

By-Laws

Approved by Governing Board



The International Alliance of Patients' Organizations (IAPO) is registered as a UK Company Limited by Guarantee (Number 8495711 – date of registration: 19 April 2013) and as a charity in England and Wales (Number 1155577 – date of registration: 31 January 2014).

These By-laws have been made under the Memorandum and Articles of Association (MAA), Article 14 By-Laws, and regulate the operation of the International Alliance of Patients' Organizations (IAPO), in conjunction with the Memorandum and Articles of Association.

ARTICLE I: PATIENTS

Section 1

Patients

A patient is defined by IAPO as “a person with any chronic disease, illness, syndrome, impairment or disability”. IAPO aims to be representative of all patients regardless of gender, race, class, culture, religious belief, age, sexuality, lifestyle or disability.

Section 2

Patient Representatives

Patient representatives are defined by IAPO as “patients’ organization representatives, family members or carers” Examples of patient representatives are a parent of someone with cystic fibrosis or the spouse of someone with Alzheimer’s Disease.

ARTICLE II: MEMBERSHIP

Section 1

Membership Categories

(Governed by Memorandum and Articles of Association Articles 29, 31 and 32)

IAPO shall consist of three categories of member organizations: Full Members, Associate Members and a new category created under Memorandum and Articles of Association Article 32 Affiliated Members.

Section 2 Full Members

IAPO Full Members are patients' organizations. These are organizations, which are patient-driven. To become Full Members, organizations must meet the following five criteria:

- (a) Must be non-profit and non-governmental.
- (b) Must have a legal status appropriate to its country of origin, with a written constitution and/or by-laws. If no appropriate legal status exists in the country of origin this criteria may be waived at the discretion of the Governing Board.
- (c) May be an international, regional, national or local organization, or an umbrella group.
- (d) The organization must demonstrate commitment to patients and the principle of patient-centred healthcare in their guiding statements, such as their vision, mission or organizational objectives, and their activities. Typically the organization's mission will be to respond to the needs of patients in a specific geographical or disease area, supporting and representing them.
- (e) The organization must be patient-driven. This means that the needs and views of patients drive the organization's strategy, policies and activities in a significant way and that the organization is capable of representing the needs and views of these patients. Around the world, organizations achieve this in different ways. Organizations must demonstrate that they use at least one of the following methods:
 - (1) The majority of the organization's voting members are patients, patient representatives or patients' organizations with the power to nominate and elect their own governing body.
 - (2) The majority of the organization's governing body are patients, patient representatives, or representatives of patients' organizations.
 - (3) The organization can demonstrate that it has a governance structure which ensures that it is patient-driven i.e. the needs and views of patients drive the organization's strategy, policies and activities in a significant way and that the organization is capable of representing the needs and views of these patients. Patients and patient representatives may in addition support and drive the organization financially through voluntary contributions. This governance structure must be

By-Laws

Approved by Governing Board



described and illustrated in a written letter, which should accompany the organization's application.

Section 3 Associate Members

IAPO Associate Members must be healthcare-related organizations who are not eligible to become IAPO Full Members, yet who meet the following four criteria:

- (a) Must be non-profit and non-governmental.
- (b) Must have a legal status appropriate to its country of origin, with a written constitution and/or by-laws. If no appropriate legal status exists in the country of origin this criteria may be waived at the discretion of the Governing Board.
- (c) May be an international, regional, national or local organization, or an umbrella group.
- (d) The organization must demonstrate commitment to improving healthcare and to the principle of patient-centred healthcare in their guiding statements, such as their vision, mission or organizational objectives and their activities. Typically the organization's mission will be to improve healthcare through raising awareness, advocacy work, raising funds for research or assisting patients' organizations. The organization may be a multi-stakeholder umbrella coalition or alliance.

Section 4 Governed by Memorandum and Articles of Association Art 32. Affiliated Members

Under MAA Art 32 the Board can extend affiliated membership to the members of IAPO's full members that are umbrella groups and alliances. These affiliated members shall not have a voting right and their privileges shall be restricted. The Board shall time to time determine, together with the parent umbrella groups and alliances, which such organisations are admitted and what their rights, obligations and privileges shall be.

By-Laws

Approved by Governing Board



Section 5 Membership Application

In order to become an IAPO member, the applying organization must complete a membership application form available from IAPO office or website. They must present on and with this form any information requested. The Governing Board can give authorization to a member of staff to assess the applying organization's suitability for membership using Article II of these By-Laws. Approval or rejection of a membership application is then determined by the Governing Board according to Article II of these By-Laws.

Section 6 Membership Fees

Membership fees may be set and amended by the Governing Board.

Section 7 Termination of Membership (Governed by Memorandum and Articles of Association Article 30)

An organization's membership may be terminated by the following:

- (a) A written letter of resignation sent to IAPO indicating the member organization's wish to terminate.
- (b) Legal liquidation proceedings or dissolution

The Governing Board, after due deliberation, may recommend the suspension or termination of any organization's membership of IAPO. Sufficient cause for suspension or termination shall be:

- (a) Violation of any stipulation of the Memorandum and Articles of Association, by-law, rule, policy or practice duly adopted at the Annual General Meeting and/or the Governing Board Meeting of IAPO
- (b) Any other conduct materially prejudicial to the interests of IAPO
- (c) Non-payment of fees for membership of IAPO

Under MAA Art 30.3.4 Such suspension or termination shall be ratified by a vote to that effect by not less than two thirds vote of a Governing Board Meeting where at least half of the Governing Board Trustees are present provided that the notice of the proposed action, specifying the grounds for such action shall

By-Laws

Approved by Governing Board



have been given to the member organization in question at least 18 days before final action is taken. Before or at the meeting at which such action is proposed to be taken, the Full Member or Associate Member in question shall be given the right to present any defence or mitigation to such charges before the aforementioned vote of the Governing Board is taken.

ARTICLE III: GENERAL ASSEMBLY

Governed by Memorandum and Articles of Associations Articles 33 to 51

Section 1

Annual General Meetings MAA Art 33

The Annual General Assembly Meeting (hereinafter: Annual General Meeting, AGM) represents the general assembly of IAPO and shall consist of one delegate from each member organization, and should strive to reflect an international representation. This delegate shall be known as an organization's IAPO Representative. S/he should be a member of the governing body of the member organization, a chief executive, or similar status. The AGM shall elect a Governing Board to act on its behalf.

Section 2

AGM Meeting Timing

Governed by Memorandum and Articles of Associations Articles 33, 35 and 38

The AGM shall be held in every calendar year and not more than 18 months shall pass between one AGM and the next, unless this period is extended by the AGM, and at such a place and hour as the Governing Board may designate. Written notice shall be given to each member organization of the time and place of each Annual General Meeting at least 28 days prior to such meeting. If a special resolution is to be proposed, this must be included in this written notice. Matters subject to the approval of the Annual General Meeting shall include:

- (a) Election of the Governing Board in accordance with Article IV
- (b) The Annual Report and Accounts for the previous financial year
- (c) Appointment of the Auditor
- (d) Any other such business as may properly come before the meeting

By-Laws

Approved by Governing Board



The Governing Board will also present any major strategic plans or programmes for the future for the information of the AGM.

Section 3

Extraordinary General Meetings

Governed by Memorandum and Articles of Associations Article 34 MAA 34.1 The Governing Board may call an Extraordinary General Meeting, defined as a general meeting other than the Annual General Meeting, at any time (MAA 34.1). The Chair of the Governing Board shall fix the time and place for such a meeting.

MAA 34.2 The Governing Board must call an Extraordinary General Meeting if required to do so by members under the Companies Acts. The Chair may call this Extraordinary General Meeting of the Member Organizations at the request in writing of not less than twenty per cent of the fully paid up Full Member organizations, and that these organizations should originate from at least five different countries or two world regions, as defined by the Governing Board. Written notice of the date, time and place of each extraordinary meeting shall be given to each member at least 28 days prior to such meeting. Extraordinary meeting has the same structure, rights and responsibilities as the Annual General Meeting, with exception to the procedure for its calling.

Section 4

Voting at Meetings

Governed by Memorandum and Articles of Associations Articles 43 to 49

Each member organization of IAPO shall have the right to cast one vote at Annual General and Extraordinary Meetings of IAPO. Such vote may be cast in person by an individual certified to the Governing Board as the member's IAPO Representative, or under MAA Article 48 by written proxy duly executed by or on behalf of such member. The proxy can be established by a written Proxy Notice document and can designate:

- (a) Another individual from the member organization who will attend the Meeting instead of the IAPO Representative.

The Governing Board may also set up procedures for postal ballots for any matter subject to the approval of the General Assembly. Votes of Full Members and Associate Members shall be weighted in the proportion two-thirds to one third respectively, to ensure that the patient-driven member organizations are in turn driving IAPO.

By-Laws

Approved by Governing Board



Section 5 Tied Votes

If the votes are tied on a motion not concerning the appointment of persons, the motion will be rejected. Voting on persons is by ballot unless the meeting decides to vote by acclamation. If as regards an appointment of persons no one secures an absolute majority, a second vote will be held (between the nominated candidates). If again no one secures an absolute majority, the Chair shall have the casting vote.

ARTICLE IV: GOVERNING BOARD

Governed by Memorandum and Articles of Associations Articles **7-13)**

Section 1 Role

The Governing Board are the Trustees of IAPO as a charity (Charity Number 1155577) and the Directors of IAPO as a limited company by guarantee (Company Number: 08495711). The business and affairs of IAPO shall be supervised, controlled and directed by the Governing Board. The Governing Board may delegate designated authority to the Chief Executive Officer or the most senior staff member for the day to day running of the association, and from time to time to committees and working groups as it may see fit.

Section 2 Composition of Board

Governed by Memorandum and Articles of Associations Articles 25 to 27

The Governing Board shall consist of those individuals nominated by Full Member and Associate Member organizations and subsequently elected by the AGM. The Governing Board shall have no more than 12 and no less than five Board Members. No more than one third of the Board Members may be elected representatives of Associate Members.(MAA Art 25) The AGM should strive to nominate and elect a Board with at least one individual from each major world region to ensure geographical diversity and representation.

Those nominated to the Governing Board must fulfil the requirements of charity and company law in the UK, where IAPO is registered. Governing Board members must be aged 18 or over, and cannot be a Governing Board member if they:

- have an unspent conviction for an offence involving dishonesty or deception;

By-Laws

Approved by Governing Board



- are currently declared bankrupt,
- are subject to bankruptcy restrictions or an interim order have an individual voluntary arrangement to pay off debts with creditors;
- are disqualified from being a company director or have previously been removed as a trustee of any organisation by either the Charity Commission or the high court due to misconduct or mismanagement.
- Have resigned from the Board without finishing their term previously
- Ousted from the Board

MAA Art. 26.9 Details of the number of Governing Board vacancies shall be provided to the members at least sixty days before the Annual General Meeting at which an election is to take place.

Section 3

Election

Governed by Memorandum and Articles of Associations Articles 25 to 27 Each member organization can nominate an individual from their organization for election to the Governing Board prior to the Annual General Meeting. These individuals should each be a member of the governing body of the member organization, a chief executive, or similar status. The member may nominate their IAPO Representative. Nominations must be received at least 30 days prior to the Annual General Meeting (MAA Art. 26.8.2). Details of the nominated representatives must be supplied to all member organizations between five and 28 days prior to the Annual General Meeting (MAA Art. 26.10).

Candidates and their Member Organisations must adhere to the New Election Code and must declare their Conflict of Interest in a Transparency Statement and a Declaration of Interests before the Elections.

Section 4

Term of Board Membership

Governed by Memorandum and Articles of Associations Article 26

The board term of each Board Member starts at 00.01 hours on the day after the AGM at which they were elected. Each Board Member is elected for a Standard Term of up to three years, subject to MAA Art 26, and particularly MAA Art 26.2 Automatic Retirement by Rotation. At each AGM one-third of the Board has to retire. Retirements take effect at 24.00 Hours on the day before an AGM at which a Board Member has to Automatically Retire. A Board Member can serve for a maximum two Standard Terms, following these two Standard Terms the Board Member must stand down and the member organization they represent cannot nominate any person from their organization for Governing Board membership for one calendar

By-Laws

Approved by Governing Board



year of 12 months. Following this year, the organization can again nominate a person for election to the Governing Board, including individuals who have previously served on the IAPO Governing Board.

IAPO's Governing Board will endeavour to synchronise Automatic Retirements by Rotations so that not all Board Members' terms of service come to an end at once. In order to maintain the Standard Three-Year Term of service of Board Members, the Governing Board may by staggering appointments and retirements increase the size of the Board and/or vary the period between each AGM (Subject to MAA Art. 33 the period cannot be more than 18 months)

Section 5

Termination of Board Membership

(Governed by Memorandum and Articles of Association Article 27.

Disqualification and Removal of Trustees)

Membership of the Board shall be terminated on grounds given under MAA Article 27.1 -27.10 by:

- (a) Disqualification by the Companies Act 2006 and Charities Act 2011, and/or Disqualification by laws and policy of their home countries
- (b) Death
- (c) Incapacity due to mental health
- (d) Resignation by the member of the Board concerned
- (e) Periodic retirement, unless followed by subsequent reappointment.
- (f) Bankruptcy and the loss by the Board Member of either partial or complete control of his financial affairs by whatever means.
- (g) Absence from three consecutive Board meetings without an apology and reasonable explanation where the Governing Board Members resolve that he or she be removed for that reason.
- (h) The Board Member ceasing to be an active employee or member of the governing board of the member organization whom they represented at the time of their election. In the event of this the Board member shall submit their resignation as a member of the IAPO Governing Board unless, with the approval of the Board, the member organization wishes them to remain as their designated representative.

By-Laws

Approved by Governing Board



- (i) Dismissal by the Board. At a meeting of the Governing Board at which at least half of the Governing Board members are present, a resolution is passed that he or she be removed from office. Such a resolution shall not be passed unless he or she has been given at least 14 clear days' notice that the resolution is to be proposed, specifying the circumstances alleged to justify removal from office, and has been afforded a reasonable opportunity of either (at his or her option) being heard by or of making written representations to the Governing Board.
- (j) A vacancy in any office occurring for any reason, including the removal of an officer, may be filled for the unexpired portion of the vacated officer's term by the Governing Board.

Section 6

Special Advisors and Honorary Board Members

Governed by Memorandum and Articles of Associations Articles 9 Special Advisors and 28 Patrons

The Governing Board can appoint Special Advisors MAA Art 9 and Patrons (MAA Art 28) as required. A Special Advisor may be someone with certain skills that add to those of the Governing Board Members. They may be able to assist the Board with a particular issue or project, or give more general support. IAPO Special Advisors use their expertise and experience to assist the Governing Board in achieving their aims. These aims are all focused on fulfilling IAPO's mission.

A Patron can be someone who particularly contributed to the development of IAPO or achievement of its vision and mission.

Special Advisors and Patrons have no voting rights within the Governing Board and no decision-making power. The Governing Board is under no obligation to act upon the advice or recommendations given by a Special Advisor or Patrons. Special Advisors and Patrons are appointed by a simple majority vote of the Governing Board Members. They serve for the period of one year, and this term can be renewed by the Board.

Section 7

Decision-Making by Trustees and Board Meetings

Governed by Memorandum and Articles of Associations Articles 15 to 24

Meetings of the Governing Board shall be held at such time and place as shall be designated therefore by the Chair as long as they number at least two per year. In addition to this, sufficient meetings to ensure the efficient governing of IAPO should be held by means of conference calling and Webex.

Special meetings of the Governing Board may be called by its Chair who shall fix the time and place for the meeting. Subject to MAA Art. 16.1 to 16.6 The Secretary can also call a Special Meeting of the

By-Laws

Approved by Governing Board



Governing Board at the request in writing of not less than four Governing Board members. Written notice of the date, time and place of each Special Meeting shall be given to each member at least 30 days prior to such meeting, unless urgent circumstances, as determined by the Chair, require shorter notice.

Section 8

Quorum

Governed by Memorandum and Articles of Associations Article 8

The quorum for Board meetings may be fixed from time to time by a decision of the Board, but must never be less than one half of the total number of Board members plus one Board member. This applies to meetings and to votes taken between meeting by email or teleconference.

Section 9

Voting

Governed by Memorandum and Articles of Associations Article 20

Subject to MAA Art. 20 at any meeting of the Governing Board, each Board Member shall be entitled to cast one vote. Votes are decided by a simple majority. In the event of a tied vote the Chair shall have a casting vote.

Section 10

Approval

Governed by Memorandum and Articles of Associations Articles 20 to 21

Any matter requiring the approval of the Governing Board shall be determined by an affirmative vote of a simple majority of members present at a quorate meeting unless otherwise provided in the Memorandum and Articles of Association. Subject to MAA Art 21 Decisions without a meeting, matters can also be approved without holding a meeting, including through electronic means, as long as all reasonable steps have been taken to make all Board members aware of the matter on which a decision is needed, Board members have had reasonable opportunity to communicate their views on the matter, a majority of Board members have expressed an opinion, and a majority of Board members vote in favour of the particular decision. Once the decision is made, it should be communicated to all Governing Board members and note of the decision and the date of approval made in the minutes of the next Board meeting.

By-Laws

Approved by Governing Board



Section 11

Delegation of day to day management powers

Governed by Memorandum and Articles of Associations Article 12

The Governing Board may appoint a Chief Executive Officer or other senior member of staff to whom it delegates the day to day management of the organization. The appointment is subject to MAA Arts 12.1 to 12.3 and IAPO's Human Resources Policy Framework, Equal Opportunities Legislation, Disclosure and Barring Service (DBS) checks and Right to work in the UK

Section 12

Remuneration

The Board Members shall not receive any salary or other remuneration for their work as such; expenses incurred for the benefit of the organization, in line with IAPO policies, shall be reimbursed if requested.

ARTICLE V: OFFICERS

Section 1

Governed by Memorandum and Articles of Associations Article 8 Officers

The officers of the Governing Board shall be the Chair, Vice-Chair, Secretary and Treasurer. The Chief Executive Officer or in his/her absence, the most senior member of staff shall serve as an officer of IAPO without vote and shall be appointed by the Governing Board. The officers constitute an Executive Committee of IAPO, established for purposes of facilitating the work of the Governing Board.

Section 2

Election and Terms

Governed by Memorandum and Articles of Associations Article, 26)

The officers shall be elected by and from the Governing Board. All officers shall hold office for a maximum of two years in any position. Subject to MAA Article 26.2 Chairs

By-Laws

Approved by Governing Board



Section 3

Removal and Vacancies

Governed by Memorandum and Articles of Associations Articles 8 and 27

Any officer elected by the Governing Board may be removed by the Board with or without cause in accordance with Article IV, Section 5. A vacancy in any office occurring for any reason, including the removal of an officer, may be filled for the unexpired portion of the vacated officer's term by the Governing Board.

- (a) If an Officer is unable to perform their duties for any reason for a period longer than 90 days, he or she shall stand down from the position and the Board may appoint someone else from within the Governing Board to take on those responsibilities for the remainder of the term of office. The Officer standing down from office shall remain a board member for the remainder of their term unless he/she decides to retire from the board.
- (b) In the case of the Chair, the Vice-Chair shall become Chair to complete the term of office of the retiring Chair.
- (c) Should the Vice-Chair become Chair through the retirement of the Chair under Section 3 (a), then the board shall elect a Vice-Chair to assist the new Chair in the performance of his/her duties.

Section 4

Chair

The Chair shall preside at all meetings of the members of IAPO, the Governing Board and the Executive Committee; and shall be an ex-officio member (with the right to vote) of all committees.

Section 5

Vice-Chair

The Vice-Chair shall chair meetings of the members of IAPO, the Governing Board and the Executive Committee in the absence or disability of the Chair. S/he shall also perform such other duties as may be assigned from time to time by the Chair or Governing Board.

Section 6

Secretary

The Secretary shall keep or cause to be kept an accurate record of the proceedings of the meetings of members, the Governing Board and the Executive Committee; shall preserve the records, documents and correspondence of IAPO as directed by the Board of Directors; shall give or cause to be given notice of all meetings of members and of the Governing Board. He/she shall also perform such other duties as may be assigned from time to time by the Chair or Governing Board.

By-Laws

Approved by Governing Board



Section 7

Treasurer

The Treasurer shall be the custodian of the association funds. The Treasurer shall deposit, or cause to be deposited, these funds in the association name in such depositories as the Governing Board shall designate. Subject to such resolutions as the Governing Board may, from time to time adopt, the Treasurer shall oversee and work with the Chief Executive Officer and other staff members who handle the day-to-day financial business of IAPO, including disbursements, accounting and auditing procedures. The Treasurer shall in addition report to the Governing Board an accurate account of the financial condition of IAPO at their two annual meetings. They shall also perform such other duties as may be assigned from time to time by the Chair or Governing Board.

ARTICLE VI: COMMITTEES

(Governed by MAA, Article 11)

Section 1

Executive Committee

Governed by Memorandum and Articles of Associations Article 11 Committees

The Executive Committee shall consist of the officers of IAPO as detailed in Article V: the Chair, Vice-Chair, Secretary and Treasurer of the Governing Board, and the Chief Executive Officer. The Executive Committee may act between meetings of the Governing Board, in accordance with the Memorandum and Articles of Association, By-Laws and policies laid down by the Governing Board. Reports of all meetings and actions taken must be reported to the Governing Board.

The Executive Committee is mandated to discuss, explore and elaborate on issues that are more operative in nature, or on matters for which additional work is needed before they are brought to the attention of the entire Board. The Executive Committee has no voting power, and can only make recommendations to the Governing Board.

By-Laws

Approved by Governing Board



Section 2

Committees and Other Bodies

Governed by Memorandum and Articles of Associations Articles 11 and 12

The Governing Board may constitute and delegate specific authorities to an Executive Committee, and to other committees and working groups, which from time to time may be required, to pursue the policies, programs, projects, commitments and membership guidelines it has established.

ARTICLE VII: AMENDMENT OF MEMORANDUM AND ARTICLES OF ASSOCIATION OR BY-LAWS

Governed by Memorandum and Articles of Association Articles 14

AGM Practicalities, Agenda and Voting

IAPO's Memorandum and Articles of Association, may (subject to adhering to company and charity law of England and Wales) be amended, repealed, or altered, in whole or in part, with a two thirds majority of the votes cast by the General Assembly at an Annual General or Extraordinary Meeting of IAPO.

Any change must be in the genuine best interests of the whole of IAPO and not just made to meet the needs of some Board Members and Member Organisations. The change cannot be used by a majority to discriminate against minority members.

Any vote by the members to amend the Memorandum and Articles of Association shall be weighted in the proportion of two thirds Full Members to one third Associate Members, respectively. Amendments may be brought before the Annual General Assembly Meeting by the Chair at the request of

- (a) The Governing Board
- (b) Not less than twenty per cent of the members. The request must be in writing. These organizations should originate from at least five different countries or two world regions, as defined by the Governing Board.

Any proposed amendment must be received by the Chair at least 60 days prior to the Annual General Meeting or Extraordinary Meeting of the General Assembly. A copy of any amendment proposed for consideration shall be sent to each member at least 30 days prior to such meeting.

Alteration to the Memorandum and Articles of Association will not come into effect until the amended versions have been submitted and approved by the relevant authorities within the UK. Each Board Member has power individually to sign any new articles.

By-Laws

Approved by Governing Board



The provisions of this Article apply analogously to a decision to merge or divide the Association.

The By-Laws may be amended by a majority decision of the Governing Board.

ARTICLE VIII: WINDING UP/ DISSOLUTION

Governed by Memorandum and Articles of Associations Articles 59

IAPO can be dissolved by a decision of the General Assembly at an Annual General Meeting. The process to be followed must adhere to charity and company law in the United Kingdom. The Governing Board members as the Trustees are empowered to oversee the winding up. They continue to be subject to the provisions concerning the appointment, suspension, dismissal and supervision of Board members. During the winding up, the other provisions of the Memorandum and Articles of Association and By-Laws remain in force as far as possible. On completion of the winding up, the books and documents of the dissolved organization will remain in the custody of the person designated by the General Assembly for that purpose for seven years. In accordance with the Memorandum and Articles of Association, the credit balance after winding up the organization will be used for particular purposes that fall within the or are similar to objects of IAPO as set out in its Memorandum and Articles of Association. Any funds can only be passed to an institution or institutions, which are or are regarded as charitable under the law of every part of the United Kingdom. The purpose and institution to which the funds are passed shall be determined by the General Assembly.

ARTICLE IX: FINAL PROVISIONS

All the powers not assigned by law or Memorandum and Articles of Association or the By-Laws to other bodies are vested in the Governing Board.

Approved by the Governing Board on this date of 9th September 2019.