

**General Assembly 8<sup>th</sup> March 2020  
MINUTES OF THE MEETING**

## In attendance:

Member	Representative
Stichting Hematon	Hans Scheurer (Chair)
Myeloma Patients Europe (MPE)	Julia Tolley (Minutes)
Myeloma Patients Europe (MPE)	Ananda Plate (CEO)
Myeloma Patients Europe (MPE)	Ana Vallejo
Myeloma Patients Europe (MPE)	Ingrid Jenisch
Myelom Deutschland e.V	Jürgen Martens
CARITA	Roman Slomkowski
Norwegian Blood Cancer Association	John C Paulshus
DMF	Jørgen Kristensen
Association of patients with haematological malignancies	Katarina Fedorova
Slovensko Združenje Bolnikov Z Limfomom In Levkemijo L&L	Kristina Modic
Inter-regional public organization for patients with hematological diseases, Russia	Nikita Shklovskiy-Kordi
Amen Israeli Myeloma Patient Foundation (AMEN)	Ron Dloomy
Myeloma Euronet Romania (MER)	Viorica Cursaru
-	Johannes Brenner
MOHA– Foundation for Hungarian Oncohaematological Patients / Magyar Onkohematológiai Betegekért Alapítvány	Agnes Magyar
Blood Cancer Association Sweden /Blodcancerförbundet Sweden	Lise-Iott Eriksson
Association of Cancer Patients in Europe / Suomen syöpöpotilaat-myelooma potilasverkosto	Riikka-Leena Manninen
SOS mielom	Lucica Nitu
Myeloma UK (MUK)	Ira Laketic-Ljubojevic
BORKA	Biba Dodeva
AMILO	Maria del Carmen Nadal
AHA - Armenian Hematology Association / Հայկազգային Արյունաբանական Անոնհայիա	Yervnad Hakobyan
Association for help and support of patients and their caregivers with hematological diseases (HEMA) / XEMA-Здружение за помош и поддршка на пациенти и нивни негуватели со хематолошки заболувања	Miriana Babamova
HULL Croatia - Croatian leukemia and lymphoma Society / Hrvatska udruga leukemija i limfomi	Dražen Vincek
KANKO/BIRKAN	Edanur Aydin
Stichting Amyloidose Nederland (SAN)	Richard Hammink

## Apologies:

Member Organisation:	Apologies from:
Multiples Myelom Selbsthilfe Oesterreich (MMSOe)	Sonja Pearsall
Myeloma Group Rhine Main - Leukemia Help Rhine Main -LHRM	Anita Waldmann
Myeloma Group Rhine Main - Leukemia Help Rhine Main -LHRM	Lara Kuerzer
Kraujas	Aistė Strelčiūnė
Associação Portuguesa Contra a Leucemia (APCL)	Lara Cunha
Foundation for the Advancement of Bone Marrow Transplantation Switzerland (SFK)	Candy Heberlein
Amyloidosis Israel	Daniel Drimer
Hematon	Ronald Voorhuis

## Minutes of the Meeting:

09:00 – 09:10	<p><b>Welcome</b> Hans Scheurer welcomed all attendees to the meeting. Remembered board member Lisa Kotschi (26<sup>th</sup> Nov 1948 – 21<sup>st</sup> Nov 2019), all attendees observed a minute's silence in remembrance of Lisa.</p>	
	<p><b>Attendance and Apologies</b>  As noted above</p>	
09:10 - 09:20	<p><b>Approval of the 2019-AGM minutes (vote)</b></p>	Ref. 1
	<p>Rikka-Leena Manninen (Secretary) outlined items of the minutes, one-by-one: <b>Minutes are approved unanimously.</b></p>	
09:20 – 09:50	<p><b>Activity Report</b></p>	Ref. 2
	<p><b>Programmes, projects and initiatives</b></p> <p>Ananda Plate (AP) introduced the MPE Activity Report 2019 and subsequently provided an overview of all key programmes. Slides circulated to members following the AGM.</p> <p>AP provided an update on:</p> <ul style="list-style-type: none"> <li>• MPE programmes and initiatives: <ul style="list-style-type: none"> <li>• MPE Access Atlas</li> <li>• Advocate Development Programme</li> <li>• Scholarship and Capacity Building Programme</li> <li>• Myeloma-CAB</li> <li>• Evidence Generation Unit</li> <li>• AL amyloidosis work</li> <li>• Educational resources</li> </ul> </li> <li>• MPE external impact: <ul style="list-style-type: none"> <li>• Advocacy and community collaboration</li> <li>• Legal agreements project</li> <li>• Stakeholder meetings and conference attendance</li> </ul> </li> <li>• Communication: <ul style="list-style-type: none"> <li>• Webinars and educational clips</li> <li>• ASH communications</li> <li>• Website</li> <li>• Social media</li> <li>• Newsletters</li> </ul> </li> <li>• European Commission projects <ul style="list-style-type: none"> <li>• Horizon2020 MMPredict</li> <li>• Horizon2020 CARAMBA</li> <li>• IMI HARMONY</li> <li>• IMI SISAQoL</li> </ul> </li> </ul> <p>Kristina Modic and Biljana Dodeva provided an update on</p> <ul style="list-style-type: none"> <li>• Central and Eastern Europe Workgroup</li> </ul> <p>No questions from members</p>	
09:50 – 11:00	<p><b>Board Matters</b></p>	
	<p><b>Committee Report</b></p>	Ref. 3
	<p><b>Constitution Committee and Nomination Committee – Ron Dloomy (RD).</b></p> <p>Internal Rules Amendment (Ref. 4): Both required and suggested amendments to the Internal Rules have been identified by the Committee and will be presented to the AGM as</p>	

	<p>part of this meeting.</p> <p>Change of Constitution (Ref. 6): Both mandatory and recommended changes to the Constitution (due to changes in Belgian legislation) have been identified and will be presented for approval as part of this meeting.</p> <p>Board Elections (Ref. 7): The Committee has been preparing the Board Elections which will take place as part of this meeting.</p> <ul style="list-style-type: none"> <li>• 6 open seats on the Board</li> <li>• The following members stand for re-election:             <ul style="list-style-type: none"> <li>• Johannes Brenner (elected 2016 – candidate for 3<sup>rd</sup> term)</li> <li>• Riikka-Leena Manninen (elected 2018 – candidate for 2<sup>nd</sup> term)</li> <li>• Kristina Modic (elected 2016 – candidate for 3<sup>rd</sup> term)</li> <li>• Hans Scheurer (elected 2016 – candidate for 3<sup>rd</sup> term)</li> <li>• Roman Slomkowski (elected 2018 – candidate for 2<sup>nd</sup> term)</li> </ul> </li> </ul>	
	<p><b>Finance Committee – Johannes Brenner (JB)</b></p>	
	<p>JB updated on the progress made during the reporting period, including:</p> <ul style="list-style-type: none"> <li>• Closure of Financial Year 2018 – approved by AGM 2019</li> <li>• Finalisation of Financial Year 2019, to be approved at AGM 2020 (Ref. 5)</li> <li>• Oversight Budget 2020, to be approved at AGM 2020 (Ref. 5)</li> <li>• Filing of quarterly VAT return within deadline</li> <li>• Finalisation of salary scale for MPE staff (applicable from January 2020)</li> <li>• Ensurance of monthly accounts and bookkeeping</li> </ul> <p>No questions from members.</p>	
	<p><b>Board Development and Communication Committee – Riikka-Leena Manninen (R-LM)</b></p>	
	<p>R-LM provided an update on progress of the Committee during 2019/20 to date:</p> <ul style="list-style-type: none"> <li>• Drafting of:             <ul style="list-style-type: none"> <li>• Internal Rules Appendix 1: Declaration of Interest (approved by Board)</li> <li>• Internal Rules Appendix 2: Confidentiality Agreement (approved by Board)</li> <li>• Internal Rules Appendix 3: Nomination Form (approved by Board)</li> </ul> </li> <li>• Amendment of Internal Rules (approved by Board)</li> <li>• Organisation of the Board Retreat, 28 Jan 2020</li> </ul> <p>No questions from members.</p>	
	<p><b>Internal Rules Amendment (vote)</b></p>	<p>Ref. 4</p>
	<p>R-LM presented members with the changes requiring approval, and members are asked to vote on these as follows:</p> <p><b>Article 4 – Election of Board Members</b>  <b>4.4.1 – Candidates standing for election</b></p> <ul style="list-style-type: none"> <li>• The General Assembly, rather than the Board, will now have the rights to:             <ul style="list-style-type: none"> <li>• Decide on whether a potential candidate standing for election may be presented or not in the event that they are not able to attend the election in person</li> <li>• Decide on whether that candidate may request the General Assembly to accept a replacement or alternative means of presentation (ie. Video)</li> </ul> </li> </ul> <p><b>Article 5 – MPE's Financial Policy</b>  <b>Section – Guidelines on reimbursement of expenses</b></p> <ul style="list-style-type: none"> <li>• Change of address to reflect new Head Office address (Myeloma Patients Europe; Avenue Louise 143; 1050; Brussels; Belgium)</li> </ul> <p><b>Article 7 – MPE Conflict of Interest Policy</b>  <b>Section – 8. Interpretation of Article 8 of the MPE Constitution</b></p>	

	<ul style="list-style-type: none"> <li>• The agenda (ordre du jour) referred to in Art. 8 "notification" refers to the PRELIMINARY agenda. It needs to be attached to the formal official call to the AGM which must be sent to all members at least four weeks prior to the meeting.</li> <li>• Members, The Board of Directors or the CEO can submit additional topics to the agenda that they wish to discuss and vote on during the AGM.</li> <li>• The FINAL agenda (referred to in Art. 8 "ordre du jour") – potentially including additional topics – needs to be sent fifteen days prior to the AGM. In accordance with the current constitution ("However, a vote may not be taken on any item which was not included in the agenda that was sent to members fifteen days before the meeting" / "Toutefois, il ne peut être procédé à un vote sur un point qui n'était pas inscrit à l'ordre du jour qui a été envoyé aux membres quinze jours avant la reunion"), all points included therein will be discussed and - if needed - voted on.</li> <li>• AGM background documents shall be sent to all members four weeks in advance, unless these items correspond to agenda items added up to fifteen days before the AGM, in which case, the background documents can be sent no later than fifteen days before the AGM. written candidacy required for members</li> </ul> <p>AP asked that members note the amendment to Internal Rule regarding Interpretation of Article 8 is a temporary amendment, which will only be in force until the Constitutional Changes are approved by the notary, since the discrepancy identified as part of article 8 will then no longer exist.</p> <p>Discussion</p> <ul style="list-style-type: none"> <li>• Vicrica Cursaru commended the suggested amendment of Article 4, section 4.4.1 and welcomed the changes which would then give the General Assembly more authority.</li> </ul> <p><b>Vote: Approved by 26 (unanimously)</b></p>	
	Finance Report	Ref. 5
	<p>Closure of Financial Year 2019 (vote) - JB</p> <p>JB provided an overview of the Financial Year 2019:</p> <ul style="list-style-type: none"> <li>• Income: some deviation in income due to reductions in funding received from industry – JB highlighted companies where negative results of clinical trials have led to general reduced expenditure. However, actual income from industry/other funding was higher than planned (€703.102 planned / €711.602 actual)</li> <li>• Cost vs. Plan: the end-of-year deviation from plan (+ €108.752) represents a more prudent approach to both planning and expenditure, and a focus on financial sustainability.</li> <li>• Income vs. Cost: a remaining balance of €190.842 was presented to members.</li> <li>• Reserve: A Reserve of €10.000 was managed during FY2019.</li> </ul> <p>No questions</p> <p><b>Vote: Approved by 26 (unanimously)</b></p> <p>Budget 2019 (vote) - JB</p> <ul style="list-style-type: none"> <li>• JB set out the prospective income and expenditure for 2020.</li> <li>• Planned cost presented to members. Staff and other costs identified for programmes, other projects and initiatives, public-funded projects and management, administration and communication respectively.</li> <li>• Income vs costs – balance of €17.000</li> <li>• Janssen funding – JB acknowledged a small risk around this being incoming however also recognised the high likelihood that this will be received.</li> <li>• JB outlined to members that diversification of funding sources, and less reliance on funding from the Pharmaceutical Industry, is a key priority for MPE in 2020. Any suggestions from members on how to progress this are welcome.</li> </ul>	



	<p><b>Comments:</b> Jørgen Kristensen sought clarification on the acronym 'CAB'. AP clarified that this stood for 'Community Advisory Board' and that a significant proportion of both income and cost, from industry and non-industry funding, was allocated to this programme of work.</p> <p><b>Vote: approved by 26 (unanimously)</b></p> <p><b>MPE Reserve (vote) – JB</b></p> <ul style="list-style-type: none"> <li>• The Board are requested to approve: <ul style="list-style-type: none"> <li>• The increase of the MPE Reserve from €205.000 to €325.000</li> <li>• The Transfer of the remaining €70.642 to the Budget 2020 (including to cover costs of maternity leave)</li> </ul> </li> <li>• JB outlined the rationale behind the request for the Board to approve the increase of the MPE Reserve: <ul style="list-style-type: none"> <li>• To ensure the sustainability of the organization and ongoing projects</li> <li>• To enable MPE to continue operating for approximately 6 months without income</li> </ul> </li> </ul> <p><b>Vote: approved by 26 (unanimously)</b></p>	
10:45-11:15	Coffee break	
11:15-12:15	Board Matters (continuation)	
	Change of Constitution - RD	Ref. 6
	RD presented the background information and context of the required and suggested changes to the Constitution. He reminded members that changes must be made before January 2023, and that the voting on changes to the constitution and subsequent notarial act will be postponed to 2021.	
	<b>MPE Membership Applications (vote)</b>	Ref. 7
	<p>HS presented the two applications for membership:</p> <ul style="list-style-type: none"> <li>• Association of Patients with Blood Diseases – DBKBS (Slovenia)</li> <li>• Association of Myeloma in Iceland – Perluvnir (Iceland)</li> </ul> <p>HS informed members that there had been five applications for membership, however three had not been presented as the applications were not approved in the prior consideration process. AP advised that one applicant, AELCLES, a Spanish organization, had been unsuccessful in their membership application but were receiving support from MPE in terms of developing their organization and would likely re-apply for membership in 2021.</p> <p><b>Comments:</b> Agnes requested an overview of the organisations. HS advised that all information had been provided to members are part of the information pack sent (pack reference 8).</p> <p>Members were asked to vote on acceptance of the applications.</p> <p>Votes for the approval of new members: In favour – 24 Against – 1 Abstention – 1</p> <p><b>Vote: approved by 24 - passed</b></p>	
12:15-12:45	<b>Elections to the Board (vote)</b>	Ref. 8
	<p>The voting of the Board was moderated by Ron Dloomy.</p> <p>The following candidates stood for election:</p> <ul style="list-style-type: none"> <li>• Hans Scheurer, Hematon, the Netherlands</li> <li>• Kristina Modic, Slovensko Združenje Bolnikov Z Limfomom In Levkemijo, L&amp;L,</li> </ul>	

	<p>Slovenia</p> <ul style="list-style-type: none"> <li>• Riikka-Leena Manninen, Suomen Syöpäpotilaat, Finland</li> <li>• Johannes Brenner, Independent Patient, Germany</li> <li>• Roman Slomkowski, Fundacja Carita, Poland</li> <li>• Nikita E. Shklovskiy-Kordi, Inter-regional public organization for patients with hematological diseases, Russia</li> </ul> <p>Each applicant was given 5 minutes to present themselves. Members provided their vote following the presentation of candidates.</p> <p>Once voting closed, RD announced to the meeting that all standing candidates had received the vote majority required to be accepted onto the MPE Board.</p> <p>The new composition of the Board was:</p> <ul style="list-style-type: none"> <li>• Hans Scheurer (President)</li> <li>• Ron Dloomy (Vice-President)</li> <li>• Riikka-Leena Manninen (Secretary)</li> <li>• Johannes Brenner</li> <li>• Lise-lott Eriksson</li> <li>• Biljana Dodeva</li> <li>• Kristina Modic</li> <li>• Roman Slomkowski</li> <li>• Nikita E. Shklovskiy-Kordi</li> </ul> <p>Members welcomed all new and re-elected members of the Board.</p> <p>Jürgen Martens asked whether standing for Board membership was possible as an individual or only as a representative of an organization. AP advised that she would discuss this outside of the meeting with Jürgen.</p>	
<p>12:45</p>	<p><b>Closing of the meeting and Plans for 2020</b></p>	
	<p>Hans Scheurer presented MPE's 2020 Plans, noting a strong focus on capturing data on patient perspective, furthering existing strong coalitions, and enforcing patient advocacy. Hans highlighted to members that MPE will celebrate its 10-year anniversary in 2021 and that plans for a celebration were already underway.</p> <p>Hans thanked members for their commitment and flexibility which enabled the AGM to take place virtually instead of face-to-face.</p> <p>Comments: Jørgen Kristensen thanked members and staff for arranging the virtual AGM meeting.</p> <p style="text-align: center;"><b>Meeting Close</b></p>	