

1. Following an initial meeting held at Oxford, England, in September 1990, the formation at that meeting of an interim organizing committee and two years of preparation,
2. The representatives of national organizations of patients with primary immune deficiencies and other interested parties meeting at Lugano, Switzerland, from 1 to 3 October 1992 hereby establish the

INTERNATIONAL PATIENT ORGANIZATION FOR PRIMARY IMMUNODEFICIENCIES (IPOPI)

and adopt the following as the

CHARTER OF THE INTERNATIONAL PATIENT ORGANIZATION FOR PRIMARY IMMUNODEFICIENCIES.

Preamble

3. The reason for the founding of IPOPI is the great need for international co-operation among patient organizations concerned with primary immunodeficiencies. As indicated in the WHO Technical Report, "Immunodeficiency", primary immunodeficiency diseases comprise at least 80 different syndromes ranging from mild to severe disease. International co-operation among patient organizations representing those with these diseases can be a source not only of moral comfort but also of practical assistance in improving standards of care and treatment world-wide.
4. The organization shall be called 'The International Patient Organization for Primary Immunodeficiencies' or such other name as the Executive Committee hereinafter constituted shall from time to time determine.

Membership

5.
 - a. Voting membership in IPOPI is open to national organizations of primary immunodeficient patients.
"National organizations of primary immunodeficient patients" are organizations that:
 - I. Are officially recognised within their home country
 - II. Are open to all patients in that country with primary immunodeficiencies recognized by WHO
 - III. Represent only the interests of patients with primary immunodeficiencies and their families
 - IV. Have a commitment to the care and treatment of patients with primary immunodeficiencies.
 - V. Have an accountable structure, with the full involvement of people with primary immunodeficiencies.
 - b. Organizations wishing to join IPOPI shall apply in writing to the Chairperson of the Executive Committee of IPOPI. Copies of their charter and statement of objectives or equivalent documents should be submitted with their application to the Executive Committee. The Executive Committee will review the application for conformity with the criteria in paragraph a. of this article. If the Executive Committee determines that the criteria are met, they shall recommend the application to the next general assembly for decision.
 - c. Organizations which do not meet the above criteria but whose aim is to do so may be admitted to non-voting associate membership of IPOPI at the discretion of the Executive Committee.
 - d. Organizations may be suspended from or re-instated from suspension of membership of IPOPI until the next General Assembly on the decision of the Executive Committee. The expulsion or reinstatement of an expelled organization shall be a decision for the general assembly.
 - e. Organizations, whether in voting or non-voting membership of IPOPI, may resign that membership subject to the presentation of three months' written notice to the Chairperson of the Executive Committee.

The purposes of IPOPI

6. IPOPI is established to promote the efficient and effective application of resources for the relief of persons with primary immunodeficiencies by national patient organizations.
7. IPOPI shall not be liable for any members' organizational business. It shall not be responsible for the success or failure of any member. It shall not be a governing body for national organizations.

The powers of IPOPI

8. In order to accomplish its purposes, IPOPI may, inter alia:
 - a. Act as a clearing-house for the distribution to its member organizations of medical information and other communications that may be of interest and benefit to them;
 - b. Publish a newsletter to keep all interested persons informed of its own and its member organizations' activities and of any other matters relevant to its purposes;
 - c. Through means including the supply of written and visual materials, visits and other contacts:
 - i Inform, advise and support member organizations and persons trying to establish new national organizations
 - ii Inform and educate doctors, nurses, patients and the general public about primary immunodeficiency diseases.
 - iii Support and give advice to all member organizations on important work promoting and bettering the patient situation.
 - d. Keep abreast of the latest developments in research and treatment of relevance to primary immunodeficiencies;
 - e. Promote and support research in the primary immunodeficiency diseases.

Finances

9. IPOPI may receive contributions from member organizations and, provided its independence is not compromised thereby, from other sources.
10. All spending by IPOPI shall be consistent with the purposes of the Organization.
11. The Executive Committee shall keep books of account and submit them for annual verification by independent registered accountants and for scrutiny by general assemblies of the Organization.

ORGANIZATIONAL MATTERS

Structure

12. The organizations belonging to IPOPI shall normally meet in General Assembly once every two years.
13. IPOPI shall have an Executive Committee comprising seven elected members who shall be elected by the General Assembly. The Executive Committee shall have the power to co-opt up to three additional members. The Committee shall be the principal organ for carrying out the Organization's purposes and shall be empowered to perform all acts consistent with that function. It shall report to each General Assembly of the Organization
14. Membership of the Committee shall be open to representatives in good standing of members entitled to vote and shall be for renewable two-year terms subject to a maximum of four terms. Elections for the Executive committee shall be held at each General Assembly of the Organization.
15. IPOPI shall have a Medical Advisory Panel comprising medically qualified specialists in primary immunodeficiencies who

- a. agree to advise IPOPI on medical matters
- b. The members of the Medical Advisory Panel shall be chosen by the Executive Committee on the basis of expertise.
- c. The members of the Medical Advisory Panel shall serve for renewable terms of two years
- d. The Chair of the Medical Advisory Panel shall be appointed by the Executive Committee and shall be entitled to attend the Executive committee meetings on an ex-officio basis.

Elections

- 16. A list of candidates for election to the Executive Committee shall be presented to each General Assembly of the Organization in line with the defined election procedure
- 17. The Executive Committee shall elect from among its members a Chairperson, Vice-Chairperson and Treasurer.

Voting at a General Assembly

- 18. In all matters decided by voting:
 - a. The votes shall be cast by authorized representatives of national organizations entitled to vote. Satisfactory written evidence of authorization shall be presented to the Executive Committee in advance of the vote;
 - b. Each organization entitled to vote shall have one vote;
 - c. Except as otherwise indicated in this Charter, decisions shall be made by a simple majority of the member organizations participating in the vote in question;
 - d. In the event of a tie, the Chairperson of the Executive Committee shall have a deciding vote.
 - e. Representatives of more than 50% of the accredited NMOs must be in attendance in order for a General Assembly to proceed to vote on any issue.

Amendment of the Charter

- 19. All proposals for the amendment of this Charter shall be submitted to the Secretary of the Executive Committee and shall be put to a vote within six months of receipt if judged by the Executive Committee to be consistent with the objectives of the organization. To become effective, they shall require the approval of at least two thirds of the organizations entitled to vote.
 No amendment shall be made to Clause 6, Clause 20 or this Clause without the prior consent in writing of the Commissioners and no amendment shall be made which would have the effect of the Organization ceasing to be a charity at law.

Dissolution of IPOPI

- 20. The dissolution of IPOPI shall require a decision by at least two thirds of the organizations entitled to vote. Disposal of funds in the possession of IPOPI shall be determined by the Executive Committee.
 Any assets remaining after the satisfaction of any proper debts and liabilities shall be given or transferred to such other charitable institution or institutions having objectives similar to the Organization as the member organizations shall determine; or failing that, shall be applied for some other charitable purpose.

IPOPI Charter
 Adopted Goteborg, Sweden: June 1996
 Amended Rhodes: October 1998
 Amended Geneva: November 2000
 Amended Weimar: November 2002
 Amended Budapest 2006