

General Assembly 29th March 2022 MINUTES OF THE MEETING

In attendance:

Attendee	Organisation
Hans Scheurer (Chair)	MPE President + 2 proxy votes for: -Society for Assistance to Patients with Oncohaematological Diseases Russia -Multiples Myelom Selbsthilfe Oesterreich
Ron Dloomy	MPE Vice President
Johannes Brenner	MPE Treasurer
Riikka-Leena Manninen	MPE Secretary + candidate for re-election
Kristina Modic	MPE Board Member + Slovensko Združenje Bolnikov Z Limfomom In Levkemijo L&L (vote)
Biljana Doveva	MPE Board Member + Borka Macedonia (vote)
Roman Slomkowski	MPE Board member + 1 proxy vote: -Carita Foundation Poland
Lise Lott Eriksson	MPE Board member + Blodcancerförbundet Sweden (vote) + 1 proxy vote for: - Suomen Syöpäpotilaat
Katie Joyner	MPE (staff)
Kate Morgan	MPE (staff)
Solene Clavreul	MPE (staff)
Ana Vallejo	MPE (staff)
Valentina Christodoulidou	MPE (staff, minuting)
Ananda Plate	MPE (former CEO) + candidate for the Board
Zvika Zilberman	AMEN Israel + candidate for the Board
Barbara Leonardi	CARITA Poland + candidate for the Board
Diane Loening-Martens	AMM Online + candidate for the Board
Jurgen Martens	AMM Online (vote)
Maria del Carmen Nadal	AMILO (vote)
Yervand Hakobyan	AHA - Armenian Hematology Association / Հայկական Արիւնահեմատոլոգիական Աղիւնահեմատոլոգիական (vote)
Mirjana Babamova	Association for help and support of patients and their caregivers with hematological diseases (HEMA) / ХЕМА-Здружение за помош и поддршка на пациенти и нивни негуватели со хематолошки заболувања (vote)
Elena Palma	Agrupación Española de Entidades de Lucha contra la Leucemia y Enfermedades de la Sangre (AELCLES) (vote)
Mira Armour	Mijelom CRO (vote)
John Paulshus	Blodkreft Foreningen (Blood Cancer Association) (vote)
Meinhardt Jacobsen	Dansk Myelomatose Forening (Danish Multiple Myeloma Association) (vote)
Florin Rupper	MPS Myelom Patienten Schweiz (vote)
Dr. Otmar Pfaff	LHRM / MM-RHEIN-MAIN (vote)
Lucita Nitu	SOS Mielom (vote)
Varda Shoham	AMEN- The Israeli Association of Myeloma Patients (vote)
Ronald Voorthuis	Stichting Hematon (vote)
Ira Laketic-Ljubojevic	Myeloma UK (vote)

Apologies:

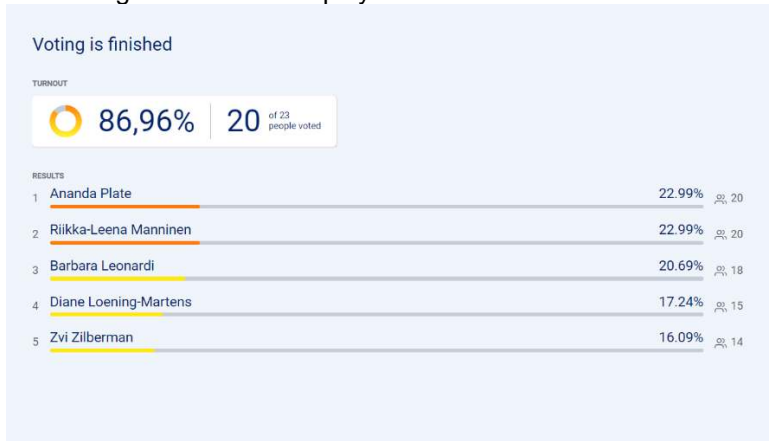
Attendee	Organisation
Rafi Amit	Amyloidosis Israel (vote)
Geraldine Walpole	Multiple Myeloma Ireland (vote)

Minutes of the Meeting:

15:15 – 15:30	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.	
15:30 – 15:40	Welcome Hans Scheurer welcomed all attendees to the meeting. Hans then talked through the agenda for the meeting and also presented MPE's new CEO, Denis Henrard and announced that he will officially join MPE on May 1 st , 2022. Hans further explained that all MPE members received the agenda as well as the entire presentation contents and reports 4 weeks prior to the AGM, however they can request the presentation again after the AGM is over.	
	Attendance and Apologies As noted above	
15:40 – 15:50	Approval of the 2020-AGM minutes (vote) Hans Scheurer presented the minutes. Riikka-Leena Manninen (Secretary) was present during the General Assembly; however, she was unable to present due to health reasons. The minutes of the 2021 General Assembly meeting were presented and members were asked to indicate if they had comments or objections. No comments from members. Minutes are approved by the majority (50% + 1): 15 of 23 votes (6 abstentions by attending members + 2 members who registered but could not attend)	Ref. 1
15:50 – 16:25	Activity Report Hans Scheurer introduced Katie Joyner, MPE's COO, who presented an overview of MPE's activities in the past year and the Capacity Building and Advocacy report. Kate Morgan (Head of Access and Policy) presented the update on the MPE Atlas and CEE workgroup as well as Patient Evidence and IMI SISAQOL updates. Solene Clavreul (Head of Medical Education and Scientific Engagement) presented updates on MPE Amyloidosis work, scientific meetings, public funding projects (Caramba and IMI Harmony) as well as the Clinical Trial Navigator. Hans explained that the members will have time for questions at the end of the Activity Report section. Katie explained that the members can also receive the presentation after the assembly. Katie Joyner, who is also head of Capacity Building and Advocacy, presented the organisations' progress with the Advocate Development Programme, Community Advisory Boards, the Taskforce and the Masterclass, which will take place this July (1-3 rd) 2022. Katie also presented updates on the Scholarship and Capacity Building Programme, Covid Workstream and other educational resources as well as MPE's Year of Action and European Myeloma Day. Ana Vallejo (Communications Manager) presented MPE's plans for the new website and the expected launch as well as disseminated social media achievements such as views, followers and posts. Discussion Question from candidate Zvika Zilberman: How many countries are participating in the CARAMBA programme? Solene Clavreul replied that four countries are involved: France, Italy, Germany and Spain and are in the escalation dose phase of the trial. She also explained that this year MPE will publish CAR-T related information and other reports for myeloma patients. Question from Mira Armour: Is MPE having any activities during March as it is Myeloma activity month and International Myeloma Day. Mira has remarked that Bloodcancer awareness month September is the starting point of MPE's Year of Action, while many organizations are having activities on March 30, which is appointed by IMF as International Myeloma Day. She would like to know if MPE is also doing anything and to ask the MPE	Ref. 2

	<p>Board to consider doing so next year. Hans has explained that the Board is aware of this, and there is a difference between what the MPE starting point of the year of action in September, and Myeloma Awareness Day in March are two separate initiatives with different aims, that should not be seen as similar: the year of action is a policy focus campaign for a whole year for the MPE community. It is not a replacement of Myeloma Awareness Day. Katie Joyner stated that MPE is supporting Int. Myeloma Day and has released a survey this month, is collaborating with pharmaceutical companies that are doing work related to Int. Myeloma Day and is keen to support the members with any activities related to this.</p> <p>Action: MPE continues to support members with International Myeloma Day activities, besides the Year of Action campaign activities.</p> <p>Question from Dr Otmar Pfaff: Otmar has thanked MPE for the Activity Report and for all the great work they have done. The question relates to the clinical trial navigator and how MPE will ensure that all trials are included in the navigator and that the information will be read in a patient-friendly manner, so that they can recommend it to all the patients in full confidence. Solene Clavreul has replied that this is indeed challenging but the aim is to use all of the resources available (official national and international registries patient organization resources, and more) to ensure all the clinical trials are included in the platform and to make sure all information is up to date, as well as stay in touch with hospitals and companies to ensure all data is correct. Otmar has expressed interest in the platform, and Solene has announced that the platform will be launched this year 2022, with members having early access to provide feedback before the official public launch.</p> <p>Hans has closed the Activity Section and has explained that the next topic on the agenda is the Financial Year Report 2021, which will then be followed by the coffee break and then proceeding with the Budget 2022.</p>	
16:25 – 16:40	<p>Financial Year Report 2021 (vote)</p> <p>Johannes Brenner provided an overview of the Financial Year 2021 and explained that there was 155.000 EUR which MPE received in 2021 but for activities allocated in 2022 and that will be reflected throughout the presentation, which explains the difference between income received and income spent. Johannes provided detailed explained about income sources, cost breakdown as well as the cost breakdown per programs and activities. There were no comments or questions from members. Members were asked to vote.</p> <p>Vote: Approved by 18 out of 23 (3 abstentions by those present + 2 abstentions from the members who registered but could not attend AGM)</p>	Ref 3
16:40- 16:50	Coffee Break	
16:50 - 17:10	<p>Budget 2022 (vote)</p> <p>Johannes Brenner resumed the presentation and presented the MPE Budget 2022. Members were invited to comment or ask questions. No comments/questions. Members were asked to vote:</p> <p>Vote: Approved by 20 out of 23 (1 abstention by those present + 2 abstentions from the members who registered but could not attend AGM)</p>	Ref. 3
17:10	<p>Finance Committee</p> <p>Johannes Brenner presented the Committee's actions during 2021. No comments or questions from members.</p>	Ref. 4
	<p>Board Development and Communication Committee</p> <p>Riikka-Leena Manninen chairs this Committee and was present during the AGM but due to health reasons, Hans Scheurer presented the Board Development and Communication Committee Report updates. Hans has explained that the Committee has been preparing for a Board meeting to help its transitioning as there are many changes happening this year (new CEO, outgoing and in coming Board members). No comments from members.</p>	Ref. 4

	Constitution Committee and Nomination Committee Ron Dloomy presented the Committee Report and explained that in 2021 the Committee prepared the Constitution Amendments which the members will vote later on during the AGM and has explained that each amendment will be voted separately. The Committee also prepared the election process for the new Board members and explained that candidates will have time to present themselves later in the AGM. No comments from members.	Ref. 4
17:20 – 17:50	Constitution Amendments (vote) Ron Dloomy presented the constitution procedure and steps that MPE took along with its lawyers to ensure that all amendments are in line with the law. The amendments were sent to members 4 weeks prior to the AGM in order to have time to read and prepare. Ron explained that each amendment will now be presented and voted separately, starting with the compulsory amendments and then the non-compulsory. Compulsory amendments in: -Article 1: Vote: Approved by 18 out of 23 (3 abstentions from attending members +2 abstentions from the members who registered but could not attend AGM) -Article 8: Vote: Approved by 18 out of 23 (3 abstentions from attending members +2 abstentions from the members who registered but could not attend AGM) -Article 12: Vote: Approved by 20 out of 23 (1 abstention from an attending member +2 abstentions from the members who registered but could not attend AGM) -Article 16: Vote: Approved by 20 out of 23 (1 abstention from an attending member +2 abstentions from the members who registered but could not attend AGM) -Article 17: Vote: Approved by 20 out of 23 (1 abstention from an attending member +2 abstentions from the members who registered but could not attend AGM) Non-compulsory amendments in: Overall changes suggested to implement throughout the document for consistency (capital letters, errors and GM instead of AGM): Vote: Approved by 20 out of 23 (1 abstention from an attending member + 2 abstentions from the members who registered but could not attend AGM) -Article 2: Vote: Approved by 20 out of 23 (1 abstention from an attending member +2 abstentions from the members who registered but could not attend AGM) -Article 6: Vote: Approved by 20 out of 23 (1 abstention from an attending member +2 abstentions from the members who registered but could not attend AGM) -Article 7: Vote: Approved by 20 out of 23 (1 abstention from an attending member +2 abstentions from the members who registered but could not attend AGM) -Article 8: Vote: Approved by 19 out of 23 (2 abstentions from attending members + 2 abstentions from the members who registered but could not attend AGM) -Article 9: Vote: Approved by 20 out of 23 (1 abstention from an attending member + 2 abstentions from the members who registered but could not attend AGM) -Article 10: Vote: Approved by 20 out of 23 (1 abstention from an attending member + 2 abstentions from the members who registered but could not attend AGM) -Article 13: Vote: Approved by 20 out of 23 (1 abstention from an attending member + 2 abstentions from the members who registered but could not attend AGM)	Ref. 5
17:50 – 18:10	Internal Rules Amendments Ron Dloomy presented the Internal Rules Amendments. The amendments were sent to members 4 weeks prior to the AGM in order to have time to read and prepare. Ron explained that each amendment will now be presented and voted separately, starting with the compulsory amendments and then the non-compulsory. Compulsory amendments: -Change of executive office address -Data protection law -Closing line before moving on to appendixes which is date of approval of Internal Rules Non-compulsory amendments: -Overall changes suggested to implement throughout the document for consistency (errors, symbols, capital letters, AGM to GM) -Amendments and revision of financial policies All amendments to the internal rules were approved by 20 out of 23 (1 abstention)	Ref. 5

	from an attending member + 2 abstentions from the members who registered but could not attend the AGM)	
18:10 – 18:50	<p>Elections (vote)</p> <p>Hans Scheurer explained to members that this year 5 board members are standing down from the Board. Hans Scheurer, Johannes Brenner and Kristina Modic due to reaching the maximum number of terms (3) and Roman Slomkowski and Nikita E.Shklovskiy-Kordi (2) are stepping down for personal reasons. The Board has accepted Roman and Nikita's decision to step down and their Board terms officially ended as of today, 29 March 2022.</p> <p>The following candidates stood for election:</p> <ul style="list-style-type: none"> • Ananda Plate (former CEO of MPE) • Riikka-Leena Manninen (Suomen Syöpäpotilaat Finland, stood for re-election) • Barbara Leonardi (Carita Foundation Poland) • Diane Loening-Martens (AMM Online Germany) • Zvika (Zvi) Zilberman (AMEN, Israel) <p>Hans Scheurer explained that according to the MPE constitution, the Board cannot have two members from the same organization, which would be the case if Ron Dloomy and Zvika Zilberman are both on the Board as they both represent AMEN. As such, Hans has asked Ron Dloomy to finish his current board term and remain for one year maximum as an independent person, not representing AMEN. This decision was made as the Board will undergo many changes this year and retaining stability and experience was deemed necessary. He asked the members to express their agreements in their vote for Zvika as a board candidate (if he would not be elected, Ron would stay as representative of AMEN, if Zvika would be elected Ron would finish his term the last year as independent board member).</p> <p>Each applicant was given 5 minutes to present themselves. It was explained that only full-members and proxies can vote. Members and proxies provided their vote following the presentation of candidates Each candidate required at least 25% of the votes of members present or represented by proxy. 20 people out of 23 voted (2 abstentions from people who registered but could not attend the meeting and 1 abstention due to technical issues). The vote is secret (anonymous).</p> <p>Once voting closed, Hans Scheurer announced to the meeting that all the candidates have been elected to the MPE Board:</p> <ul style="list-style-type: none"> • Ananda Plate (former CEO of MPE) 20 out of 23 votes • Riikka-Leena Manninen (Suomen Syöpäpotilaat Finland, stood for re-election) 20 out of 23 votes • Barbara Leonardi (Carita Foundation Poland) 18 out of 23 votes • Diane Loening-Martens (AMM Online Germany) 15 out of 23 votes • Zvika (Zvi) Zilberman (AMEN, Israel) 14 out of 23 votes <p>The voting results were displayed to members as below:</p> 	Ref. 6
18:50 –	AOB / Closing of the Meeting	

19:00	<p>Hans Scheurer has invited all the members to ask any questions or make any comments prior to officially ending the meeting. Members did not have questions or comments.</p> <p>Hans gave a short presentation into MPE's plans for 2022 and invited all members to attend the MPE Masterclass in July 1-3rd in Amsterdam. This will be the first face-to-face meeting since Covid-19 restrictions and will present to the members the new CEO, the new Board and the new president and treasurer (who will be chosen in the first board meeting after the general Assembly – in the bridging period Hans Scheurer will remain being the president until the new president is chosen by the new board).</p> <p>Hans thanked everyone for attending and participating in this year's General Assembly and for supporting MPE.</p>	
Meeting Close		

Signature