

## **Constitution of Myeloma Patients Europe AISBL**

Myeloma Patients Europe (MPE) was registered on October 26, 2011 in Belgium.

The original constitution of MPE is written in French according to Belgian law.

### **Article 1: Name**

A non-profit international association under Belgian law named Myeloma Patients Europe is established under the laws of June 27, 1921 and May 2, 2002.

### **Article 2: Location**

The organisation's headquarters are located at Avenue Louise 149/24, 1050 Brussels, Belgium.

The headquarters may be transferred at any time to any location in the Kingdom of Belgium upon the decision of the board. Notification of the decision on the change of location will be published in the Moniteur Belge no more than three months after it is made.

### **Article 3: Purpose**

Myeloma Patients Europe is a European umbrella association of myeloma patient groups that are working together to improve the lives and prospects of myeloma patients by:

- Providing a strong, collective voice for European myeloma patients in European health policy debates;
- Raising public and health professionals' awareness about myeloma and related conditions<sup>1</sup>;
- Strengthening members' capacity to advocate for myeloma patients to have their disease diagnosed in a timely manner and have access to appropriate treatment, information and support;
- Stimulating research to benefit myeloma patients.

To pursue these objectives Myeloma Patients Europe focuses on a range of activities including but not limited to:

- Providing a platform for members of Myeloma Patients Europe to collaborate and share experiences/resources so that they can be more effective in meeting the needs of myeloma patients;
- Providing opportunities for members of Myeloma Patients Europe to strengthen their organisations and improve their long-term sustainability;
- Facilitating the establishment of myeloma patient groups in European countries and regions where they do not already exist;

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<sup>1</sup> The term 'related conditions' refers to diseases that are linked to myeloma such as AL amyloidosis, MGUS, Solitary extramedullary plasmacytoma and plasma cell leukaemia. The term 'myeloma patients' is used throughout this document to refer to patients with myeloma and/or related conditions.

- Providing members with relevant information and updates in different formats on all aspects of the disease but especially about advances in diagnosis, treatment and care;
- Influencing European health policies that impact on access to diagnostics, innovative treatments and specialist care;
- Representing the voice of myeloma patients in various European committees and forums;
- Collaborating with national, European and international cancer and/or haematological organisations to increase Myeloma Patients Europe's ability to shape European and global health policy in the interests of myeloma patients and join forces to take action to address common problems;
- Promoting better access to clinical trials especially in countries where patients have limited opportunities to gain access to innovative medicines;
- Promoting myeloma patient involvement in all aspects of the drug development process and provide myeloma patient advocates with the opportunity to develop their ability to contribute effectively to discussions about the design and conduct of clinical trials.

#### **Article 4: Members**

There are three types of member:

Full members with the right to vote

Associate members with no right to vote

Supporting members with no right to vote.

##### Full members

Full members are non-profit patient organisations that are registered in a European country (as defined by WHO Regional Office for Europe) and fulfil the following criteria:

- Focused on meeting the needs of those living with myeloma or related diseases;
- Share the goals of Myeloma Patients Europe;
- Willing to exchange experience and knowledge in a constructive fashion;
- Ready to engage in the activities of this organisation;
- Registered as a non-profit organisation.

##### Associate members

Any individual person who shares Myeloma Patients Europe's goals and all other non-profit organisations that do not fulfil the criteria for full membership.

##### Supporting members

Supporting members are individuals, foundations or corporations who have chosen to support the activities of the organisation through financial contributions or in-kind services. The type and amount of donation will be determined by the Board.

## **Article 5: Members' rights and responsibilities**

All members must respect the association's constitution and its internal rules of order.

Only full members have the right to vote at the annual general meeting (AGM). Associate members do not have a vote.

Each full member will designate one person as its representative who will be responsible both for representing the member's position and for reporting back to the member organisation about MPE's work and potential collaborative opportunities.

All members, except supporting members, must pay membership dues if such dues are established by a decision of the AGM.

Members have the right to resign their membership at the end of the financial year and written notification of resignation has to be sent to the Board.

Members may resign their membership with immediate effect within one month of:

- a. Being notified of a resolution to convert the Association into a different legal form or to merge or split up the Association;
- b. Becoming aware or being notified of a resolution under which their rights have been restricted or their obligations increased.

Members may also resign their membership with immediate effect if they cannot reasonably be required to continue their membership.

Members cannot resign with immediate effect if an obligation of a financial nature is amended.

In all cases of resignation with immediate effect, the member will notify the board of its resignation in writing.

## **Article 6: Suspension and exclusion of the association's members**

The association reserves the right to suspend or exclude any of its members for the following reasons:

- a. A member does not fulfil its responsibilities towards MPE, which are outlined in Article 5 of this constitution;
- b. A member engages in behaviour that contravenes the objectives and mission of MPE;
- c. A member no longer satisfies the requirements for membership.

The board can suspend a member with immediate effect if in its opinion MPE cannot be reasonably required to permit the membership to continue. A member may only be suspended by a two thirds majority decision of the Board. This decision must be ratified at the next AGM by a simple majority vote. Should the member wish to contest the matter, they will be allowed to present their case to the AGM prior to the vote. The AGM may decide to overturn the Board's decision, continue the suspension or exclude the member permanently. This decision cannot be appealed.

Any member who ceases to belong to MPE will forfeit all rights enjoyed by the members, yet will be responsible for any membership dues for the calendar year during which it ceases to be a member.

## **Article 7: Annual General Meeting**

### Structure

The AGM is the highest governing body of MPE and is made up of full and associate members. Supporting members have no involvement in the AGM.

### Powers

- The AGM holds full powers to achieve the goals of the association.
- The AGM may delegate some of its powers to the Board. The following powers however may not be delegated to the Board:
- Approval of the budget and accounts;
- Modification of the constitution;
- Dissolution of the organisation;
- Election and dismissal of Board members;
- Approval of the admission, suspension or exclusion of a full, associate or supporting member;
- Ratification of the internal rules and regulations;
- Determination of annual membership dues, if the principle is adopted

### Meetings

Each year an AGM will be called by the board and chaired by the President of the said Board, or in case of absence by the Vice-President. The AGM will be held at the venue indicated on the notification.

An extraordinary general meeting (EGM) can be called by the Board or at least one fifth of all full members of the association. The EGM has to take place within six weeks of the submission of the request to call the meeting. The purpose of this meeting must be mentioned on the notification and should appear on the agenda.

All AMGs and EGMs can be held via video-conference.

## **Article 8: Annual General Meeting – Rules of procedure**

### Notification

Notice of the AGM must be sent, with the agenda, to all full and associate members at least four weeks beforehand.

### Representation

Each full member organisation has only one vote.

Each full member may be represented by another full member who has received a written, duly completed proxy form. No full member may represent more than two people.

### Agenda

Each full member may ask the President to include items on the agenda at the start of the meeting and have the item discussed. 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.

### Quorum

The AGM may take place whatever the number of members present or represented, except in particular cases mentioned in this constitution.

Decisions will be made on a simple majority of votes by members present either for themselves or in representing others, except in particular cases mentioned in this constitution. In the case of a tie, the President's vote will be decisive.

Should a specific quorum be required but not reached, a new AGM will be called in the next three months, with the same agenda.

This second AGM will then be able to rule on a simple majority, regardless of the number of members present or represented. This meeting can take place via video conference.

### Minutes

All decisions made at the AGM will be recorded in the meeting minutes which will be sent to members within four weeks.

## **Article 9: The Board of Directors**

### Structure

The organisation is run by a Board of Directors (Board) comprising at least six and not more than nine members, appointed for a two-year period. At least half of Board members will be patients or carers. Each Board member may be consecutively re-elected twice.

A full member may nominate a candidate for the Board. The Board may not include more than two members of the same nationality or who represent the same country. Full members may have no more than one representative on the board.

An individual who is not associated with a full member organisation may be appointed to the Board. However, at least half of the Board must be associated with a full member organisation.

The officers - President, Vice-President, Secretary and Treasurer - will be elected by the Board from among its members. The roles and responsibilities of the officers and board members are outlined in the internal rules.

Board members' duties end on death, resignation, civil incapacity or temporary placement under administration, dismissal or expiry of their mandate. If a board member is unable to fulfil his/her obligations for whatever reason, an election to replace the board member will be held at the next AGM.

The Board may decide to suspend one of its members if:

- a. The member does not fulfil his/her responsibilities to MPE as laid down in the internal rules;
- b. The member engages in behaviour that is in conflict with the objectives and mission of MPE;
- c. The member's behaviour undermines the work of the Board.

A board member may only be suspended by a two thirds majority decision of the Board. This decision must to be ratified by the members within three months either at an AGM or at an EGM that is called by the Board. The suspended board member has the right to appeal his/her suspension at this meeting. Members will make a decision to reinstate or dismiss the Board member by a simple majority decision of those present or represented at the AGM.

### Powers

The Board will hold all powers of day-to-day management and administration of the organisation's affairs, excluding those powers that may not be delegated to the Board under the terms of this constitution.

It may delegate the powers of day-to-day management to one of the Board members or to the Chief Executive Officer in compliance with article 10 of this constitution.

The Board may, if it wishes, delegate some of its powers to a task force or sub-committee. The procedures governing task forces and sub-committees are outlined in the internal rules.

### Meetings

The Board will convene as often as necessary on request of the President. The President will chair the Board meeting.

### Quorum

The Board may conduct business if half of its members are in attendance.

Decisions will be made by simple majority of votes except in those circumstances laid down in this Constitution. In the case of a tie, the President's vote will be decisive.

### Miscellaneous

Members of the Board bear no personal liability for acts carried out in the exercise of their mandate. They are merely responsible for performing their duties correctly. These duties are carried out on a voluntary basis.

Board decisions will be made known to members by the publication of minutes and via the organisation's website.

### **Article 10: Chief Executive Officer**

The Board may decide by simple majority to appoint a Chief Executive Officer (CEO) who will be responsible for the day to day operations of the organisation. The CEO may be dismissed at any time by a two-thirds majority decision of the Board.

The duties of the CEO will be established by the Board and will include the power to manage the daily affairs of the Association as well as to represent the Association as needed.

The CEO may appoint and remove persons in all staff positions, provided that all budgetary or other limits established by the Board are respected. The CEO attends the AGM and Board

meetings in an *ex-officio* supportive and advisory role, without voting rights, unless otherwise desired by the Board.

The CEO will report to the Board of Directors on the activities, programmes and accounts of the Association at the sole discretion of the Board.

In no case may the CEO make a commitment on behalf of the organisation unless a mandate has been given to do so. The Board may at all times quash a decision made by the CEO.

#### **Article 11: Finances**

The Board may recommend and the AGM approve membership dues for full and associate members.

The financial year will run from 1st January to 31st December.

The Board will submit accounts of the past financial year and the budget for the next financial year to the AGM for its approval.

Approval of the accounts by the AGM will discharge the Board members from liability for all acts set out in the annual financial documents.

No part of the assets, income, profits or net earnings of the Association will be to the benefit of any officer, employee, agent, trustee, director or other person except as reasonable compensation for services rendered to MPE in relation to its purpose.

#### **Article 12: Internal rules**

The Board is responsible for drafting and updating the internal rules which will specify this constitution and its applications. Internal rules will be followed on a provisional basis subject to their ratification by the next AGM. Internal rules will be reviewed annually by the Board.

#### **Article 13: Representation**

In accordance with Article 10 of this constitution, the CEO will have the power to manage the daily affairs and business of the Association as well as to represent the Association as needed in order to implement such daily management powers.

Any transaction outside the scope of daily management that binds the Association will, subject to any monetary limits set by the Board in the Internal Rules of the Association, be signed by the President, Treasurer, or the CEO, acting alone below limits defined in the Internal Rules and jointly above the said limits, or by any other person or persons receiving a delegation of powers in accordance with Article 9 of this constitution, as confirmed in a resolution of the Board signed in accordance with Article 9 above. The preceding persons need not offer proof of their authority to third parties.

Two members of the Board, one of whom one must be the President or the Secretary, must sign any commitments made by the organisation. The Board may delegate this task to the CEO.

#### **Article 14: Legal actions**

Legal action involving MPE, whether as plaintiff or as defendant, will be taken by the Board, represented:

- by its President, or
- by a member of the Board appointed for such purpose, or
- by the CEO if appointed to do so

#### **Article 15: Conflict of Interest**

Board members will have a duty of trust and loyalty to MPE and should adhere to the conflict of interest procedure as further described in the Internal Rules. Potential conflicts of interest should be declared prior to election to the Board and on an annual basis.

In the event that a matter requiring discussion involves a conflict of interest for one or more members of the Board present or represented at a meeting where such a matter is to be discussed, that member will be required to declare that interest to the President of the Board (or person chairing the meeting). Such declaration will be recorded in the minutes of the meeting.

Where a conflict of interest has been declared under this Article, the member or members of the Board in question will refrain from participating in the discussion or vote on the matter in question, and will temporarily leave the meeting while the matter is deliberated, unless otherwise authorised by the President of the Board (or person chairing the meeting).

#### **Article 16: Modification to the Constitution and Dissolution**

Modifications to this constitution will be made by the AGM. A decision to modify the constitution must be approved by a two-thirds majority of members present or represented by proxy.

Modifications to the constitution will only take effect after approval by the competent authorities, in compliance with article 50, § 3 of the law, and after publication in the annexes of the Moniteur Belge, in compliance with article 51, § 3 of the said law.

The AGM can only decide on the dissolution of the association if at least two-thirds of the members are present or represented by proxy. Should the organisation be liquidated, the Meeting will determine the course of the liquidation and appoint a liquidator.

The AGM will decide how the remaining funds will be distributed to another organisation with aims similar to those of Myeloma Patients Europe.

#### **Article 17: Final Provisions**

This organisation is ruled by the Belgian law of the twenty-seventh of June nineteen twenty-one, last amended on the second of May two thousand and two.

The law always takes precedence over this constitution. The law is auxiliary to this constitution.