

**General Assembly 22nd March 2021
MINUTES OF THE MEETING
4pm – 7pm CET teleconference**

In attendance:

Attendee	Organisation
Hans Scheurer (Chair)	Stichting Hematon
Julia Tolley (Minutes)	MPE
Ananda Plate	CEO, MPE
Ana Vallejo	MPE
Kate Morgan	MPE
Ronald Voorthuis	Hematon
John C Paulshus	Norwegian Blood Cancer Association
Aistė Vadlūgaitė Strelčiūnė	Kraujas
Sonja Pearsall	Multiples Myelom Selbsthilfe Oesterreich (MMSOe)
Kristina Modic	Slovensko Združenje Bolnikov Z Limfomom In Levkemijo L&L
Nikita Shklovskiy-Kordi	Inter-regional public organization for patients with hematological diseases, Russia
Ron Dloomy	Amen Israeli Myeloma Patient Foundation (AMEN)
Viorica Cursaru	Myeloma Euronet Romania (MER)
Johannes Brenner	-
Lise-Iott Eriksson	Blood Cancer Association Sweden /Blodcancerförbundet Sweden
Riikka-Leena Manninen	Association of Cancer Patients in Europe / Suomen syöpäpotilait-myelooma potilasverkosto
Ira Laketic-Ljubojevic	Myeloma UK (MUK)
Biba Dodeva	BORKA
Maria del Carmen Nadal	AMILO
Yervand Hakobyan	AHA - Armenian Hematology Association / Հայկական Արյունաբանական Անոցաղիւ
Miriana 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
Oksana Chirun	Inter-regional public organization for patients with hematological diseases, Russia
Mira Armour	Mijelom CRO
Johann Creemers	AMM-Online
Camelia Soceanu	S.O.S. Mielom Romania
Meinhardt Jacobsen	Dansk Myelomatose Forening (Danish Multiple Myeloma Association)
Richard Hammink	Stichting Amyloidose Nederland
Dr. Otmar Pfaff	LHRM / MM-RHEIN-MAIN
Carlos Costa	APCL
Varda Shoham	AMEN- The Israeli Association of Myeloma Patients


Apologies:

Attendee	Organisation
Daniel Drimer	Amyloidosis Israel
Roman Slomkowski	CARITA
Drazen Vincek	HULL Croatia - Croatian leukemia and lymphoma Society / Hrvatska udruga leukemija i limfomi

Minutes of the Meeting:

15:30 – 16:00	Technical Support for Virtual AGM Members joined the call. Julia Tolley and Ana Vallejo provided technical support to ensure all attendees were able to fully participate in the meeting as required.	
16:00 – 16:15	Welcome Hans Scheurer welcomed all attendees to the meeting and gave apologies from members unable to attend. Hans then talked through the agenda for the meeting. All attendees observed a minute's silence in remembrance of Anna Rovira and Candy Heberlein, and for remembrance of those lost within the community.	
	Attendance and Apologies As noted above	
16:15 – 16:30	Approval of the 2020-AGM minutes (vote) Riikka-Leena Manninen (Secretary) presented the minutes of the 2020 General Assembly meeting and asked members to indicate if they had comments or objections. No comments from members. Minutes are approved by the majority – 20 of 22 votes (2 abstentions by members who were not at the 2020 meeting)	Ref. 1
15:30 – 17:00	Activity Report Ananda Plate presented. Kristina Modic and Biba Dodeva presented the update on the MPE Atlas CEE workgroup. Discussion Question from Dr. Otmar Pfaff, LHRM, regarding CEE Workgroup: Dr. Pfaff is interested to understand who is writing and reviewing the report on the minimum standards of infrastructure for clinical trials, overseen by the CEE workgroup. This question is asked in the context of the new regulations in Europe around clinical trials – Dr. Pfaff has experience in working in regulatory affairs within the pharmaceutical industry and offers some support here if this is useful. Biba Dodeva confirmed that two vendors have been sub-contracted to provide report-writing and data analysis, however workgroup members are very welcome to be part of the review process, and there is significant benefit to involvement of members who offer opportunity to learn from best practice and experiences in Western Europe. Action: MPE to follow up with Dr. Pfaff following the meeting. Comment from Viorica Cursaru – thanks to the initiative of Ananda, and the subsequent work carried out by the staff, MPE has ended up with a powerful tool for advocacy which maps the status of health in individual countries. However, having been involved in the establishment of the CEE workgroup, Viorica was under the impression that the group would not only work to understand issues at a national level, but also look to make recommendations at a European level regarding access, and influence the European Commission in order to support mandatory standards across Europe in relation to access. Question – there have clearly been concentrated efforts to understand the access landscape across Europe and per country. Have motions been submitted to the European Commission to raise awareness of the Atlas and the data contained within it? Hans Scheurer advised that MPE are looking at ways to highlight this, especially within the context of the EU Beating Cancer Plan, and the areas of focus contained within this. Hans highlighted that MPE work closely with WECAN around the EU Beating Cancer Plan in order to identify opportunities to highlight inequities such as this for myeloma patients across Europe, and that the Atlas, and the data within it, will contribute to that. Ananda Plate added that MPE focus has been on strengthening and growing the organisation in order to best support and serve its members, and Viorica's point about moving into policy, and working more visibly with the European Commission, is a logical next step and one that is currently being considered in the business plan for 2021. Comment from Dr. Otmar Pfaff – as a first-time participant in the meeting, Dr. Pfaff	Ref. 2

	congratulated MPE on the impressive work presented in the Activity Update.	
17:00 – 17:10	Coffee Break	
17:10	Board Matters	
17:10 – 17:20	Committee Report	Ref. 3
	<p>Constitution Committee and Nomination Committee</p> <p>Ron Dloomy presented. No comments from members.</p>	
	<p>Board Development and Communication Committee</p> <p>Riikka-Leena Manninen presented. No comments from members.</p>	
	<p>Finance Committee</p> <p>Johannes Brenner presented. No comments from members.</p>	
17:20 – 17:40	<p>Finance Report</p> <p>Closure of Financial Year 2020 (vote) - JB</p> <p>Johannes Brenner provided an overview of the Financial Year 2020.</p> <p>Discussion:</p> <p>Mira Amour requested clarification of what admin and management costs included. Johannes Brenner clarified that this pertains to costs around:</p> <ul style="list-style-type: none"> - office and associated overheads such as office space, hardware, software, phone, virtual platforms, email accounts etc. - Board management and General Assembly - staff management e.g., Line management <p>Ananda Plate confirmed that the biggest proportion of these budgeted costs are staff costs dedicated to planning member events, and general admin such as line management, staff meetings</p> <p>Vote: Approved by 22 (unanimously)</p> <p>Budget 2021 (vote)</p> <p>Johannes Brenner presented the Budget 2021. No comments from members.</p> <p>Vote: approved by 22 (unanimously)</p>	Ref. 4
17:40 – 18:10	<p>Elections to the MPE Board (vote)</p> <p>The voting of the Board was moderated by Hans Scheurer.</p> <p>The following candidates stood for election:</p> <ul style="list-style-type: none"> • Biba Dodeva (BORKA for each new day, Macedonia) • Lise-Lott Eriksson (Blodkraft, Sweden) • Ron Dloomy (AMEN, Israel) • Viorica Cursaru (Myeloma Euronet Romania, Romania) <p>Each applicant was given 5 minutes to present themselves. Members provided their vote following the presentation of candidates.</p>	Ref. 5

	<p>Once voting closed, Hans Scheurer announced to the meeting that the following candidates have been elected to the MPE Board:</p> <ul style="list-style-type: none"> • Biba Dodeva (BORKA for each new day, Macedonia) • Lise-Lott Eriksson (Blodkraft, Sweden) • Ron Dloomy (AMEN, Israel) <p>The voting results were displayed to members as below:</p>  <p>Members welcomed all re-elected members of the Board.</p>	
<p>18:10 – 18:30</p>	<p>Membership Applications (vote)</p> <p>Hans Scheurer presented the three membership applications for consideration. Members were asked to vote on each application individually following presentation.</p> <p>The three members presented for approval were:</p> <p>AELCLES, Spain (application for full membership) Multiple Myeloma Ireland, Ireland (application for full membership) Independent Advocate – Lara Said, Malta (application for associate membership)</p> <p>Discussion</p> <p>Question – Meinhardt Jacobssen asked for clarification on the requirements for application for full membership and whether this can be made by an individual or whether it must be by a patient organisation. Hans Scheurer clarified that the criteria for full membership includes having an organisation with a constitution in place and registration as a patient organisation in the respective country. Single patient advocates are not able to apply for full membership.</p> <p>Question – Sonja Pearsall asked for clarification around the nonprofit status of AELCLES in Spain as the slide presented stated that the organisation has been a nonprofit organisation since 2009 and Sonja requested clarification of whether the organisation was for-profit before that date. Hans Scheurer confirmed that this was the date of establishment for the organisation and that it was not a for-profit organisation before that date.</p> <p>Vote: All applications were approved unanimously by members.</p>	<p>Ref. 6</p>
<p>18:30 – 19:00</p>	<p>Plans for 2021</p> <p>Hans Scheurer presented plans for 2021 to members.</p>	

	<p>Ananda Plate presented the plans around the Clinical Trial Engine and invited members to engage in the planning process to ensure the tool and project is of optimal value to members.</p> <p>Question – Meinhardt Jacobsen – reflected on learnings from MPE Advocate Development Programme around difficulty of accessing outcomes / results of clinical trials which are not made available through public databases and asked whether this was being addressed through this project.</p> <p>Ananda Plate invited Meinhardt to be part of the ongoing discussions around development of the Clinical Trial Engine to ensure that points such as this are considered during planning stages.</p> <p>Comment – Sonja Pearsall – suggested to Meinhardt Jacobsen that the Clinical Trial Engine could be a discussion topic for the ADP in the coming months.</p> <p>Question – Mira Armour – asked whether there is a programme for access to myeloma drugs across Europe, not just clinical trials, and whether there is a need to understand this in the context of being as useful as possible to patients. Mira reflected that it is a problem to recruit patients in clinical trials outside of their country of residence and that there is an additional problem which must be considered in parallel around access to drugs, especially those considered “basic” drugs and whether these are accessible to all patients in Europe.</p> <p>Hans Scheurer agreed that this is a critical question and one that remains prominent in MPE’s objectives and work programme, especially seen in the Access programme (in the Atlas and CEE workgroup). Hans agreed that the clinical trial engine is one element of a wider strategy to address disparities in access to drugs, therapies and trials across Europe and</p> <p>Biba Dodeva added that there was an intention that the position paper of the CEE workgroup around minimum infrastructure required for clinical trials to take place in CEE would be provided to patients and patient advocates in a format that would act as a tool to drive forward progress in ensuring patients access to trials across borders and over all European countries.</p> <p>Ananda Plate agreed that a strategy around access is not straightforward and therefore requires a complex, multi-faceted approach which includes consideration of all aspects which promote better accessibility for patients in Europe. Ananda welcomed feedback and input from members on ensuring that the clinical trial engine project, as with all the Access programme, develops into the best possible tool for patients and advocates.</p> <p>Mira Armour agreed that this project is very much intertwined with the wider access programme, and that was a need to continue efforts in ensuring access for patients across Europe to drugs such as Bortezomib, Lenalidomide and Thalidomide and she advised that she hoped to see MPE continuing efforts through programmes such as this to gain access to not just trials but these essential drugs for all patients across Europe.</p> <p>Hans Scheurer thanked Mira for her feedback and assured Mira that programmes such as this do not replace MPE’s support to individual members to advocate for access to drugs at a national level, but they add to the support and tools that are provided to members. Ananda Plate suggested that Mira would be extremely welcome to join the CEE Workgroup and her contribution there would be well-received.</p> <p>Comment – Viorica Cursaru – suggested the addition of an additional objective – that MPE would advocate for the expansion of existing clinical trials in Europe to include Eastern European Countries. Viorica suggested that this would be beneficial to the workstream and the patient community, especially considering the influence that MPE have with the pharmaceutical industry.</p>	
19:00	<p>AOB and Closing the Meeting</p> <p>Ananda Plate presented the European Myeloma Patient Advocacy Initiative.</p> <p>Question – Mira Armour – requested clarification on why September was chosen for the potential date of the initiative. Hans Scheurer clarified that March and September were considered and the final date would be decided through the committee. Hans invited Mira to</p>	

	<p>join the committee where her input would be most welcome.</p> <p>Hans Scheurer presented “looking back” through 2020, and an update on plans for celebration of MPE’s 10th Anniversary. Members were notified that they would shortly receive an invitation to take part in a celebratory video for MPE’s anniversary and Hans invited all members to take part.</p> <p>Hans ended the meeting by thanking members for their time and participation in this year’s General Assembly.</p>	
<p>Meeting Close</p>		