



Internal rules

Myeloma Patients
Europe (MPE)

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1. MPE board

1.1 Introduction

It is acknowledged that a high performing board is likely to make a significant contribution to the overall effectiveness and success of the organisation. Therefore, MPE is committed to investing in supporting and developing its board. To this end, all new board members will be given a board pack which includes information that will help orientate them to the board's role and responsibilities and MPE's governance. The pack will be updated annually and distributed to all board members.

1.2 The board's role

The board has the role to:

- Ensure MPE has the appropriate policies in place to govern and manage its people and its business
- Develop strategies that ensure that MPE delivers on its vision and mission
- Take legal responsibilities for the organisation by ensuring appropriate systems are in place to protect and grow the organisation in accordance with the strategy
- Board members are also expected to act as ambassadors for MPE as well as represent the interests of MPE and not their home organisation

1.3 The board's responsibilities

The general responsibilities of the Board are to:

- Ensure that MPE is meeting its mission, objectives and purposes as stated in its constitution
- Promote and uphold MPE's Values: Transparency, Passion for Patients, Excellence in Delivering Exceptional Results and Trustworthiness
- Ensure that the organisation complies with legal obligations under the Belgian Code of Companies and Associations
- Ensure the organisation develops effectively and is fit to practice in accordance with MPE's constitution
- Ensure the financial viability of the organisation, through ensuring the necessary funding is acquired at all times and managed to best effect
- Approve the budget, before it is approved by the GM, and ensure funding is used according to the agreed objectives
- Provide accountability to MPE's members through ensuring the accounts are kept as required by law and operating good practice
- Ensure prudent risk assessment is conducted and regularly reviewed, and if applicable, insurance policies are obtained
- Ensure that legally binding undertakings are entered into carefully and correctly

- Elect board officers from among its members
- Ensure that property and other resources that are owned or leased by the organisation are properly maintained and managed, and in accordance with all relevant legal requirements, such as Health and Safety
- Maintain effective working practices as a board, between board members and between the board and MPE's CEO
- Induct any new board members and to continually assess board performance
- Recruit, support and dismiss the CEO, and ensure there is a suitable succession plan
- Ensure the board and executive office work in effective partnership
- Provide oversight of the CEO and monitor the performance of the CEO against agreed criteria

The general responsibilities of individual board members are to:

- Attend all board meetings and committee meetings where required
- Review agenda and supporting materials prior to board meetings
- Be aware of the organisation's vision, mission, core values and policies and keep up to date about MPE's projects and programmes
- Keep up to date about scientific advances and issues within the myeloma setting
- Be aware of the board's fiduciary responsibilities and be accountable for MPE's financial health
- Promote the work of MPE where relevant and act as an ambassador for the organisation within their own network and at relevant events
- Volunteer to take on special assignments where appropriate
- Recommend possible nominees to the board who can make significant contributions to the work of the board and the organisation
- Adhere to generally accepted standards of how a board member should behave
- Use the official email address provided to each board member by MPE for any matters related to MPE
- Update the executive office about any changes in contact details

1.4 Honorary officers

The Board has 4 honorary officers roles: president, vice- president, treasurer, and secretary. Honorary officers are appointed for a term of two years unless their board term ends before. Honorary officers may resign, be dismissed, or re-appointed by the board.

The following rules apply for their appointment:

- Only current board members may submit their candidacy to become honorary officer.
- Honorary officers shall be appointed during any board meeting before the next AGM
- The president shall inform the board at least four weeks before the appointment of honorary officers
- Candidates shall inform the current president of their wish to become honorary officers no later than 3 weeks prior to the date of appointment.

This clause can be overruled, in exceptional circumstances, by a majority vote of the MPE Board members.

1.4.1 Honorary officers' responsibilities

The president

The president is responsible for:

- Maintaining regular and ad hoc contact with the CEO
- Ensuring the effective operation of the board, including chairing meetings
- Managing any board conflicts to ensure the best interests of MPE are being served
- Being a spokesperson for the organisation if required
- Liaising with the secretary regarding board meetings and setting the agenda
- Ensuring that all actions are recorded, delegated and completed
- Providing employee support and as the final arbiter in any disciplinary or grievance matters with an employee

Vice-president

The vice-president is responsible for:

- Presiding at meetings whenever the president is unable to attend the meeting
- Taking over if the office of the president is vacated for any reason
- Attending meetings on behalf of the president when required

Treasurer

The treasurer is responsible for:

- Overseeing the financial affairs of MPE. The CEO is responsible for the day to day financial operations (e.g. banking)
- Performing financial duties as outlined here and in accordance with the financial policy (Section 5)
- Ensuring that processes are in place to:
 - Produce the annual budget
 - Control income and expenditure and monitor cash flow
 - Provide financial reports to the board as appropriate
 - Oversee the production of annual accounts to be approved by the board
- Co-ordinating the audit of accounts should this be necessary
- Ensuring compliance with relevant NGO and financial legislation

Secretary

The secretary is responsible for:

- Overseeing the administrative affairs of MPE. The CEO is responsible for the day to day administrative operations.
- Ensuring that appropriate administrative processes are in place and obligations of MPE are kept.
- Ensuring that all the organisation's records are kept on file and up to date
- Ensuring that official notification of election to office or appointment as a committee member are sent to new appointees and that they have the necessary documents and training to fulfil their duties
- Ensuring that minutes are accurate and circulated on time and are signed in the correct manner
- Ensuring that official documents of the organisation are kept up to date and include changes that have been made through the amendment process
- Ensuring that members receive notice of AGM and EGM meetings within the timeframe laid down in the

Constitution

- Ensuring that the necessary documents and supplies are brought to each meeting

1.5 Obligations of new board members

It is expected that within six weeks of their election all new board members will:

- Complete the board on-boarding training
- Submit a declaration of interest form (Appendix 1)
- Submit a short biography for the website
- Submit a photograph
- Submit the information required by the Moniteur Belge (copy of passport, contact details, etc)

1.6 Board operations

Board values

The following values underpin the way the board works:

- Respect for the organisation, the management, the employees and other members of the board
- Respect the principles of good governance
- Openness in board discussions
- Confidentiality for all matters relating to board discussions. Every board member must sign a confidentiality agreement (Appendix 2)

Board meetings

- Board meetings are held at least four times per year either face to face or virtually. Board members are required to attend these meetings. In exceptional circumstances, board members may join a face to face meeting via teleconference.
- In addition, board retreats may be conducted for the purpose of developing a strategic plan or to discuss a significant project plan. Non-board members may also attend the retreat if they have been expressly invited to do so by the board
- Board meetings may be held if half or more of the board members are present
- Board meetings are attended by the CEO. The CEO has a supportive role, and can be asked to give input and advice on the points of the agenda by the board.
- Exceptionally, board meetings may be attended by a different member of staff (in addition or as a replacement of the CEO) if asked to do so by the president. The CEO may also be asked by the board not to attend a certain board meeting or part of a board meeting
- At its discretion the board may decide to invite other non-board members to participate in a board meeting.
- Board meetings follow a formal structure and process determined by the agenda. Supporting papers will be provided at least one week in advance and board members are required to digest the information and contribute to discussions at the meetings.
- Minutes are produced for each meeting, approved by the president and circulated within two weeks of the

meeting.

Managing conflicts of interest during board meetings

- Board members should declare their interest at the earliest opportunity.
- If the board member fails to declare a conflict of interest that is known to the MPE CEO, president or MPE staff member, the CEO will declare that interest.

- If a conflict of interest (real or apparent) is declared at the start or during a meeting, this will be recorded in the Minutes. The report will record:
 - The nature and extent of the conflict;
 - An outline of the discussion;
 - The actions taken to manage the conflict.
- The board member concerned may not vote on matters affecting their own interests. They may participate in the discussion but not to the decision-making process.
- The meeting chair must ensure that there is a quorum of the remaining members present.
- Further details about conflicts of interest are covered in the MPE Conflict of Interest policy.

Board performance

The board will complete a self-assessment questionnaire on its performance at least annually. Under-performance within the board will be addressed in a timely manner

1.7 Liability insurance

- MPE is to hold an insurance policy (“D&O insurance”) to cover board members and the CEO for liability in the performance of their functions

1.8 Honorary officers’ end of term, hand-over and appointment process

An honorary officer whose term ends (president, vice-president, treasurer, and secretary) is expected to contribute to a smooth handover to their successor, with the following actions:

- Introduce the role and responsibilities to potential honorary officer candidates.
- Provide an in depth briefing about the tasks and responsibilities of the role.
- Provide mentoring and assistance to the appointed honorary officer for at least three months after the appointment.
- Attending the meeting at which the successor will be appointed and contributing to a smooth handover and assistance to the newly appointed honorary officer. Whenever this meeting takes place face to face, MPE shall fund the travel and accommodation of the outgoing honorary officer to attend.

2. Role and responsibilities of MPE's Chief executive officer (CEO)

The board delegates to the MPE CEO the ability to independently decide and act on all day to day management issues, fully implement the strategy and work plan as set out and agreed by the board ("operational management").

The CEO is also responsible and will be held accountable, while provided with adequate resources, for:

2.1 Strategic plan implementation

- Oversee the implementation of MPE's strategic plan by developing annual action plans and metrics to ensure the continued relevance to the membership of existing activities, as well as exploring the development of new services and programmes to serve the membership
- Ensure that MPE's programmes and services are consistent with the highest professional standards and meet the needs of its members
- Confer as necessary with legal and/or other advisors to seek guidance when developing various programmes and make recommendations for implementing such programmes based on this guidance.
- Keep the president and board fully informed about significant issues that could impact on MPE's ability to fulfil its strategic objectives

2.2 Organisational sustainability

- Maintain relations with sustaining partners
- Propose ways of driving MPE's growth through diversification of funding and the development of new revenue sources

2.3 Governance

- Ensure that the policies and procedures laid down in the constitution and internal rules are respected
- Support the president in his/her role including the preparation of the agenda for board meetings
- Support the secretary in the preparation of the minutes arising from board meetings
- Progress work arising from the meetings of the board and its appointed committees
- Provide regular updates to the board on MPE's activities, risk registry and performance
- Consult regularly with the president, officers and board individually or collectively
- Prepare and present the proposed annual budget to the board for approval, and make available a copy of the approved budget and audited financial statement to all members at the AGM
- Manage MPE's day to day finances.
- Strive to keep the president and board members informed on all matters requiring action and supply them with sufficient information upon which decisions can be based.

2.4 Operations

- Establish MPE's organisational and staff structure and oversee the overall administration of MPE

- Lead and manage MPE's staff including interviewing, selecting, training, assigning tasks, evaluating work performance and terminations
- Oversee the negotiation and sign contracts with suppliers and sponsors

2.5 Membership

- Develop mechanisms to recruit and retain members
- Oversee engagement with and the provision of services to members
- Ensure effective communication between MPE and its members
- Be available for consultation with individual members as required

2.6 Communications and representation

- Deepen and refine all aspects of internal and external communications—from web presence to external relations with the goal of further developing MPE's image
- Represent MPE on committees, conferences and at meetings
- Represent MPE when dealing with any stakeholder or authority
- Use opportunities when representing MPE at external events to raise awareness about the organisation and its purpose.

2.7 Other duties

Other duties and specific responsibilities delegated to the CEO, as agreed with the board

2.8 CEO compensation

- The CEO's compensation is determined by the Compensation Committee based on the CEO's performance and annual review
- An increase in the CEO's salary only needs approval from the board if it involves a change in the annual budget

3. Standing committees and working groups

- To increase its knowledge base and depth of available expertise and to further the work of the organisation, the [board has the power to establish standing committees and work groups]. The description of the role and functioning of standing committees and work groups and any special policies related to their role and relationship to the board are outlined in these rules
- Standing committees are on-going advisory groups appointed by the board to assist MPE in carrying out its mission. Standing committees are permanent and play an important role in the operation of MPE. Even though members change, the purpose and functions of standing committees do not change. Standing Committees should not be created to do something that is within the designated function of a workgroup.
- MPE has the following standing committees:
 - Constitution Committee
 - Finance Committee
 - Compensation Committee
 - Nomination Committee
 - Board Development and Communication Committee
- The Constitution Committee is responsible for reviewing annually MPE's Constitution and internal rules to determine if any changes are needed. The Committee is also responsible for liaising with MPE's legal advisor to understand if there are any changes in Belgian law that impact on MPE's status as an AISBL
- The Compensation Committee is in charge of monitoring the CEO's performance and agreeing the CEO's and staff's salary (staff salary always on recommendation of CEO)
- The Nomination Committee is responsible for:
 - Ensuring that the tenure of board members is reviewed annually to determine when the different board members' tenure of office ends
 - Maintaining and updating the board profile matrix and highlighting to the members the specific skill set required for the board so that they will take this into consideration when deciding who to nominate for board membership
 - Reviewing the nominations made by the members to ensure that the candidates nominated fulfil the required criteria for board membership
 - Recommending potential new board members who are not associated with a full member organisation
 - Ensuring that the board membership obligations laid down in the Constitution are respected
- In addition, MPE also has a number of workgroups which are created to perform a specific task or/and with a temporary scope. Workgroups should not be created to do something that is within the designated function of a Standing Committee.
- Currently MPE has three workgroups:
 - AGM Committee
 - MPE Advocacy and Policy Workgroup
 - AL Amyloidosis Taskforce

- A workgroup refers to any group appointed by the board to assist in carrying out various time-limited tasks such as projects or review of a specific issue.
- The CEO will assign a staff member to serve the committees and workgroups in a staff capacity
- Committees and workgroups should operate according to a set of standard operating procedures as well as any special conditions set down by the board
- Committees and workgroups will not infringe on the powers of the members or the board

3.1 Standard operating procedures for Standing Committees and workgroups

Appointment of committee and workgroups members

- Appointments to committees and workgroups are made when each one needs to be activated
- The committee will consist on the appropriate number of members necessary to fulfil the committee objectives
- The Chair of each Committee and workgroup will be appointed by the board on the basis of proven individual expertise, skills and experience in the field concerned.
- Members of all MPE Committees and workgroups will be appointed by the board and, if relevant, following recommendations from the Committee Chair. Members should have proven experience in the field dealt with by the Committee. Committee members can be dismissed if in the board's opinion they are not fulfilling their responsibilities as a committee member.
- Members should declare any potential conflict of interest in accordance with the MPE conflict of interest policy
- Committees and workgroups will be empowered to invite additional experts on an ad hoc basis to provide specific advice

Role of committee/workgroup chairs:

- The chair is responsible to develop together with MPE staff an annual work plan to be adopted by the committee/workgroup as a whole and approved by the board.
- The chair is responsible for the implementation of the committee's/workgroup's action plan and will report to the board on progress quarterly.

Meetings

- MPE's Committees/workgroups shall meet as necessary to further their work within the constraints of the available budget
- Meetings normally take place by phone/video conference and in exceptional circumstances a face to face meeting may take place. If a face to face meeting is deemed necessary, prior approval must be sought from the board
- Face to face meetings will be held preferably during meetings in which the majority of members will be in attendance
- The CEO and president may attend all committee/workgroup meetings in an ex-officio capacity.

Reporting relationship

- A report of activities from each committee and workgroup must be submitted to the MPE board meetings on a quarterly basis.
- Progress on the work of different committees will be presented to the AGM by the board.

Remuneration

- In accordance with MPE's internal rules, the membership of committees/task forces is unpaid
- Committee/task force members will be reimbursed for all reasonable travel and accommodation expenses incurred in accordance with MPE's financial policy.

4. Election of board members

4.1 Introduction

The board of directors has the responsibility for overseeing policy development, establishing organizational strategy as well as providing oversight to ensure organizational effectiveness and sustainability. English is the standard language of communication in MPE (meetings, official documents, website, mail etc.), like it is in the international field we operate.

It is acknowledged that a high performing board is likely to make a significant contribution to the overall effectiveness and success of the organization. Therefore, MPE is committed to investing in supporting and developing its board. To this end, all new board members will be given a board pack which includes information that will help orientate them to the board's role and responsibilities and MPE's governance. The pack will be updated annually and distributed to all board members.

4.2 Nominations

- The Nomination Committee will announce the number of vacancies on the board and send an invitation to Full Members to nominate candidates at least two months before the election.
- An individual can be nominated for the MPE board either by a full member or by the Nomination Committee.
- Nominations from members must be submitted within the time period indicated in the invitation to submit nominations.
- The nomination must be submitted on a nomination form (Appendix 3) with information about the candidate's background and a short paragraph describing his/her motivation for being elected to the board
- The Nominating Committee will review all nominations to ensure that they fulfil the required criteria for board membership
- The names of all the nominated candidates who fulfil these criteria (regardless of if they are nominated by the members or the Nomination Committee) must be included in the election ballot papers.

4.3 Profile of ideal MPE board member

It is highly desirable that the board contain a mix of professionals that have expertise in the relevant work areas of the organisation. This will ensure the board is aligned to the organisation strategy and supports high quality decision-making by ensuring there are individuals with the relevant experience to guide discussions.

Those with a personal interest in the organisation such as patients with the relevant expertise should be encouraged to consider standing for election to the board

The following characteristics are desirable for MPE board members:

Ability to:

- Read, write and communicate fluent in English language
- Listen, analyse and think clearly and creatively
- Work well with other people both individually and in a group

Willingness to:

- Prepare for and participate in board and committee meetings
- Ask questions
- Take responsibility and follow through on a given assignment
- Open up doors in the community and to potential sources of income
- Develop certain skills if they do not already possess them, such as: Cultivate and solicit potential funds, cultivate and identify potential board members and other volunteers
- Read and understand financial statements
- Learn more about the internal rules, programmes and services of MPE

To possess:

- Honesty, sensitivity and a tolerance of differing views
- A friendly, responsive and positive approach
- A genuine concern for the development and work of MPE

Other important board characteristics:

- People who enjoy working as part of a team and are willing to find solutions when faced with challenging situations
- People who are 'on the way up' but not already overcommitted
- Well positioned leaders in respective fields who will contribute time and talent

4.4 Election procedure

1. Candidate standing for election
 - A list of candidates will be sent to members one month prior to the GM at which the election will take place
 - All candidates must submit a written presentation of their candidacy in time and in the format requested
 - Candidates must present themselves in person at the GM immediately prior to the vote
 - Whenever a candidate cannot attend in person, the board will have the final decision on whether a candidacy may be presented or not
 - In exceptional circumstances, the candidate may ask the board to accept a replacement or alternative means (e.g. video). This will only be possible if felt appropriate by the board

2. The voting procedure
 - Only members who are present or represented by proxy at the GM can vote
 - The election will be by secret ballot
 - Members will be given blank ballots and invited to tick the names of their preferred candidates
 - The ballots will be counted by two individuals appointed by the GM who have no interest in the election result
 - Ballot papers that are blank or not readable will be discarded
 - The candidates who receive the highest number of votes will be deemed elected. The number of candidates elected will depend on the number of board positions available.
 - To become elected as member of the board, a candidate must receive at least 25% of the votes of members present or represented by proxy.

- In the event of a tied vote between two or more candidates, a second round of voting will be organised. This will only involve the candidates who were not elected in the first round. Rounds of voting will continue until all the positions are filled.

The newly elected board members will start their term of office immediately after their election.

4.5 Board Preparation for the Elections

The following items shall be reviewed and discussed during the Board meeting prior to the Elections:

- List of board members whose term expires.
- List of board members who plan to stand for re-election.
- List board members that wish to resign from their Board membership.
- List of board members who will not stand for re-election.
- Honorary officers shall be clearly identified as such on these lists.
- Board members whose term does not end, taking into account experience and skills, in order to identify potential honorary officers.
- Discuss transition plans for each of the outgoing honorary officers.

4.6 Appointment of president

The president will be elected by vote of the board for a period of two years.

The board should aim to appoint the new president by consensus, guided by the principle of inclusiveness and debate, and avoiding the creation of parties or polarisation within the board. A vote should confirm the president by simple majority. In case of more than one candidate, the candidate with the highest number of votes shall be appointed as president.

Any candidate to the role of president shall inform the current president about his/her intention no later than 3 weeks prior to the board meeting at which the elections will take place.

The president will share the list of candidates with the board no later than 2 weeks prior to the appointment. This will allow the board to reach out to the candidates.

The president will be elected in the nearest board meeting in one of these cases:

- The term of current president is coming to an end at the Annual General Meeting.
- The current president has resigned.
- In case there is no current president.

This clause can be overruled, in exceptional circumstances, by a majority vote of the MPE Board members.

4.7 Appointment of vice-president

The vice-president (VP) will be elected by vote of the board for a period of two years.

In case of more than one candidate, the candidate with the highest number of votes will be selected.

Any candidate to the role of VP shall inform the current president about his/her intention no later than 3 weeks prior to the board meeting at which the elections will take place.

The president will share the candidates for the VP role with the board no later than 2 weeks prior to the appointment. This will allow the board members to reach out to the candidates.

The VP will be elected in the nearest board meeting in one of these cases:

- The term of current VP is coming to an end at the Annual General Meeting.
- The current VP has resigned.
- In case there is no current VP.

This clause can be overruled, in exceptional circumstances, by a majority vote of the MPE Board members.

4.8 Appointment of treasurer

A treasurer will be elected by vote of the MPE board for a period of two years.

In case of more than one candidate, the candidate with the highest number of votes will be selected.

Any candidate to the role of treasurer shall inform the current president about his/her intention no later than 3 weeks prior to the board meeting at which the elections will take place.

The president will share the candidates for the treasurer role with the board no later than 2 weeks prior to the appointment. This will allow the board members to reach out to the candidates.

The treasurer will be elected in the nearest board meeting in one of these cases:

- The term of current treasurer is coming to an end at the Annual General Meeting.
- The current treasurer has resigned.
- In case there is no current treasurer.

This clause can be overruled, in exceptional circumstances, by a majority vote of the MPE Board members.

4.9 Appointment of secretary

A secretary will be elected by vote of the MPE board for a period of two years.

In case of more than one candidate, the candidate with the highest number of votes will be selected.

Any candidate to the role of secretary shall inform the current president about his/her intention no later than 3 weeks prior to the board meeting at which the elections will take place.

The president will share the candidates for the secretary role with the board no later than 2 weeks prior to the appointment. This will allow the board members to reach out to the candidates.

The secretary will be elected in the nearest board meeting in one of these cases:

- The term of current secretary is coming to an end at the Annual General Meeting
- The current secretary has resigned.
- In case there is no current secretary.

This clause can be overruled, in exceptional circumstances, by a majority vote of the MPE Board members.

5 MPE's financial policy

MPE follows generally accepted accounting principles and guidelines as required by law. The following are the organisation's policies relating to financial operations.

5.1 Financial reporting and budgeting

- The organisation's fiscal year is January to December
- Each year the CEO will draft the budget which will then be reviewed by the finance committee before being presented to the board for approval.
- The Board will approve the annual budget prior to the beginning of the budget period. Subsequently it will require the approval of the GM.
- Any significant change or variance in income or expenditure during the year will be reflected in a revised budget and approved by the board.
- Quarterly management accounts comparing revenue and expenditure including a balance sheet will be provided to the board, with significant variances between progress and plan explained. The report shall be done with a template developed by the CEO and the finance committee.
- A formal presentation of the annual accounts will be made to the members at the GM. Relevant financial information will be circulated to the members along with other GM papers at least one month before the date of the GM.
- If necessary MPE will appoint an auditor to audit the accounts. In the event of the auditors finding any anomalies, they will report these to the MPE board prior to the GM. MPE will report the final findings of the auditors to the members at the GM.

5.2 Monitoring financial operations

- The executive office will send all invoices and receipts to the accountant on a monthly basis and provide the finance committee with a copy of the bank statements
- The MPE board will be provided with a quarterly financial update.

5.3 Annual Reserve

- MPE must have a reserve. In order to ensure the sustainability of the organisation and ongoing projects the MPE board may decide to keep a proportion of MPE's income as a reserve.

5.4 Bank signatories

- MPE's bank signatories are the president, treasurer, CEO and one member of staff.
- All payments are made by the executive office. Payments made by the staff member must be co-signed by the CEO.
- Any transaction above 10,000 Euro requires the signature of two bank signatories to carry out the transaction.

5.5 MPE's Credit and Other Bank Cards

- MPE will have two credit cards – one for the CEO and the other for the office. No other person will be allowed to use the MPE credit cards and other bank cards for payments.
- The credit card limit shall be 15,000 Euro.
- The limit for expenditure on any one item using the credit card will be 15,000 Euro. Any expenditure above this will require the approval of the treasurer.
- The credit card or any other bank card will not be used for cash withdrawals.

5.6 Policy on general expenditure – MPE programmes and activities

- Once the budget of an MPE activity or project has been approved by the board, MPE's CEO will not require any further authorisation from the board, as long as expenditure stays within the approved budget.
- The CEO does not require prior authorisation for non-budgeted transactions of 1,000 Euro or below.
- Non-budgeted expenses of 1,000 Euro or above should be submitted to the finance committee for approval. These items cannot be purchased or expenses paid without written approval of the finance committee.

Amendments and revision of financial policies

These financial policies may be revised by the finance committee over time as circumstances demand.

Amendments to financial policies shall be approved by the board. Amendments will enter into force the day after the board approval. This decision will be included in the Board meeting minutes.

Financial policies approved by the board are in force until the next AGM, where they will be ratified.

5.7 Guidelines on reimbursement of expenses

MPE members or invited participants

When taking part in agreed MPE activities, such as Masterclasses and the AGM, or other events where MPE gives a particular member a mandate to represent MPE, MPE members are entitled to reclaim expenses.

The following rules apply:

- Expenses claims must be submitted on the official MPE reimbursement form
- Original receipts and the signed reimbursement form should be sent by post (originals) to the Executive Office (Myeloma Patients Europe; Avenue Louise 143/4; 1050 Brussels; Belgium) no later than one month after expenditure has taken place. In addition, expenses claimed may be sent via email (scanned) to accelerate the approval process. No reimbursement will be made without having received the original receipts/invoices
- If the expenditure is in any currency other than the Euro, the exchange rate should be noted on the claim form using the rates published on the following website: http://ec.europa.eu/budget/contracts_grants/info_contracts/infoeuro/infoeuro_en.cfm. The exchange rate shall be the rate of the day/month/year in which the expense was incurred
- Normally, expenses will be reimbursed via bank transfer within one month of receiving the fully completed and signed reimbursement form together with all original receipts
- The Executive Office shall report to the treasurer any requests for refunds that seem unjustifiable. If the treasurer

agrees that the expense is unjustifiable, then the payment will not be made. If the treasurer has doubts, then the Finance Committee will decide if this should be paid or not. This decision will be reported in the minutes of the Finance Committee

- The following principles apply for travel:
 - Travel and accommodation will normally be booked via MPE.
 - If otherwise stated on the invitation, then the following principles apply:
 - The maximum amount claimed in relation to travel is 400 Euro unless agreed otherwise
 - Booking must be done well in advance to ensure best prices
 - Travel is to be in economy or second class only
 - Travel is normally limited to two people per member organisation unless agreed otherwise
 - Accommodation shall not cost more than 150 Euro per night unless agreed otherwise
 - All other expenditure must be approved in advance
 - Travel by car is allowed when other means of travel are more expensive or not possible. This option requires prior approval from the Executive Office.
 - Taxis will only be reimbursed when there are exceptional circumstances or issues of health and safety, and prior approval from the Executive Office. The reason for using a taxi should be justified on the reimbursement form when submitting it.

MPE staff and board members

When attending meetings on behalf of MPE, such as board meetings, external advisory boards or meetings with stakeholders, board members and staff are entitled to reclaim expenses. The following rules apply:

- All expenses claimed must be sent via ordinary post (originals) to the executive office. No reimbursements will be made without having received the original receipts/invoices. In addition, expenses claimed may be sent via email (scanned) to accelerate the approval process.
- Travel should be by the most economical and practical way with economy class air tickets and second-class train travel. Business class for staff or board members shall only be booked in exceptional circumstances prior approval from the executive office
- Public transport should be used as a general rule. Taxis will only be reimbursed when there are exceptional circumstances or issues of health and safety. The reason for using a taxi should be justified on the reimbursement form when submitting it
- If traveling by car, mileage will be refunded on the basis of 0.30 Euro per km. Toll charges for motorways and parking can be reclaimed with original receipts.
- Accommodation may be booked by the person travelling or centrally by MPE, depending on the event. Where possible, hotels should be booked early directly with the hotel or through a recognised reservation site (e bookers, skyscanner.net, HRS etc.) in order to get the best deal.
- Hotel room costs should be limited to a maximum of 150 Euro per night unless it can be shown that this was impossible in particular situations, where hotels are full or where hotel costs are particularly high in a specific destination. This demands early reservations for travel and hotels.

- MPE reserves the right not to reimburse accommodation that is unreasonably expensive and/or has been booked unreasonably late in time.
- Staff, board members and any person officially representing MPE will be reimbursed for reasonable food and beverages expenses incurred while travelling to or from the meeting or during the meeting. These expenses shall be reimbursed by the MPE office without further reference to the board or the treasurer.

Small items of expenditure – up to 250 Euro per transaction

- MPE will reimburse small items of expenditure by board members when carrying out their duties and might include post, paper or replacing ink cartridges.
- These expenses shall only be reimbursed with prior agreement with the executive office, following a request by e-mail. The executive office shall reply to this request within 24 hours (working days).

6. Policy on partnership with commercial organisations

6.1 Introduction

MPE understands the importance of working in partnership with all stakeholders with an interest in myeloma and related diseases to achieve common goals. The pharmaceutical industry is a key stakeholder for MPE and MPE wishes to work in collaboration with different pharmaceutical companies. MPE recognises the need for such collaboration to be transparent and able to stand up to scrutiny. As a result, MPE has developed this policy document that defines how we engage with the pharmaceutical industry. This will ensure we can withstand external scrutiny of our decisions and actions whilst at the same time allowing us freedom to work in a way which ultimately benefits myeloma patients and their families.

6.2 Purpose of policy

The purpose of this policy is to:

- Ensure that MPE has a consistent and transparent approach to working with and accepting financial support from pharmaceutical companies
- Demonstrate how MPE maintains its independence and clarify its position to its various stakeholders
- Ensure that pharmaceutical companies are aware of our policy in regard to working with them

6.3 Funding: guiding principles

MPE will foster dialogue and establish appropriate relations with any company whose products, actions and commercial decisions affect the chance of survival and quality of life of myeloma patients in Europe.

Patient groups working with the pharmaceutical industry are sometimes viewed with scepticism by decision-makers and the general public. Some believe that pharmaceutical companies coerce patient organisations into conforming to their marketing agenda. In order to protect MPE's reputation and demonstrate that it does not conform to commercial agendas, MPE will adhere to the following principles when soliciting or accepting project funding, sponsorship, grants or donations from the pharmaceutical industry:

MPE will maintain an open and transparent relationship with every company it works with. Before soliciting or accepting funding, the MPE board must be satisfied that:

- There are strong grounds for believing the donation, grant or sponsorship will help MPE achieve its mission and not undermine MPE's credibility
- No adverse publicity will result from accepting the funds
- MPE will closely review the corporate governance policies and reputation of every company it solicits or accepts funds from. MPE will reject the funding if there is any reasonable or demonstrable cause for concern
- MPE will not endorse or promote individual products or services
- A company's support will be acknowledged in an appropriate way following discussions with the company concerned
- MPE will sign a memorandum of agreement with all companies outlining each partner's contribution and responsibilities. The company must agree to abide with the guidelines outlined here

- If a company makes any attempt to coerce MPE to conform to its marketing agenda, either explicitly or implicitly, or does not conform to the memorandum of agreement, MPE will reject the funds or terminate an on-going project
- Where possible, MPE will solicit funding from consortia composed of two or more companies working in the field of myeloma
- As a general rule, honoraria paid by industry for talks or other services provided in representation of MPE, should be paid to MPE and not to the individual providing the service. The Finance Committee may decide on a case by case basis that the honorarium can be paid to the individual instead.

6.4 Ways in which industry can support MPE financially

Project funding:

This is where MPE will work in partnership with a pharmaceutical company to undertake a project relating to an issue of mutual interest. The following features will apply to these projects:

- MPE maintains editorial control over all materials (hard and soft copies) produced in connection with the project
- The company will be appropriately acknowledged according to the following appendix 4
- MPE will not endorse or promote individual products, devices, procedures, tests or
- services
- The wording and/or position of the acknowledgement will be agreed in negotiations with the company

Sponsorship:

This is where a company funds a single activity such as a meeting or newsletter. In this case the following will apply:

- The company has no involvement in the activity for which the sponsorship is granted
- MPE maintains editorial control over all materials or meeting programmes
- MPE will not endorse or promote the sponsor's products or services
- Sponsorship shall be appropriately acknowledged in the activity, according to the following appendix 4
- The wording and/or position of the acknowledgement are part of the sponsorship negotiations with the company

Unrestricted grants:

The following features will apply:

- The company has no involvement in the project for which the grant is used
- The grant will be appropriately acknowledged according to Appendix 4
- MPE controls the wording and position of the acknowledgement

Other:

Companies may offer financial donations and in-kind support to MPE. All donations and support will be acknowledged in an open and transparent manner.

7.MPE Conflict of Interest policy

7.1 Rationale for policy

- All individuals associated with MPE must act, and be seen to act, in the best interests of MPE and not for their own private interest or gain or that of another organisation
- The purpose of this conflict of interest policy is to protect MPE from any suggestion of impropriety and ensure transparency of interests. This policy applies to members of the MPE board and committees, MPE staff and MPE service providers and collaborators (subsequently referred to collectively as 'MPE officers').
- The policy establishes standards of conduct for MPE officers in the exercise of any power or the performance of any duty or function on behalf of MPE. It is intended to support MPE's integrity, to promote its goals and to enhance public, stakeholder and donor confidence in the organisation and those associated with it. It supplements any provisions of the MPE constitution and its committees' terms of reference.

7.2 Types of conflict of interest

- Conflicts of interest may arise when an MPE officer's personal, business, occupational or professional interests' conflict with those of MPE.
- Conflicts of interest may be real or apparent. A real conflict of interest occurs when, in the course of their MPE functions, MPE officers are privy to MPE decisions, documents or transactions that provide opportunities to obtain personal, business, economic, occupational or professional benefits for themselves and/or third parties.
- An apparent conflict of interest exists when there is a reasonable perception on the part of well-informed persons that an MPE officer is in a conflict of interest situation.

7.3 Confidential Information

- MPE officers shall guard the confidentiality of information to which they become privy through participating in MPE internal or external activities.
- They shall not use such information for their personal or their own organisations' direct or indirect benefit.
- They shall not disclose such information to other individuals or to organisations in such a manner that a direct or indirect benefit may be conferred to such individuals or organisations.

7.4 Corporate Opportunity

- MPE officers shall advance MPE's legitimate interests when corporate opportunities arise.
- They shall not take advantage for themselves personally of opportunities that are discovered through the use of MPE's corporate property, its confidential information or their position in relation to MPE.

7.5 Fair Dealing

- MPE officers shall deal fairly with MPE's stakeholders, partners, sponsors etc.
- They shall not take unfair advantage of anyone through manipulation, concealment, abuse of privileged information, misrepresentation of material facts or any other unfair dealing practice.

7.6 Declaration of interests

- MPE's officers are required to disclose the nature and extent of any existing or potential conflict of interest, real or apparent, when they accept an MPE function. This includes declaring links to/funding from external funding sources that might be in conflict with MPE's mission.
- Each MPE officer must declare their interest at least annually by completing and signing a Declaration of Interest (DOI) Form (Appendix 1).
- The Declaration of Interest form confirms that the officer:
 - Has received a copy of the conflict of interest policy
 - Has read and understood the policy
 - Has agreed to comply with the policy
 - Has filled in and returned the disclosure statement.
- MPE may request additional information to clarify the exact nature of a declared interest
- Based on the internal rules, the president shall decide whether there is a conflict of interest. If it's the president who has the potential conflict, it should be the vice-president who decides.
- Where a conflict of interest is identified, the officer may have to abstain from voting on or involvement in related matters.

7.7 Data Protection

- The organisation will maintain a register of its officers' declared interests on a secure database. The database will be accessible by the president of the MPE board and by the MPE CEO.
- The information provided will be processed in accordance with data protection principles as set out in Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation).
- Data will be processed only to ensure that MPE officers act in the best interests of MPE. The information provided will not be used for any other purpose.

(Revised and approved by the MPE board on 23 March 2023)

Appendix 1: Declaration of interest form

Appendix 2. Confidentiality agreement

Appendix 3. Nominating form

Appendix 4. Guidelines for pharmaceutical companies proposing to work with or provide funding to MPE

MPE will not embark on any project or venture with industry that might damage its reputation or result in the dissemination of biased and inaccurate information. Therefore, when working with MPE, pharmaceutical companies should adhere to the following guidelines:

- MPE must be consulted whenever and wherever its name is used, particularly in external communications. Approval must be sought for any copy produced which refers to a network initiative supported by a commercial organisation
- At no time can the MPE logo be used without its written permission
- MPE will not contribute to press releases produced by the industry. If there is an interest in the topic reported by a company, MPE will do its own press release or public statement
- MPE retains a veto over all materials produced in connection with an initiative. Adequate approval time needs to be allowed for this as it may require approval from one or more Board members or require feedback from the MPE medical advisory committee
- Where more than one branded version of a product exists, any materials produced, as part of an initiative will use either the scientific name or several different brand names. It may not be practical to mention every brand at every stage in a publication but overall the effect will be one of impartiality
- MPE agrees to work with PR/advertising and marketing agencies of commercial organisations once a project is underway. However, in the first instance when a project is being planned or suggested MPE requires a representative from the company to be present as well as the agency
- One point of contact should be identified within the company and/or agency to liaise with the appropriate contact person number in MPE. Clear lines of communication need to be established at an early stage with respective responsibilities and assignments agreed to ensure smooth progress with a project