

# INTERNATIONAL PATIENT ORGANISATION FOR PRIMARY IMMUNODEFICIENCIES



## Introduction.

The purpose of the proposals in this document is to set out a broad framework for the operation and interaction of the main IPOPI bodies - the General Assembly (representing the NMOs), the Executive Committee and Committees. It is not designed to be entirely consistent with the IPOPI charter. The purpose of the Charter is to fulfill the requirements for registration as a registered charity in the UK. The Charter does not contain sufficient detail to clarify the role of each body. To put such detail in to the charter would not be practical given the requirements of UK charitable law.

## PROPOSAL ON REVISION OF RULES OF PROCEDURE

### **ITEM 1. Membership**

IPOPI recognises as members: National Member Organisations (NMO and Associate NMOs). Membership of IPOPI shall consist of one NMO from each country. The NMO shall represent the interests of persons (adults and children) with primary immunodeficiency in that country. Accreditation as an NMO shall be decided by the General Assembly of IPOPI based on the criteria set out in the NMO accreditation Criteria document. NMOs shall have the right to vote at the General Assembly. The category of Associate NMOs is for national member organisations which do not currently fulfill the criteria for accreditation as full NMOs but who are working to achieve same. This category for membership is also available for NMOs representing patients in special territories (ie not falling under the list of UN-recognized countries). Associate NMOs shall not be eligible to vote at the General Assembly

The level of dues and privileges attached to such membership shall be determined from time to time by the Executive Committee.

### **ITEM 2. Responsibilities of a National Member Organization**

1. It shall inform IPOPI of the name and address of the President or Chairperson of the NMO / Associate NMO who shall be considered responsible for maintaining contacts with IPOPI, unless the NMO informs IPOPI that this task has been entrusted to another duly designated person.
2. NMOs and Associate NMOs must supply with their application for membership such evidences as IPOPI may require to substantiate the status of the applicant and its entitlement to be elected as a National Member Organization in accordance with the IPOPI NMO accreditation criteria.
3. National Member Organizations (NMOs) and associate NMOs must agree, if their application for membership is accepted, to pay to IPOPI such annual assessments as are determined by the Executive Committee of IPOPI and, according to the Charter, conform with all other provisions of the Charter which are applicable to it. Assessment amounts shall be published on the IPOPI website.

### **ITEM 3. Termination of Membership and Associate Membership of National Member Organizations**

Subject to confirmation by the General Assembly membership of IPOPI shall cease:

1. By resignation addressed to IPOPI in which case it shall take effect at the end of the current financial year.
2. By dissolution of the organization, in which case it shall take immediate effect.

3. By default in payments of assessments for two consecutive years, provided that the NMO has received a warning notice from IPOPI at least three months before the end of this two-year period. The termination shall take effect as from the pronouncement of exclusion of the NMO by the General Assembly, which shall have authority to postpone the termination if particular circumstances make this desirable.
4. If an NMO/Associate NMO no longer fulfils the criteria for IPOPI membership, termination of their membership may be proposed by the Executive Committee for decision by the General Assembly.
5. Organisations may be suspended from membership or be re-instated from suspension by decision of the Executive Committee until the next General Assembly.

#### **ITEM 4. General Assembly**

1. The General Assembly is the supreme body of IPOPI.
2. The General Assembly shall be composed of one voting delegate or their designated alternate from each National Member Organization.
3. The General Assembly shall meet in regular session every second year.
4. In the years where a full General assembly is not held, a General Assembly will be convened by conference call for the purpose of considering the audited annual accounts and any other such business as the Executive Committee may decide.
5. Special sessions may be convened by the Executive Committee or at least a majority of the current NMO membership.

#### **Voting**

- a) Each NMO which is up to date with the payment of its annual assessment shall have one vote in the General Assembly which shall be cast by the duly accredited voting delegate or named alternate delegate;
- b) The quorum for the regular General Assembly shall be one half of the current NMO membership. The quorum for the conference call General Assembly shall be the Executive Committee.
- c) If the necessary quorum is not attained, decisions taken are not valid until the Executive Office obtains by electronic vote a response from a majority of NMOs after circulating to all NMOs. The majority of these responses must be in the affirmative to decide the issue.
- d) If urgent matters occur in between General Assemblies which are the responsibility of the General Assembly to decide, an electronic ballot will be instituted. Decisions taken are not valid until the Executive Office obtains by electronic vote a response from a majority of NMOs upon the particular issue after circulating to all NMOs. The majority of these responses must be in the affirmative to decide the issue.

- e) At the General Assembly, all questions shall be decided by the simple majority of accredited NMO delegates present.
- f)

### **General Assembly Procedures**

1. 30 days prior to each General Assembly each NMO must advise the Executive Office of the name of its voting delegate (and alternate delegate if available)
2. Only the named delegate or in his/her absence the alternate delegate may vote and speak on behalf of their NMO. E-voting or vote by proxy letter may be envisaged in certain circumstances, subject to a decision by the Executive Committee. However, in order to vote for members of the Executive Committee, the voting delegate or alternate must attend in person.
3. The Executive Committee shall select a Chairperson for each General Assembly, normally at least two months in advance of the meeting
4. Other individuals may address the Assembly at the invitation of the Chairperson.
5. The place and date of any session, as well as the proposed Agenda, shall be notified at least two months in advance to NMOs.
6. Any written proposition received by the Executive Office before the opening of any ordinary or special session shall be added to the proposed Agenda, only if the Assembly at the beginning of its session so decides.
7. The General Assembly shall:
  - a) Direct and instruct on the general policy of IPOPI.
  - b) Elect the members of the Executive Committee.
  - c) Decide on admission to membership and termination of membership of NMOs.
  - d) Approve the reports presented by the Executive Director and Treasurer.
  - e) Appoint the auditors for the next financial year
  - f) Approve the audited annual accounts.
  - g) Deal with any other matter with the agreement of the General Assembly Chairperson.
8. NMOs which have not paid their annual assessments by the required date shall not be entitled to vote.
  - a) Voting at any meeting of the General Assembly may be by show of hands, or by ballot as may be determined at any meeting. In between meetings of the Assembly, questions may be resolved by electronic vote.
  - b) The election of members of the Executive Committee shall always be by ballot.

### **ITEM 5. The Executive Committee of IPOPI**

The Executive Committee, elected by the General Assembly, shall be the Executive body of IPOPI, responsible to the General Assembly. It shall consist of not more than 10 voting members who will elect from their number as follows:

- a) Three officers:
  - 1. The Chairperson, who shall be elected by the Executive Committee and shall be the legal representative of IPOPI.
  - 2. The Vice Chairperson who shall be elected by the Executive Committee
  - 3. The Treasurer who shall be elected by the Executive Committee
- b) Four members.
- c) In addition, the Executive Committee may co-opt a maximum of three members who will serve a two-year term. Should a situation arise where there are not enough nominated and elected members to reach 10 voting members, the difference could be made up through the co-option procedure.

Terms of office for elected members are four years. However, candidates in the middle of a 4-year mandate or starting a co-opted mandate may be subject to two-year terms as officers. Officers and members are eligible for re-election but no officer or member may serve more than eight consecutive years on the Executive Committee. An extension may be given through the co-option procedure in two exceptional circumstances: the need to comply with the Charter with regards to having a UK Trustee at all times and the need to retain Board members who have more than four years historical corporate knowledge of IPOPI. Such extensions are subject to decision by the Executive Committee.

Co-opted members serve a two-year term subject to a maximum of eight consecutive years on the Executive Committee.

The Chair and Vice-Chair of the Medical Advisory Panel and the Executive Director may attend Executive Committee meetings on an ex-officio basis.

### **Nomination and election procedure for the Executive Committee**

The nomination and election procedure for the Executive Committee shall take place as follows:

The nomination and election process will be conducted by the IPOPI Executive Director under the supervision of the Chairperson.

Only accredited NMOs who have paid their assessment in the current year may nominate people to stand for election to the Executive Committee

## **Nomination Process**

150 days prior to the General Assembly a call shall be made to all eligible NMOs to submit nominations as follows:

### Nomination of Members

Each NMO may nominate a maximum of one candidate for the Executive Committee.

Nomination forms for all nominees must be signed by the Chairperson of the nominating NMOs.

## **Election Process**

The process for selecting the candidates who will appear on the final election slate at the General Assembly is as follows:

90 days prior to the General Assembly the nominations will close and the Executive Director shall:

- a) Collate and check the nominations received for the Executive Committee members.
- b) Request CVs of the nominees being put forward for election and their signed consent to appear on the slate.
- c) Prepare the final election slate.

### **Election Process-General Assembly**

At the General Assembly all accredited NMOs will vote on the final election slate. (Note - Associate NMOs do not vote)

In the event of a tied vote at the General Assembly, a selection by lot shall be made by the General Assembly Chairperson.

### **Additional Appointments**

Co-option of up to three additional Executive Committee members **may** take place at the first or subsequent meeting of the Executive Committee following a General Assembly. In deciding on the co-options, the Executive Committee will have regard to ensure that specific expertise or experience is included and the Executive Committee shall be as representative as is practicable. The requirement to have a trustee from the UK to conform to the Charter must also be adhered to. Under special circumstances, co-option may take place from within the Executive Committee (see item 5 above).

### **Terms of Reference of the Executive Committee**

1. The Executive Committee shall be chaired by the Chairperson. In the absence of the Chairperson, the Vice-Chairperson shall chair the meeting. In the absence of both the Executive Committee shall select an Acting Chairperson from among the members
2. A minimum of six Executive Committee meetings must take place during each calendar year. All elected Executive Committee members are required to attend a minimum of 5.

3. The quorum for a meeting of the Executive Committee is 50% plus one.
4. Decisions shall be taken by the simple majority of members present and voting.
5. Vacancies
  - a) Vacancies occurring in the Executive Committee in between General Assemblies may be filled by the Executive Committee by appointing persons to fill that vacancy until the next session of the General Assembly.
  - b) In the case of a vacancy of the Chairperson, the vacancy shall be filled by the Vice-Chair, until the next General Assembly.

**The Executive Committee shall:**

- a) Supervise and direct the work of the Executive Director who in turn supervises and directs staff.
- b) Prepare for General Assembly meetings and supervise the organization of Congresses.
- c) Take all necessary steps and initiatives within the context of the Charter and Rules of Procedure in the interest of the objectives of IPOPI.
- d) Decide on membership dues and privileges of accredited and associate NMOs.
- e) Be entitled to organise fund raising campaigns.
- f) Decide on the acceptance of gifts, bequests or endowments to IPOPI.
- g) Maintain relations with other organisations and bodies.
- h) Appoint a Medical Advisory Panel and assign responsibilities to same.

To assist in carrying out its functions and performing the duties for which it is responsible, the Executive Committee may as it considers necessary:

- a) Establish Committees comprising either some of its members or other persons or representatives of NMOs in order to pursue particular tasks within the context of the objectives of IPOPI.
- b) Allocate particular functions to its members or other suitable persons
- c) Appoint representatives to other organizations.

All persons so appointed must act in accordance with IPOPI policies and in the best interest of IPOPI.

**ITEM 6. The Medical Advisory Panel (MAP)**

1. This Panel shall consist of members appointed by the Executive Committee of IPOPI. The Chairperson and Vice-Chairperson of the MAP shall be selected by the Executive Committee and may be entitled to attend Executive Committee meetings on an ex-officio basis. Members of the Panel shall be selected for their expertise and experience in the treatment of primary immunodeficiencies and for their commitment to work with and for IPOPI.
2. The Medical Advisory Panel shall advise the Executive Committee on medical matters and may undertake responsibilities assigned to them by the Executive Committee.

**ITEM 7. The Executive Office**

1. The Executive Office staff shall administer the affairs of IPOPI.
2. The Executive Office is headed by the Executive Director who is appointed and whose conditions of employment are determined by the Executive Committee. The Executive Director reports to the Executive Committee through the Chairperson.

The Executive Director is the chief administrative officer of the IPOPI and is responsible for implementing policies and programs, as defined by the Executive Committee and General Assembly.

The responsibilities of the Executive Director are established by the Executive Committee which periodically sets out specific goals and objectives and reviews performance.

The responsibilities of the Executive Director generally include: the preparation and administration of the budget; the employment and deployment of staff, in consultation with the Chairperson; the administration of all programs and projects; public relations, representation and fundraising.

**ITEM 8. Finances**

1. The financial year of IPOPI shall be from January 1 to December 31.
2. IPOPI shall be financed by:
  - a) Grants, donations, bequests, endowments to IPOPI from NMOs, public and private bodies and persons, including industry, provided that they are consistent with the objectives of IPOPI and do not impede its freedom of action.
  - b) Annual assessments from NMOs as specified in the NMO assessment protocol
  - c) Other means as approved by the Executive Committee.
3. The Executive Director, Chairperson and Treasurer will prepare a budget each year for approval by the Executive Committee.
4. Annual assessments from NMOs become due on the first day of each financial year and shall be paid in the course of that year.



5. IPOPI may raise funds through public appeals. Appeals by IPOPI for funds shall be made in any country only after consultations with the corresponding NMO.
6. The Executive Director shall, under the supervision and direction of the Executive Committee, and in consultation with the Chairperson and Treasurer, be responsible for the administration of the funds of IPOPI. The Executive Committee shall adopt policies as required on such matters as investments, signatories to IPOPI accounts, travel allowances.
7. The Executive Office staff shall, under the supervision of the Treasurer, keep proper accounts.
8. The Executive Office shall, under the supervision of the Treasurer, prepare an annual audited financial report and submit to NMOs.
9. The auditor shall be appointed annually by the General Assembly.

### **ITEM 9. IPOPI Committees**

Chairs of IPOPI Committees will be chosen by the Executive Committee. Committee members will be chosen by the IPOPI Chairperson and Committee Chair. Membership should be as regionally representative as is practicable.

Each Committee's official designation and terms of reference are determined by the Executive Committee. The Committee's terms of reference must be filed with the Executive Office. Each Committee's terms of reference are to contain:

1. The Committee's objectives and the scope of its activity.
2. The period of time necessary for the Committee to carry out its purposes.
3. The person/position to whom the Committee report
4. A description of the duties for which the Committee is responsible, and, if such duties are not solely advisory, a specification of the authority for such functions.
5. The estimated annual operating costs and personnel time required for such Committees.
6. The estimated number and frequency of Committee meetings.
7. The Committee's termination date, if ad hoc.
8. The date, the terms of reference are filed with the signature of the Committee Chairperson confirming he or she is in accord with IPOPI Rules of Procedures for Committees.
9. The IPOPI Chairperson, or his/her designate, is an ex-officio member of all Committees.

**ITEM 10. World and Regional Congresses**

The Executive Committee:

- a) May organise World or Regional Congresses.
- b) May receive and examine proposals from NMOs desiring to act as host for a World or Regional Congress.
- c) Shall organise the General Assembly of IPOPI to take place during the course of an IPOPI Congress

**ITEM 11. Conflict of Interest Declaration**

All members of the IPOPI Executive Committee and all IPOPI Committee Chairs will complete and sign a Conflict of Interest declaration annually.

**ITEM 12. Amendments to the Rules of Procedure**

These Rules of Procedure may be amended by the Executive Committee but any such amendments must be ratified by the next General Assembly in order to stay in effect. NMOs may also propose amendments at least three months in advance of the AGM which shall be placed on the agenda for the next meeting of the General Assembly for decision.

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Adopted Barcelona, September 2016