

# INTERNATIONAL PATIENT ORGANISATION FOR PRIMARY IMMUNODEFICIENCIES

*IPOPI aisbl is an international non-profit association registered in Belgium.  
Numéro d'entreprise BE 0761.784.055*



## 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.

**The purpose of the statutes is to fulfill the requirements for registration as a registered international non-profit association in Belgium. As per the provisions of IPOPI's statutes, the Executive Committee can implement rules of procedure aimed at complementing the statutes and facilitating the internal functioning of IPOPI.**

## **ITEM 1. Membership**

IPOPI recognises as members, national organisations of patients with primary immunodeficiencies and their families, hereby called National Member Organisations (NMO). IPOPI recognises two membership categories: voting members, also called Full NMOs, and non-voting members, also called Associate NMOs.

1. 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
2. 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. Full NMOs shall have the right to vote at the General Assembly.
3. The category of Associate NMOs is decided by the Executive Committee based on the criteria set out in the NMO accreditation criteria document. Associate NMOs have the same rights as full NMOs except they are not eligible to vote or nominate candidates for the Executive Committee at the General Assembly.

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

1. It shall inform IPOPI of the names and contact details of the Executive Committee members of the NMO including the President or Chairperson of the 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. Full NMOs and Associate NMOs must supply with their application for membership such evidence as IPOPI may require to substantiate the status of the applicant and its entitlement to be elected as a National Member Organisation in accordance with the IPOPI NMO accreditation criteria.
3. 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 Statutes, as well conform with all other provisions of the Statutes 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 Organisations**

Membership of IPOPI shall cease:

1. By resignation addressed to IPOPI by presenting three months' written notice to the Chairperson of the Executive Committee. Any resignation of membership will be noted during the next General Assembly.
2. By dissolution of the organisation, in which case it shall take immediate effect. Any termination of membership due to a dissolution will be noted during the next General Assembly.
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 no longer fulfills 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 which will decide about reinstatement or exclusion.

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

##### ITEM 4.A. General Assembly Body

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 Full NMO.
3. The General Assembly will meet in the form of a face-to-face meeting at least every second year and as a teleconference/online meeting the other year. Whenever global circumstances do not allow the face-to-face meeting (i.e. pandemics or other global crises that may prevent the in-person attendance of the NMOs), the General Assembly will meet in the form of a teleconference/online meeting.
4. The Executive Committee decides upon the exact date, timing, and agenda items, if relevant, place, by sending the invitations with the agenda and proposals to be voted on (including amendments to the statutes) by email at the latest one month in advance.
5. A teleconference/online meeting by the AGM must be held before the 30<sup>th</sup> of June of each year in order to approve the annual accounts.
6. Special sessions may be convened by the Executive Committee or at least a majority of the current NMO membership.

##### ITEM 4. B. Voting

- a) Each voting member (Full NMO) who 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) For the General Assembly representatives of more than 50% of the voting members (Full NMOs) must be in attendance in order to proceed to vote for issues relating to amending the statutes, dissolving IPOPI or expelling a voting member, and a two-third majority of the attending voting members is required.
- c) For any other matters, a simple majority of the voting members in attendance is required, without any minimal attendance quorum required.
- d) Abstentions are not counted.
- e) One proxy per voting member is allowed as per the statutes

## General Assembly Procedures

1. 45 days prior to each General Assembly each Full 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 Full NMO. E-voting or vote by proxy letter may be envisaged in certain circumstances, subject to a decision by the Executive Committee. Every voting member may give a written proxy to another voting member. Nobody may cast more than one proxy.
3. The place and date of any session, as well as the proposed Agenda, shall be notified at least one month in advance to NMOs. Any other business should be sent to the Executive Office at least 15 days in advance. Any urgent topic could nevertheless be added to the agenda on the day of the general assembly if all voting members present unanimously decide to do so.
4. The General Assembly shall:
  - a) Direct and instruct on the general policy of IPOPI.
  - b) Elect the members of the Executive Committee either at the regular session of the General Assembly or prior by certified electronic voting.
  - c) Decide on admission to membership and termination of membership of NMOs.
  - d) Approve the annual report presented by the Chairperson.
  - e) Appoint the auditors for the next financial year
  - f) Approve the audited annual accounts presented by the Treasurer.
  - g) Deal with any other matter with the prior agreement of the Executive Committee.
5. Full NMOs that 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**

IPOPI shall have an Executive Committee comprising at most seven elected members who shall be elected by the General Assembly either at the in-person session or prior through certified electronic voting. The Executive Committee shall have the power to co-opt up to three additional members and may issue special mandates to persons outside the executive committee to represent IPOPI. The Executive Committee shall be the Executive body of IPOPI, responsible to the General Assembly. The elected members 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) 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, the difference could be made up through the co-option procedure.

Terms of office for elected members are four years and may be renewed once. No member may serve more than two consecutive *elected* mandates.

Notable Exceptions: If a Member of the Executive Committee leaves the Executive Committee during their mandate, is unable to complete their mandate or is dismissed by the Executive Committee, extraordinary elections upon decision by the Executive Committee may be held by certified electronic voting with the purpose of replacing the departed Executive Committee Member. The newly elected Member, under this procedure, will complete the remaining term of the original mandate and is then eligible to run for re-election.(\*)

Co-opted members serve a two-year term, and may be renewed four times. Previously co-opted members may also be eligible for election.

Upon decision by the Executive Committee, Executive Committee members who have served two consecutive mandates may be retained on the Executive Committee through the co-option procedure.

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 Full 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 and the Chairperson shall:

- a) Collate, check and validate 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**

All Full NMOs will vote on the final election slate either at the General Assembly Meeting or prior by certified electronic voting.

In the event of a tied vote, 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 meetings 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.

## **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.

3. The Executive Committee decides by a simple majority (i.e. more votes in favour of the proposal than votes against it, the abstentions being not counted). The Board may not decide without the participation to the vote of at least half of its members. No proxy is admitted.

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

Vacancies occurring in the Executive Committee in between General Assemblies may be filled by the Executive Committee appointing persons to fill that vacancy through the co-option procedure until the next session of the General Assembly or until extraordinary Executive Committee elections can be organised.

**The Executive Committee shall:**

- a) Have all the powers to run the affairs of IPOPI except those under the responsibility of the General Assembly. This includes among others:
- b) Supervise and direct the work of the Executive Director who in turn supervises and directs staff.
- c) Prepare for General Assembly meetings and supervise the organisation of Congresses.
- d) Take all necessary steps and initiatives within the context of the Statutes and Rules of Procedure in the interest of the objectives of IPOPI.
- e) Be entitled to organise projects, events and campaigns.
- f) Maintain relations with other organisations and bodies.
- g) 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 organisations.

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**

The Executive Office shall administer the affairs of IPOPI and 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 executive officer of IPOPI and is responsible for implementing policies and programmes, as defined by the Executive Committee.

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 membership dues from NMOs
  - 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. The Executive Director shall, under the supervision and direction of the Executive Committee, and in cooperation with the Chairperson and Treasurer, be responsible for the administration of the funds of IPOPI. The Executive Committee has adopted policies as required on such matters as investments, signatories to IPOPI accounts, travel allowances.
6. The Executive Office staff shall, under the supervision of the Executive Director and in cooperation with the Treasurer, keep proper accounts.



7. The Executive Office shall, under the supervision of the Executive Director and in cooperation with the Treasurer, prepare an annual audited financial report and submit to NMOs.
8. The auditor shall be appointed annually by the General Assembly.

**ITEM 9. IPOPI Committees and Task Forces**

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

Each Committee and Task Force's official designation, the scope of activity, objectives, means, and milestones are determined by the Executive Committee which keeps an updated list of all committees and task forces.

**ITEM 10. Confidentiality agreement**

All members of the IPOPI Executive Committee sign a non-disclosure agreement upon their election to the Board.

**ITEM 11. Amendments to the Rules of Procedure**

These Rules of Procedure may be amended by the Executive Committee, any such amendments will be communicated to the members.

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