

# Myeloma Patients Europe (MPE)

## **Minutes AGM 2019** – Ref. 1 –

**Annual General Meeting**  
08.03.2020

**General Assembly 17 March 2019, Munich (Germany)**  
**MINUTES**

<b>8:30-8:40</b>	<b>Welcome &amp; apologies</b>	
	<p>MPE member from Switzerland is the only member not present:</p> <ul style="list-style-type: none"> <li>• Florian Rupper Myelom Kontaktgruppe Schweiz (MKgS)</li> <li>• 25 members present, so maximum number of votes is 25</li> </ul> <p>General Assembly opened by Hans Scheurer (HS) HS: Explained the General Assembly Function and Paperwork</p>	
<b>8:40-8:50</b>	<b>Approval of the 2018-AGM minutes (vote)</b>	<b>Ref. 1</b>
	<p>Riikka-Leena Manninen (RLM) introduced as the new secretary, in charge of signing off minutes. RLM outlined items of the minutes, one-by-one: <b>Minutes are approved by unanimity.</b></p>	
<b>8:50-9:30</b>	<b>Activity Report</b>	<b>Ref. 2</b>
	<p><b>Programmes, projects and initiatives</b></p> <p>Ananda Plate (AP) provided introduction to MPE Activity Report 2018. AP and Kate Morgan (KM) 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>• Advocate Development Programme</li> <li>• Scholarship and Capacity Building Programme</li> <li>• Annual General Meeting</li> <li>• Reasonable Agreements between advocates and pharmaceutical companies</li> <li>• Hem-CAB</li> <li>• Myeloma-CAB</li> <li>• EMA patient preference study</li> <li>• Amgen Patient Preferences Survey</li> <li>• Plans for the coming year</li> </ul> <p>KM gave an update on:</p> <ul style="list-style-type: none"> <li>• MPE Access Atlas</li> <li>• Horizon2020 projects</li> <li>• IMI2 Harmony</li> <li>• Amgen patient preference project</li> </ul>	
	<p><b>Workgroups &amp; work streams</b></p> <p><b>Central and Eastern Europe (CEE) Access Workgroup – Kristina Modic (KMc) and Biba Dodeva (BD)</b></p> <ul style="list-style-type: none"> <li>• KMc and BD launched the new Central and Eastern European (CEE) Working Group, under the umbrella of the MPE Access Atlas</li> <li>• KMc outlined that MPE has been doing a lot of work with individual members on access issues</li> <li>• Unmet need for coordinated action at a European level on key themes: medicines access, off-patent medicines not reaching patients, late diagnosis, clinical trials not launching and workforce planning</li> <li>• Focus on patient advocates to strengthen them and develop their capacities, to help members with what they are facing nationally</li> <li>• Capacity building, information sharing and problem solving</li> <li>• Aim to build the CEE working group – identifying key issues, share best practice and stakeholders, promote campaigns and problems, two-way communication between members</li> </ul>	

	<ul style="list-style-type: none"> <li>• Kristina outlined the steering group has been formed – this has been developed and inviting all CEE</li> <li>• MPE will email all CEE members asking them to outline their interest in the group. MPE will hold a virtual meeting (all members to create the working group)</li> </ul> <p><b>AL amyloidosis group – Daniel Drimer (DD)</b></p> <ul style="list-style-type: none"> <li>• DD outlined the development of an AL amyloidosis steering group for MPE, designed to expand the remit of MPE under AL amyloidosis (particularly given the constitutional change)</li> <li>• 10-15% patients develop AL amyloidosis – very important for MPE to develop a group</li> <li>• Developing a strategy for MPE on AL amyloidosis</li> <li>• Developing links with the Amyloidosis Alliance and collaboration around strategy alliances (working on division of task)</li> </ul>	
<b>9:30-10:45</b>	<b>Board Matters</b>	
	<b>Committee Report</b>	<b>Ref. 3</b>
	<p><b>Constitution Committee and Nomination Committee – Ron Dloomy (RD).</b></p> <p>Internal Rules Amendment (Ref 4): Last year approved Internal Rules for MPE, but after approval of the new MPE Constitution, the MPE Constitution Committee advised the Board to make changes to internal rules document. Changes to the Internal Rules have been made and approved by the Board.</p>	
	<b>Finance Committee</b>	
	<p>Johannes Brenner reported good progress of the Committee, including:</p> <ul style="list-style-type: none"> <li>• insurance for MPE, to ensure we are all covered as part of the activity</li> <li>• progress reports on finances since 2017</li> <li>• audit of FY2017</li> <li>• putting in place a new reporting structure for MPE accounts, to enable comparison with previous periods</li> </ul> <p>No questions from members.</p> <p>Ananda Plate asked for comments on how to improve paperwork. Anita Waldmann outlined an idea to ensure the comparative accounts between different years are set out, in order to agree more transparency. AP agreed this was a good suggestion, which will be taken into account next year.</p> <p>Anita also outlined her ideas for raising awareness of MPE with doctors, including a stand at EBMT.</p>	
	<b>Internal Rules Amendment (vote)</b>	<b>Ref. 4</b>
	<p>Based on the overview of the Constitution and Nominating Committee, the AGM was requested by Ron Dloomy to vote on the following amendments to the Internal Rules:</p> <p><b>Article 4.4</b></p> <p><b>4.4.1 – Candidates standing for election</b></p> <ul style="list-style-type: none"> <li>• Written candidacy required for members</li> <li>• Board to have a final decision on whether a candidacy may be presented</li> <li>• Candidate may ask the Board to accept a presentation replacement or alternative means – only appropriate if MPE board agrees</li> </ul> <p><b>Discussion</b></p>	

	<ul style="list-style-type: none"> <li>• Jacob Hygen (JH), Norwegian member queried about the situation about why the Board would have a say on attendance by a board candidate if they did not attend. Ron outlined that if someone doesn't attend then the Board would want to review whether someone is an appropriate candidate.</li> <li>• HS outlined that the intention is not to dictate to people who they can and cannot vote for. Board thinks it is very important for people to take their role seriously and for members to have a clear presented candidate to vote on</li> <li>• Roman: Main rule is election by members but someone needs a final say on these matters if someone is not able to attend (if the situation arises)</li> <li>• Danish member, Jorgen Kristensen made commented that it is not up to the Board to rule on this, if someone is not able to attend</li> <li>• Discussion around alternative options</li> <li>• JH: not power on the board, at AGM level. Too arbitrary</li> <li>• AP: Outlined situations where people did not attend as not a priority. Perhaps need clarification around this or we should just skip these points, as they were not crucial</li> <li>• It was decided not to vote on the last two points</li> </ul> <p><b>VOTE: 24 yes</b></p> <p><b>4.4.2:</b> 25% members present or represented by proxy. Minor consensus needs to be represented by proxy</p> <p><b>VOTE: 23 yes</b></p>	
	<b>Finance Report</b>	<b>Ref. 5</b>
	<p><b>Closure of Financial Year 2018 (vote)</b></p> <p>Income: budget for 515,000 euros and income in-line with this. Slight difference in sources of income (public and industry). Industry commitments depend on success of medicines coming to market. Prothena and MSD are a good example of when a medicine doesn't make it to- or is taken off the market. Administrative costs slightly higher than expected, but discrepancy small. MPE did not manage to put a reserve in place this year. This should be added next year. Slight shortfall – expenditure of 10,000 EUR more than budgeted. Small number in the context. No questions</p> <p><b>Vote: Approved by 24 (one member had left)</b></p> <p><b>Budget 2019</b></p> <ul style="list-style-type: none"> <li>• Johannes set out the prospective income and expenditure for 2019</li> <li>• Planned cost – balanced budget in relation to cost</li> <li>• Income vs costs – balanced of 17,000</li> <li>• Daniel Drimer, outlined that Caelum Bioscience – potential funding. AP: outlined Takeda, Janssen, GSK are also on the agenda. DD: smaller company maybe likely to get funding to us asap</li> <li>• BMS and Celgene merger has been taken into account. AP: have a commitment of both companies to still have the same commitment.</li> <li>• This year it is fine but will continue to ensure we prepare for the merger</li> </ul> <p><b>Vote: approved by 25 votes</b></p>	
<b>10:45-11:15</b>	<b>Coffee break</b>	
<b>11:15-12:15</b>	<b>Board Matters (continuation)</b>	
	<b>Strategic Plan 2019 – 2024 (vote)</b>	<b>Ref. 6</b>
	<p>HS outlined draft of Strategic Plan has been circulated and approved. See circulated slides. Outlined how we developed the strategic areas for MPE and the key</p>	

	<p>issues that underpinned the strategic planning progress and the key steps taken to get to the signed off strategic plan (which had been circulated). Defined MPEs unique value and key objectives for the MPE community. Outlined our work with related diseases and why we are involved in AL amyloidosis. There were no questions or comments about this. Pictures of board, staff and all members taken. Then last vote on strategic planning. Hans and Biba will sing a song together during the next AGM. Biba and Ira from MPE left at 12.30am, before vote on strategic plan.</p> <p><b>Vote: 22 votes in favour of the strategic plan 2019-2024</b></p>	
	<b>Elections to the Board (vote)</b>	<b>Ref. 7</b>
	<p>There were 4 Board Candidates and 3 open positions.</p> <p>HS outlined the voting procedure and how the voting operation will be taken forward (including Proxy vote and 25% for votes to become a board member). Attendees can choose up to 3 candidates.</p> <p>Roman Slomkowski outlined vote counting (25% to become a board member). RD and BD stand for re-election. Two new candidates – Daniel Drimer (Israel) and Lise-lott Eriksson (Sweden)</p> <ul style="list-style-type: none"> <li>• RD presented himself (bio included in paperwork)</li> <li>• BB presents herself for re-election (bio included in paper work)</li> <li>• LLE presented herself to board (bio included in paper work)</li> <li>• DD presented himself to the board (bio included in paper work)</li> </ul> <p>Roman Slomkowski outlined voting procedures. Each member received a new voting form. One voting form for each organisation. Need to put a “cross” by the names they wish to choose (up to 3 members). Members we are asked to confirm who from each organisation participated in voting.</p> <p>The MPE Voting Commission was established. This consisted of Ana V and Ingrid from MPE and two representatives of MPE members (Ira Laketic – Ljubojevic, UK and Sonia Pearsall, Austria). The election was overseen by Hans and Roman from MPE board.</p> <p><b>RD: 21 votes</b> <b>BD: 20 votes</b> <b>DD: 10 votes</b> <b>LLE: 19 votes</b></p> <p><b>RD, BD and DD elected, with over 25% of votes.</b></p>	
<b>12:15-12:45</b>	<b>MPE Membership Applications (vote)</b>	<b>Ref. 8</b>
	<p>The approval of new members was moderated by Lisa Kotschi.</p> <p><b>Vote for Hema, Macedonia – 24 votes in favour APPROVED</b> <b>HULL Croatia – 24 votes in favour APPROVED</b> <b>AMILO Spain – 24 votes in favour APPROVED</b> <b>Amyloidose Netherlands – 24 in favour APPROVED</b></p> <p>Note for vote counting: Slovakian member left early. (11.44am)</p>	
<b>12:45</b>	<b>Closing of the meeting</b>	
	Hans Scheurer closed the meeting. He thanked everyone for attending and wished safe travels	