

Ipopi Meeting

Budapest 2006

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Presentation of IPOPI Rules of Procedure and
Assessment

The global organisation working to improve the quality of life for people with primary immunodeficiencies



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IPOPI

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IPOPI is a

GROWING

LIVELY

DYNAMIC

GLOBAL ORGANISATION

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As we grow we need guidelines

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IPOPI

INTERNATIONAL
PATIENT ORGANISATION
FOR PRIMARY IMMUNODEFICIENCIES

**STRATEGIC PLAN
2005-2009**

Reviewed March 2006

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As we grow we need to review our Charter

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1. Following an initial meeting held at Oxford, England, in September 1990, the formation of 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
(IPOP)**

and adopt the following as the

**CHARTER OF THE INTERNATIONAL PATIENT ORGANIZATION
FOR PRIMARY IMMUNODEFICIENCIES.**

Preamble

3. The reason for the founding of IPOP 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 100 different syndromes ranging from mild to severe disease. International cooperation among patient organizations representing those with these diseases can be a source not only of moral support but also of practical assistance in improving standards of care and treatment available.

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 IPOP is open to national organizations of primary immunodeficient patients. "National organizations of primary immunodeficient patients" are organizations that:
 - i. Are legally established 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 voluntarily demonstrated their commitment to the care and treatment of patients with primary immunodeficiencies.
 - v. Have an accountable and democratic structure, with the full involvement of people with primary immunodeficiencies through self-help groups, advice and information.
 - b. Organizations wishing to join IPOP shall apply in writing to the Chairperson of the Executive Committee of IPOP. Copies of their charter and a 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, the organization shall immediately become a full member of IPOP and be notified in writing of its admission.
 - c. Organizations which do not meet the above criteria but whose aims to do so may be admitted to non-voting membership of IPOP at the discretion of the Executive Committee.
 - d. Organizations may be suspended from or expelled from suspension of membership of IPOP on the decision of the Executive Committee. The expulsion or the dismissal of an expelled organization shall require the approval in writing of at least two thirds of the organizations entitled to vote. No reason need be given for suspension or expulsion.



As we grow we need Rules of Procedure

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INTERNATIONAL PATIENT ORGANISATION FOR PRIMARY IMMUNODEFICIENCIES



Introduction.

The purpose of the proposal 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 NPOs), the Executive Committee and Committees. It is intended to be entirely consistent with the IPOPI charter. The purpose of the Charter is to fulfil 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. Topics not dealt with in the charter would not be placed against the requirements of UK charity law.

NOTE: The terms 'Executive Committee' and 'Board' have the same meaning and are interchangeable.

and many MORE

Not only for today...but for tomorrow as well

- **MEMBERSHIP**
- **RESPONSIBILITIES OF NMOS**
- **TERMINATION OF MEMBERSHIP**
- **GENERAL ASSEMBLY**
- **EXECUTIVE COMMITTEE – THE BOARD**
- **MEDICAL ADVISORY PANEL**
- **HEADQUARTERS**
- **FINANCES**
- **COMMITTEES**
- **CONGRESSES**
- **Conflicts of interest and Amendments to RoP**

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this GIVES

- **GREATER TRANSPARENCY**
- **ADDITIONAL RESPONSIBILITY TO NMOs THROUGH GENERAL ASSEMBLY**
- **A MORE CREDIBLE IPOPI**

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ACCREDITATION

NOTHING NEW IN HAVING CRITERIA:

- **ALL Primary immunodeficiencies – i.e. adult and child**
- **NATIONAL coverage**

ACCREDITATION

NEW CATEGORY:

ASSOCIATE MEMBERSHIP

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ACCREDITATION

Membership issues **ONLY** decided by

GENERAL ASSEMBLY

(see termination of Membership above)

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ACCREDITATION

By having shared responsibilities
IPOPI will be a stronger and
more effective organisation!

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..and finally ASSESSMENTS

WHY?

HOW MUCH?

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ASSESSMENTS

WHY?

Our funders require evidence of NMO financial commitment to IPOPI

We value what we pay for

IPOPI Membership is a good deal!

ASSESSMENTS

HOW MUCH

This will vary from country to country based on:

- **Gross Domestic Product per capita**
- **United Nations % shares**
- **Comparison with WFH**

Our **AIM** is to raise E.10,000 from this source – Total budget E.193,000 - so around 5% of total budget

ASSESSMENTS

NO National Patient Organisation will be excluded because of non-payment

However.....? Voting rights.....? Nomination rights???