

General Assembly 23rd March 2023 MINUTES OF THE MEETING

In attendance:

Attendee	Organisation
Liselott Eriksson (Chair)	MPE President + candidate for re-election (no vote)
Ron Dloomy	MPE (former) Board Member + representative of AMEN Israel (vote)
Ananda Plate	MPE Board member (Vice President)
Riikka-Leena Manninen	MPE Secretary and representative of Suomen Syöpäpotilaat Finland+ 1 proxy for: Swedish Blood Cancer Association Blodcancerförbundet (vote)
Zvika Zilberman	MPE Board Member
Barbara Leonardi	MPE Board Member (Treasurer) + representative Carita Poland (vote)
Diane Loening Martens	MPE Board member + representative of AMM Online Germany (vote)
Biljana Dodeva	MPE (former) Board member + representative for BORKA Macedonia (vote)
Katie Joyner	MPE (staff)
Kate Morgan	MPE (staff)
Solene Clavreul	MPE (staff)
Ana Vallejo	MPE (staff)
Valentina Christodoulidou	MPE (staff, minuting)
Linda Christopher	MPE (staff)
Silene ten Seldam	MPE (staff)
Reidar Nordby	Candidate for the Board (from the Norwegian Blood cancer association, just candidate, no vote)
Kristina Modic	Slovensko Združenje Bolnikov Z Limfomom In Levkemijo L&L (vote) + 1 proxy for: Mercy Bridge Russia (vote)
Dražen Vincek	HULL Croatia - Croatian Leukemia and Lymphoma Society (vote)
Lara Cunha	APCL - Associação Portuguesa Contra a Leucemia (vote)
Maria del Carmen Nadal	AMILO Spain (vote)
Yervand Hakobyan	AHA - Armenian Hematology Association / Հայկական Արիւնահարանային Անցիւղաղիւ (vote)
Edanur Tunç	KANKO/BIRKAN Turkey (vote)
John C Paulshus	Blodcancerförbundet Norway (vote)
Mira Armour	Mijelom CRO (vote)
Cvetka Flajs Cotic	Association of Patients with Blood Diseases Slovenia / Društvo bolnikov s krvnimi boleznimi Slovenije (Društvo BKB Slovenija) (vote)
Lidija Pecova	HEMA Macedonia (vote)
Fionnuala Duffy	Multiple Myeloma Ireland (vote)
Dr. Otmar Pfaff	LHRM / MM-RHEIN-MAIN (vote)
Ric-Paul Hammink	Amyloidosis Foundation Netherlands (SAN) (vote)
Viorica Cursaru	Myeloma Euronet Romania (MER) (vote)
Ronald Voorthuis	Stichting Hematon (vote)

Apologies:

Attendee	Organisation
Rafi Amit	Amyloidosis Israel (vote)
Elena Palma	AELCLES Spain (vote)
Alice Onderková	KPMM Czech Republic (associate member, no 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. Liselott then explained that she is also running for re-election at this AGM. Liselott lost connection and Katie Joyner took over and highlighted the affected members/patients in Turkey, Syria and Ukraine. A minute of silence was observed for all patients lost. Liselott resumed and talked through the agenda for the meeting and presented the new management team, MPE's new CEO-Director General Katie Joyner and co-CEO Kate Morgan, with the approval of the board. Liselott informed the AGM that on the 23rd of March 23 the Board delegated the day-to-day management of the association to Ms. Katie Joyner, Germany, as Directrice Générale (CEO) of the association in accordance with the article 10 of the statutes of the association.	
	Attendance and Apologies As noted above	
09:10- 09:20	Approval of the 2020-AGM minutes (vote) Riikka-Leena Manninen (Secretary) presented the minutes of 2022 General Assembly. 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): 18 of 22 votes. (4 abstentions from attending members).	Ref. 1
09:20 – 09:55	Activity Report Kate Morgan presented an overview of MPE's work programme and the activities in the past year in the Access and Policy workstream, including the Access Atlas, the CEE workgroup and the Ukraine Rapid Response Workstream. Solène Clavreul (Head of Medical Education and Scientific Engagement) presented updates on the MPE Clinical Trial Navigator, Amyloidosis workstream, scientific meetings, and two public funded projects (Caramba and IMI Harmony and T2EVOLVE). Question from member, John C Paulshus on CARAMBA project: John asked about a particular drug and its response rate. Solène replied that the trial is at the escalation phase at the moment with no current concerns but also that not all the results have been publicized at this instant. Question from member Otmar Pfaff on MAC (Medical Advisory Committee): Otmar asked who attends those meetings and if they are a good representation. Solène clarified that the Committee currently consists of 18 members, all listed publicly on the website. Solène further explained that the method for recruitment was to ensure we had both specialists for Myeloma and AL Amyloidosis from multiple countries as a good representation of MPE and where MPE has members. Solène also explained that if there is a suggestion from Otmar's own country, he can send them to Solène and she will reach out to them. Silene ten Seldam (Research Assistant) presented the Patient Evidence projects in collaboration with universities, industry partners and other patient organisations, including the project on shared decision making, research on patient and haematologist perspectives on minimal residual diseases and the publication on the advocacy report on myeloma diagnosis across Europe. Silene also presented the progress on the public funded project IMI SISAQOL. Katie Joyner, presented the 2022 major achievements from the department of Member and Patient Community Programmes, including the Advocate Development Programme (ADP) which in 2022 had the largest group to date and already kickstarted the 2023 Programme.	Ref. 2

	<p>She also mentioned the highlights of the Scholarship Programme, as well as the 2022 Masterclass which was the first in-person event since 2019 and Covid, and welcomed members to join the Masterclass 2023 in Croatia. Then she went through other department updates on quarterly member meetings, the community advisory board, the myeloma community taskforce, and MPE's first European Myeloma Day event in 2022.</p> <p>Ana Vallejo (Head of Communications) presented MPE's Communications achievements in 2022 in terms of filming, video-editing and graphic design, with over 50 published videos (Sisaqol, Masterclass, EHA, ASH etc) and the publication of MPE's Year in Review 2022. Ana also highlighted the increase of views, subscriptions and interaction with MPE's social media and informed members of MPE's brand new website.</p>	
09:55 – 10:30	<p>Financial Year Report (vote) <u>Closure of Financial Year 2022</u></p> <p>Katie Joyner provided an overview of the Financial Year 2022 and explained that the difference in the expected income at the AGM 2022 and at the end of the year was a result of staff hires and also asked members to note income received in 2022 but for projects allocated in 2023. Katie also presented further breakdown of the costs, expenses and income received, by programme, project and industry funders. There were no questions or comments from members. Valentina asked members to vote for the financial year 2022.</p> <p>Vote: Approved by 18 out of 22 (50%+1). (4 abstentions by those present)</p> <p><u>Budget 2023</u></p> <p>Katie Joyner then moved on to the proposed income for 2023 and explained the industry and public funded projects and the expected amounts per company and workstream. Katie also broke down the received income to this date and the next amounts expected. She further showed the planned costs and expenditures broken down in categories, departments and projects. Lastly, Katie presented the overview of expected income vs expected costs for 2023. There were no questions or comments from members. Valentina asked members to vote for MPE's budget 2023.</p> <p>Vote: Approved by 21 out of 22 (50%+1) (1 abstentions by those present)</p>	Ref 3
10:30-10:40	Coffee Break	
10:40 – 10:50	<p>MPE Committee Report</p> <p>Katie Joyner presented the Finance and Compensation Committee Report and the progress made in 2022, monitoring of MPE's finances, VAT filing and closing of fiscal year 2022.</p> <p>Ron Dloomy (board member-former Vice President) presented the updates of the Constitution and Nomination Committee for 2022, including the frequent meetings for the internal rules amendments, the appointment of board members and candidates for AGM 2023.</p> <p>Riikka-Leena Manninen (Board secretary) presented the board Development and Communications Committee, including the monitoring of newsletter, the organisation of board and AGM minutes and the preparation and organisation of the MPE board retreat that will also take place in Croatia.</p> <p>There were no questions or comments from members.</p>	Ref. 4
10:50–11:30	<p>Elections to MPE Board (election runner vote)</p> <p>Valentina (staff) presented the elections to the MPE Board. Valentina also gave a brief explanation of how the board works and the election process according to the constitution and explained how the voting platform works.</p> <p>Valentina mentioned that this year:</p> <ul style="list-style-type: none"> two board members, Ron Dloomy and Biljana Dodeva, are resigning from the board due to the end of their third mandate; and the second mandate of (president) Liselott Eriksson comes to an end. 	Ref. 5

The following candidates stood for election:

- Liselott Eriksson (MPE President), Swedish Blood Cancer Association, standing for re-election for her third and last term; and
- Reidar Nordby, Norwegian Blood Cancer Association, standing for his first mandate.

There were no questions or comments from members. The two candidates (Liselott Eriksson and Reidar Nordby) 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.

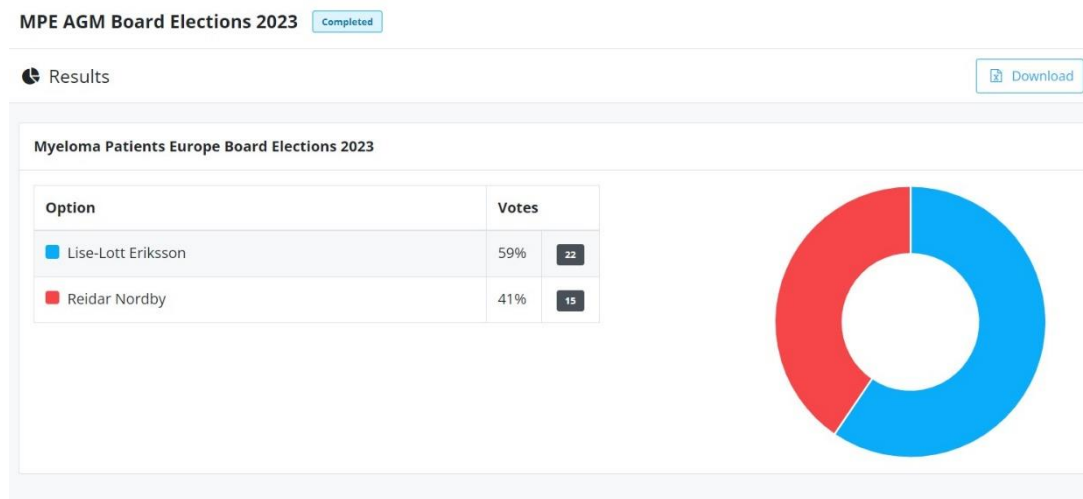
Once the voting closed, Valentina presented the results:

Liselott Eriksson: 22 out of 22 votes

Reidar Nordby: 15 out of 22 votes

Both candidates have been elected to the Board of Directors as they both successfully received at least 25% of the votes of members present or represented by proxy as per the constitution guidelines. Out of the 22 registered votes (including proxies) all 22 submitted their ballot.

The voting results were displayed to members as below:



11:30 –
11:40

MPE Membership applications (vote)

Kate Morgan presented the two membership applications MPE received. The first application is from a German support group, Myelom Online e.V. Kate gave a brief overview of Myelom Online e.V, including its founding year, number of members, activities and goals. Kate explained to members that Myelom Online e.V has applied for full membership. There were no questions or comments from members. Valentina asked members to vote on the membership of Myelom Online e.V

Membership approved with 18 out of 22 votes (4 abstention from an attending members)

Kate Morgan then proceeded to present the second application MPE received, Myeloma Canada, and gave a brief overview of the organisation, including their activities, goals, founding year and number of members. Kate explained to members that as per MPE’s Constitution, Myeloma Canada applied for associate membership, and also explained the difference between full and associate memberships. There were no questions or comments from members. Valentina asked members to vote on the membership of Myeloma Canada.

Membership approved with 18 out of 22 votes (4 abstentions from an attending members)

Valentina announced that both organisations are now members of MPE, Myelom Online as a full member and Myeloma Canada as an associate member.

Ref. 6

11:40 –

MPE Internal Rules Amendment

Ref. 7

12:20	<p>Zvika Zilberman (board member) presented the internal rules amendments and gave a brief overview of all the proposed amendments, including the appointment, resignation, dismissal and re-appointment of honorary officer positions (president, vice president, treasurer and secretary), the election process, and the increase of credit card expenditure from 10.000 euros to 15.000 euros. Zvika also explained that if these amendments passed, the latest version of the internal rules would also be updated to this date of the AGM, March 23rd, 2023, and be noted down in the Constitution.</p> <p>Member Viorica Cursaru asked whether the amendment concerning the dismissal and re-appointment of honorary officers is a reach of power by the MPE Board as the appointment of board members can only be done at an AGM by the attending members voting. Viorica asked Zvika if this amendment would overpass the General Assembly. Member Mira Armour also expressed the same enquiry and hesitation.</p> <p>Zvika explained that it would not, as the amendment does not concern the election into the Board, which is indeed only possible with the vote of members during a General Assembly, but rather the appointment of positions (president, vice-president, secretary and treasurer). Zvika further explained that the appointment of positions takes place via vote within the board as in line with MPE constitution and internal rules, and that this amendment only better refines the process. Zvika also mentioned that the amendments were reviewed by MPE's legal advisors. Reidar also commented that the term honorary can be used differently, either meaning the appointment in a position without pay or the appointment to a board with an honorary position, allowing access to conferences but not access to the board, which is elected at a General Assembly as well. Member Fionnuala Duffy also added that the term "honorary" officers might be misleading as well as the phrasing alluded to the AGM elections. Katie Joyner agreed and further reiterated that the amendment only concerns the refining of the appointment of the four positions within the board and not the general elections held at the AGM, nor any removal/addition of powers. Mira commented that the amendment is now clear. Zvika went through the amendments one by one and explained them in detail. Viorica asked if the normal term in the board is two years or three. Zvika confirmed that it is two years with the possibility of re-election for two more terms, making it a maximum of 6 years.</p> <p>Valentina asked whether the voting should happen separately on the amendment for the appointment of board positions (also addressed as honorary officers) and the credit card limit as it concerns two separate things in the internal rules. Zvika confirmed the voting should be separate for these two issues. Viorica reiterated her hesitation for the first set of amendments.</p> <p>Valentina asked members to vote on the first set of amendments (in sections 1 and sections 4 of the internal rules) on the appointment of board positions (honorary officers).</p> <p>Internal rules amendments on sections 1 and 4 approved with 16 out of 22 votes (50%+1) (6 abstentions from an attending members).</p> <p>Valentina then presented the other amendment to the members in detail, concerning the increase of the section 5 amendment on credit card limit from 10.000 euros to 15.000 euros and the reasoning behind it. Valentina asked members to vote on this amendment for the credit card limit increase.</p> <p>Internal rules amendment on section 5 approved with 19 out of 22 votes (50%+1) (3 abstentions from an attending members).</p> <p>Valentina confirmed that all the Internal Rules amendments have passed and confirmed that now the new approved version of the internal rules is dated 23 March 2023 with the vote of the AGM and the new date will also be registered in the Constitution in accordance with MPE rules.</p> <p>Valentina thanked everyone for voting and participating in all the elections and votes and gave the floor back to Liselott.</p>	
12:20 –	AOB / Closing of the Meeting	

12:30	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 Croatia and formally closed the meeting.	
Meeting Close		

Signatures

Liselott Eriksson
MPE President

Riikka-Leena Manninen
MPE Secretary