Membership approved with 14 out of 22 votes (7 abstentions from an attending members)</p> <p>Lastly, Kate then presented the last application MPE received, Sanaa, Hungary. After providing all the organisational details, Katie explained that Sanaa applied for associate membership. Subsequently members were asked to vote.</p> <p>Associate Membership approved with 15 out of 21 votes (6 abstentions from an attending members)</p>	Ref. 6														

	Valentina then announced that all four organisations are now members of MPE, Kierunek Zdrowie, Poland and Blodcancerforum (BCF), Sweden as full members and Associazione Italiana Pazienti Mieloma Multiplo, Italy and Sanaa, Hungary as associate members.	
12:30	AOB / Closing of the Meeting Liselott thanked everyone for staying and participating in the General Meeting and engaging in discussions around everything that MPE is doing. Liselott also mentioned that she is looking forward to seeing everyone in Madrid for Masterclass and formally closed the meeting.	
Meeting Close		

Signature

Liselott Eriksson
 MPE President