



IPOPI Overview of Activities & How can we help?

29 September 2013

Johan Prevot

IPOPI – AAIAT
First Thai PID Patients Meeting
Novotel Ploenchit Hotel
Bangkok, Thailand

Contents

1. Introduction and History of IPOPI
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Mission Statement

- IPOPI is the Association of national patient organisations dedicated to improving awareness, access to early diagnosis and optimal treatments for primary immunodeficiency patients worldwide

History

- IPOPI came into being as a result of an initial meeting in Oxford, UK, in September 1990, when an interim organising committee was established
- Two years later in 1992, IPOPI was formally established. in Lugano, Switzerland.



IPOPI has 49 National Member Organisations (NMOs)

- **Argentina, Australia, Austria, Belarus, Belgium, Bosnia & Herzegovina (A), Brazil, Bulgaria (A), Canada, Chile, Colombia, Cyprus, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, India, Iran, Ireland, Italy, Japan, Mexico, Morocco, The Netherlands, New Zealand, Norway, Peru (A), Poland, Portugal , Romania, Russia, Serbia, Slovenia (A), South Africa, Spain, Sweden, Switzerland, Turkey, United Kingdom, United States of America (2), Uganda (A), Uruguay, Venezuela**

Board of Directors

Jose Drabwell, Chair (UK)
Martine Pergent, Vice-Chair (France)
Sven Fandrup, Treasurer (Denmark)
Marcia Boyle (USA)
Dragana Koruga (Serbia)
Maria Michelfelder (Sweden)
Christine Jeffery (Australia)
Roberta Pena (Argentina)
Joy Rosario (South Africa)
Vicky Modell (USA – JMF Strategic Partner)

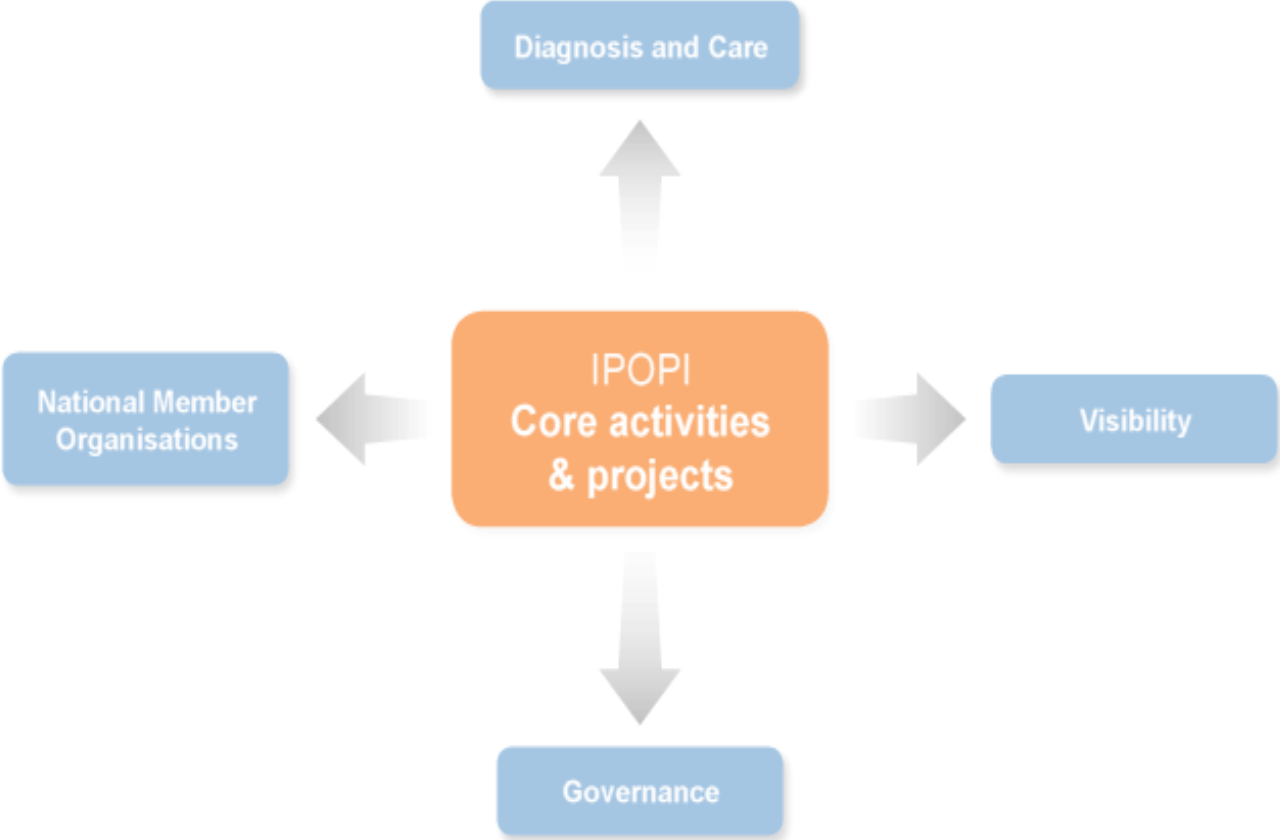
Staff

Johan Prévot Executive Director
Magda Lourenço, Communications/NMOs
Carla Morgado, Executive Assistant
Carol Tavener & Clare Glynn, Fincances
David Watters, Consultant
Health Policy & Advocacy Manager as of 2014

Medical Advisory Panel

Dr. Teresa Espanol, Outgoing Chair (Spain)
Prof. Bobby Gaspar, Incoming Chair (UK)
Dr. Nizar Mahlaoui, Incoming Vice Chair (France)
Prof. Ewa Bernatowska (Poland)
Dr. Jose Franco (Colombia)
Prof. Andrew Cant (UK)
Dr. Esther de Vries (Netherlands)
Prof. Luigi Notarangelo (Italy/USA)
Dr. Monika Esser (South Africa)
Prof. Alessandro Plebani (Italy)
Prof. Amos Etzioni (Israel)
Prof. Surjit Singh (India)
Prof. Alain Fischer (France)
Dr. Klaus Warnatz (Germany)

Objectives



IPOPI implements these objectives by

- Being the global advocate of the PID patient community
 - in all relevant policy, legislative and regulatory matters
 - for improved access to early diagnosis and safe and effective treatment for PID patients
- Working in close collaboration
 - with its NMOs, other plasma protein user groups and relevant stakeholders
- Monitoring the international supply of immunoglobulins
- Assisting in the development of new NMOs
 - through twinning, advocacy and support programmes
- Organising key events
 - including a biennial conference in close partnership with the professional organisations for clinicians (ESID) and nurses (INGID)

EU Advocacy Campaigns

- European Parliament STOA Panel, 17 March 2004



European Primary Immunodeficiencies
Consensus Conference
19 – 20 June 2006
Paul-Ehrlich-Institut, Langen, Germany

European Primary Immunodeficiencies
Consensus Conference

Consensus Report and Recommendations



Recommendations on:

1. Awareness & Education
2. Screening & Diagnosis
3. Treatment & Management



Recommendations of the PID Expert group chaired by
Jorgo Chatzimarkakis MEP

Involvement in key policies:

1. Rare diseases policies
 2. Cross border healthcare
 3. EMA & EUCERD
- & more.....

PID Forums & Follow up National campaigns



**Building political momentum
around PID issues**



**Recommendations,
Parliamentary Questions
and EP resolutions**



**National policy & media
follow up campaigns**

Regional Meetings and Campaigns

- LASID/ IPOPI Meetings for Latin American PID patient groups, Cartagena & Mexico City
- Eastern Europe: Moscow, Belgrade, Berlin.....
- ASID/IPOPI in Africa

Hope for Africa
Ithemba le Afrika Congress 2013
allergy | immunodeficiency | pulmonology & thoracic surgery
Sun City • South Africa • 5-9 June



IPOPI Biennial Meetings with



Group picture

Past Meetings:

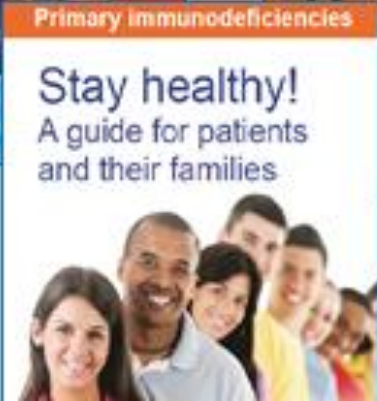
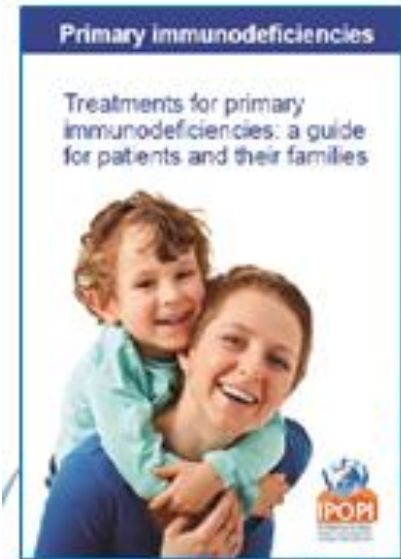
1992 Lugano, Switzerland
1994 Sitges, Spain
1996 Goteborg, Sweden
1998 Rhodos, Greece
2000 Geneva, Switzerland
2002 Weimar, Germany
2004 Versailles, France
2006 Budapest, Hungary
2008 Den Bosch, Holland
2010 Istanbul
2012 Florence

Upcoming Meetings:

2014 Prague
2016 Barcelona


Communications Tools


- IPOPI Website provides efficient online resource for PID patients and stakeholders
- New Social Media Tools
- eNews – quarterly electronic newsletter
- IG Database: online directory of IG therapies available worldwide
- Publications



Surveys

New!






PID Patient Needs & Outlooks Survey

Shortened report
Prepared by BRYTER

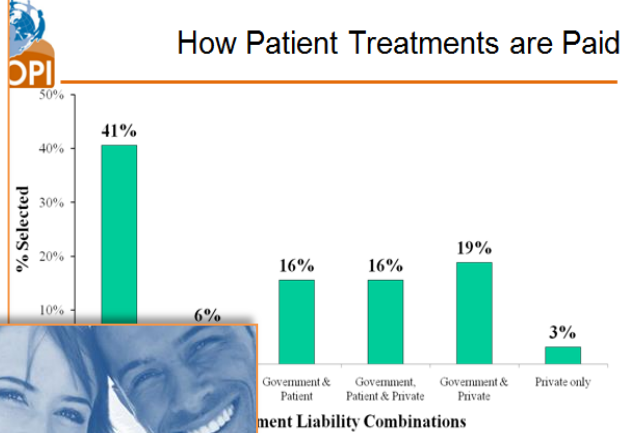
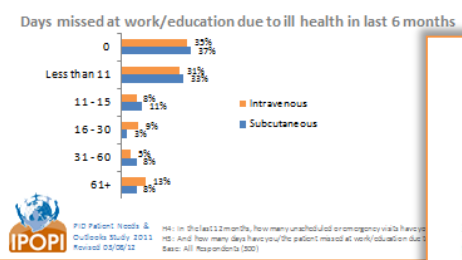
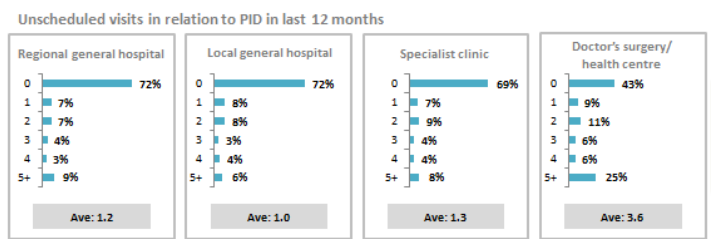
Revised 3 August 2012



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

1st IPOPI National Patient Organisations Survey

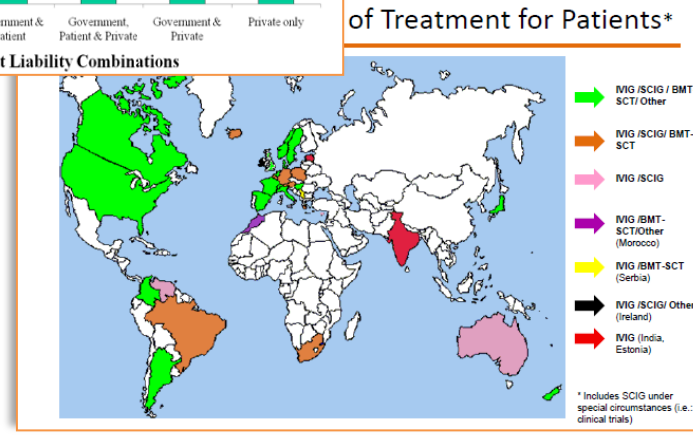
Sixty-six percent (using intravenous Ig) and 70% (using subcutaneous Ig) report missing 10 or fewer work/school days during the past 6 months. Of these, 35% (using intravenous Ig) and 37% (using subcutaneous Ig) missed 0 days





III. Future Treatment Needs

Ideal treatments and conjoint analysis



IPOPI NMO Support Programmes and Toolkits

- **To support NMOs carry out awareness and advocacy campaigns:**
 - Awareness Campaign Workshops (national)
 - Advocacy and Media Training Workshop (regional)
 - NMO Professionalization Programme
 - IPOPI NMO Support Grant Programme
 - IPOPI World PI Week Support Grant Programme
 - IPOPI Toolkits and Guidelines
 - IPOPI Nmo website support tool

Awareness Campaign Toolkit

- **Broadcast Guideline**
- **Government Fact Sheet**
- **Media Guidelines**
- **Template Celebrity letter**
- **Corporate Sponsorship Guideline**
- **Celebrity guidelines**
- **Family/School guidelines**
- **PID leaflet guideline**
- **Facts for the Medical Community Guideline**
- **World PI Week Toolkit**
- **NMO Website Toolkit**

Advocacy and Media Training Toolkit

- **Press conference check list**
- **Effective use of the media**
- **Government outreach**
- **Broadcast guideline**
- **Celebrity guideline**
- **Medical profession factsheet**
- **Government relations: making your case effectively**
- **Government factsheet**
- **Media guideline**
- **World PI Week toolkit**

Online resources:

www.ipopi.org

www.worldpiweek.org

IPOPI website contains a wealth of other resources (publications, position statements, latest news, IG database..)

IPOPI NMO PID Awareness Campaign Workshop – Belgium (2011)

- BOPPI – Patient Group
- BPIDG – PID Physician Group
- Support local patient group through identification of national objectives in cooperation with doctors.
- Establish action plan
- Presentation of **IPOPI Awareness Toolkit**
- Follow up awareness campaign:



The logo for Nieuwsblad.be, with the text 'Nieuwsblad.be' in white on a blue background and 'NIEUWSITE VAN HET JAAR' in smaller text below.

Hoog bezoek in Bloso domein Hofstade - 21/04/2013

Zemst - Een Belg op 2000 lijdt aan Primaire Immunoïnstabiliteit (PI). Om de ziekte uit de anonimiteit te halen én om patiënten de kans te geven elkaar te ontmoeten, organiseerden de BOPPI (de Belgische Organisatie voor Patiënten met Primaire Immunoïnstabiliteit) en de BPIDG (de Belgische Primaire Immuno Deficiëntie Groep van Artsen) de eerste PI familiedag ooit. De première in het Bloso domein van Hofstade werd zaterdag officieel ingeleid door Europees President Herman Van Rompuy. Meer dan de helft van de patiënten is vandaag nog niet gediagnosticeerd, nochtans is een tijdige en correcte diagnose belangrijk om de levenskwaliteit van de patiënt te bevorderen. Een grotere bewustwording deze deficiëntie kan het leven redden of minstens de levenskwaliteit van vele patiënten verbeteren.

A photograph of Paul Van Welden, a man in a suit, speaking at a podium during the event.

PAUL VAN WELDEN



IPOPI NMO PID Awareness Campaign Workshops – Ireland and Spain (2012)

- ✓ Elaboration of national PID awareness & advocacy campaign action plans in Ireland and Spain
- ✓ Improved NMO's skills set
- ✓ Strengthened network of re-motivated and more efficient NMOs
- ✓ Case study reports to all IPOPI's NMOs



IPOPI NMO PID Awareness Campaign Workshops – Brazil (2013)

- ✓ First ever joint meeting of two key patient groups and doctors
- ✓ Decision to move forward with joint national PID awareness campaign:
 - ❖ Joint response to National RD Consultation outlining PID community priorities
 - ❖ Political awareness and advocacy campaign planned for 2013
 - ❖ Joint event during WPIW 2014
- ✓ Strengthened network of stakeholders and UNIFIED approach



IPOPI NMO Regional Advocacy and Media Training Workshop – Eastern Europe

- ✓ Increased number of efficient patient advocates – Closer regional NMO Network
- ✓ Attendance of 6 countries NMOs incl. Romania, Russia, Poland, Serbia, Hungary, Turkey
- ✓ Increase in advocacy campaigns to improve access to diagnosis and care in target countries
- ✓ Regional priorities identified –i.e. lack of appropriate adult care
- ✓ Re-motivated NMO leaders in the region

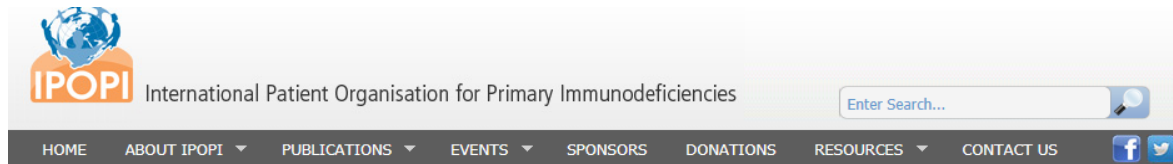


IPOPI in Africa

- IPOPI Regional African Patient Meeting in South Africa, back to back with 2013 ASID congress
 - ✓ Increased number of efficient patient advocates – Closer regional NMO Network
 - ✓ Attendance of several countries: South Africa, Uganda, Morocco, Senegal, Zambia.....
 - ✓ Regional priorities identified & action plans established
 - ✓ Launch of new NMO in Uganda



IPOPI NMO Website Toolkit



NMO Website Toolkit

Welcome to the IPOPI NMO Website Toolkit page!

The IPOPI NMO Website toolkit is a tool made exclusively available to IPOPI's National Member Organisations.

This toolkit was created to help IPOPI's National Member Organisations (NMOs) set up their own websites and learn how to use the Content Management System (CMS) to update and change it.

The IPOPI Toolkit is a simple user interface that will enable NMOs to create, add to and edit their website.

An IPOPI Website Builder & CMS User Guide was created to help you get familiarized with the system. Please make sure you read it carefully before starting working on your website.

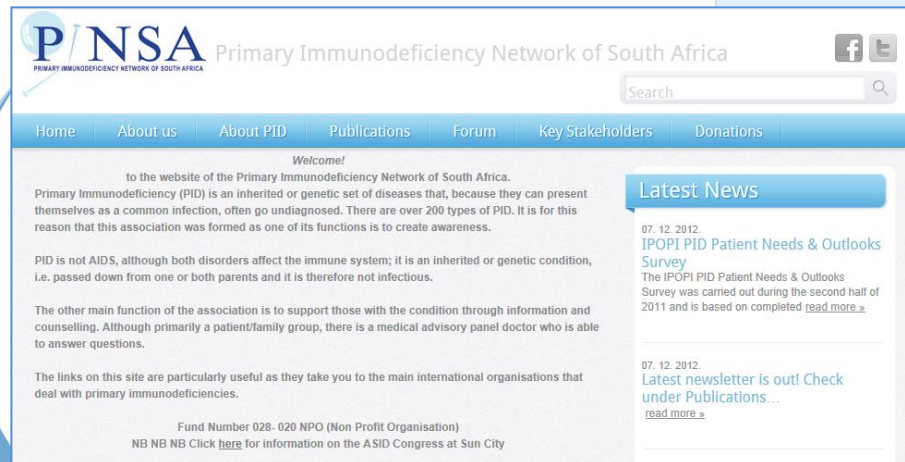
To start working on your new website and to access the User Guide, please login below:

To apply for a password please send a request to magda@ipopi.org.

Please login to see content.

Email Address:

Password:



IPOPI World Primary Immunodeficiency Week NMO Programme

- Launched in 2011
- Over 3 years, IPOPI supported the organisation of 31 national World PI Week campaigns so far including:

- Media outreach campaigns
- Medical & public awareness campaigns
- Advocacy campaigns
- Targeted events
- Publications



World PI Week

22 - 29. April 2013

**Primary Immunodeficiency:
Turning Hope into Action!**

TEST, DIAGNOSE, TREAT



Working with others....

- Doctors (LASID, ASID, ASIA,....)
- Regulators – EMA, FDA and NCAs
- Nurses
- Industry
- WHO
- EU Institutions
- Stakeholder platforms:
 - Eurordis
 - Epposi
 - IAPO
 - etc

Essential Medicines 15th edition (March 2007)
WHO Model List (revised March 2007)

WHO Model List (revised March 2007)

Explanatory Notes

The core list presents a list of minimum medicine needs for a basic health care system, listing the most efficacious, safe and cost-effective medicines for priority conditions. Priority conditions are selected on the basis of current and estimated future public health relevance, and potential for safe and cost-effective treatment.

The complementary list presents essential medicines for priority diseases for which specialized training are is of consistent



Platform of Plasma Protein Users

- IPOPI successful in launching many NMOs worldwide
- Support tools and support programmes are available!
- Work together with local stakeholders to ensure that:
 - **The PID community's voice is heard**
 - **Your priorities are acted upon**
 - **Your messages and actions are delivered consistently.**
 - **Patients with a PID can be diagnosed early and get access to their appropriate treatment.**
- Next steps for Thailand:
 - Decide on key people to involve in Thai NMO
 - Objectives & structure – IPOPI associate membership
 - Register the NMO – IPOPI Full membership
 - Increase awareness, improve diagnosis & treatment

Upcoming Events

- ❖ First International Primary Immunodeficiencies Congress - *7& 8 November 2013, Estoril, Portugal*



Focus on clinical care and diagnosis

- ❖ IPOPI Malaysian PID Workshop, NACLIS6 Meeting, Kula Lumpur, October 2013
- ❖ IPOPI Participation in PID Workshop, Hong Kong, December 2013
- ❖and more actions in Asia in 2014 we hope!

IPOPI wishes to thank:

octapharma
For the safe and optimal use of human proteins



IPOPI Bob LeBien Asian
Programme

For their support to this event!



**Thank you for your
attention!**