



WHAT HELP IS AVAILABLE FROM IPOPI?

7 JUNE 2013

**Jose Drabwell
President**

**IPOPI Regional Patient Meeting
ASID Congress, Sun City
South Africa**



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PROGRAMMES AND TOOLS
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1. INTRODUCTION

WELCOME

- PINSA DELEGATES
- HAJAR
- UGANDA
- DOCTORS, NURSES AND INDUSTRY



2. IPOPI NMO SUPPORT PROGRAMMES AND TOOLKITS



- IPOPI HAS DEVELOPED SEVERAL PROGRAMMES AND TOOLKITS TO SUPPORT NMOS CARRY OUT AWARENESS AND ADVOCACY CAMPAIGNS
- AWARENESS CAMPAIGN WORKSHOPS (NATIONAL)
- ADVOCACY AND MEDIA TRAINING INTENSIVE 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

2. IPOPI SUPPORT PROGRAMMES AND TOOLKITS



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**

2. IPOPI SUPPORT PROGRAMMES AND TOOLKITS



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)



PILOT PROGRAMME

- 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



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

Zemst - Een Belg op 2000 lijdt aan Primaire Immunostoornissen (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 Immunostoornissen) en de BPIDG (de Belgische Primaire Immun 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.



PAUL VAN WELDEN



2013 - La première journée familiale pour les patients atteints d'Immunodéficiência Primaire (IP) s'est tenue le week-end passé au domaine provincial d'Hofstade (Zemst) ée par le **Président du Conseil européen Herman Van Rompuy**. Avec la participation de plus de 300 patients IP et leurs familles, la journée fut un véritable succès.



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

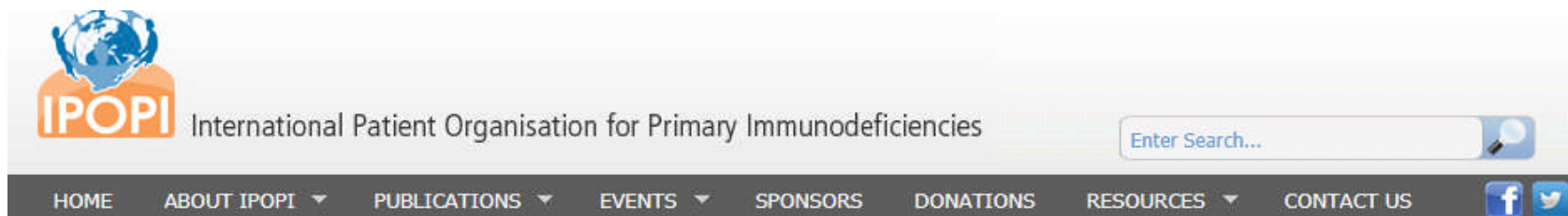


IPOPI NMO Regional Advocacy and Media Training Workshop – Eastern Europe

- ✓ 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
- ✓ Remotivated NMO leaders in the region



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:

☐ Remember me on this computer

Sign in

IPOPI NMO Website Toolkit



P/NSA Primary Immunodeficiency Network of South Africa
PRIMARY IMMUNODEFICIENCY NETWORK OF SOUTH AFRICA

Home About us About PID Publications Forum Key Stakeholders Donations

Welcome!

to the website of the Primary Immunodeficiency Network of South Africa. Primary Immunodeficiency (PID) is an inherited or genetic set of diseases that, because they can present themselves as a common infection, often go undiagnosed. There are over 200 types of PID. It is for this reason that this association was formed as one of its functions is to create awareness.

PID is not AIDS, although both disorders affect the immune system; it is an inherited or genetic condition, i.e. passed down from one or both parents and it is therefore

The other main function of the association is to support those counselling. Although primarily a patient/family group, there to answer questions.

The links on this site are particularly useful as they take you to deal with primary immunodeficiencies.

Fund Number 028- 020 NPO (Non Profit Organisation)
NB NB NB Click [here](#) for information on the

Latest News

07. 12. 2012.
[IPOPI PID Patient Needs & Outlooks Survey](#)

arpid

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Acasa Despre ARPID Despre IDP Evenimente Link-uri utile

→ **BUN VENIT!** » Logo arpid

arpid

Latest News

08. 05. 2013.
Puteti directiona 2% din impozitul pe anul trecut, catre ARPID!
formular 230 Se completeaza doar la rubricile de la punctul I, semnatura si data.
Se depun la Agentia Fiscala de care [read more »](#)

24. 04. 2013.
Evenimente
Saptamana Mondiala a IDP
Padurea IDP a fost plantata! Speram sa ajutam la cresterea gradului de constientizare a IDP, ajutand in acest fel la [read more »](#)



World Primary Immunodeficiencies Week

- **Driving recognition of primary immunodeficiencies (PI)** as an increasingly important disease group;
- **Increasing understanding amongst medical professionals, researchers, nurses, parents, school teachers, day care employees and the public;**
- **Stimulating efforts to improve recognition, diagnosis, treatment and quality of life** of people living with PI world-wide;
- **Encouraging health authorities to use awareness materials** produced by IPOPI, JMF and other stakeholders to promote timely diagnosis and treatment;
- **Promoting the model of combining physician education and global awareness with the infrastructure to diagnose and treat PI.**



World Primary Immunodeficiencies Week

- New revamped **Website launched in 2013** with new features including **Patient Story Book**
- New social media tools including **Facebook and Twitter account**
- Creation of **Poster and Postcard translated in several languages**
- **Table of events** shared with all members ahead of WPIW to inspire activities
- List of IPOPI's participating countries shared with all other members to **encourage collaboration** between doctors, nurses, patients groups, industry..
- **Scientific Editorial, also translated into several languages** to secure dissemination at local level. Cover letter co-signed by authors to facilitate publication
- **Press Release on Rare Disease Day** to link both campaigns and increase the visibility of WPIW among rare disease stakeholders and audience
- **Official WPIW Press Release** to support NMOs media activities
- **Updated Advocacy Toolkits** to support NMOs to organise events, collaborate with partners and outreach to governments
- **Monthly E-blasts** between October to April to guide NMOs on use of campaign materials and motivate them to drive activities

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



Jeffrey Modell
Foundation



Working with others....



- Reinstatement of Immunoglobulins in the World Health Organisation (WHO)'s List of Essential Medicines

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

Application for the inclusion of Polyvalent Human
Immunoglobulins
in the WHO Model List of Essential Medicines

WHO Model List (revised March 2007)

Submitted by

Explanatory Notes

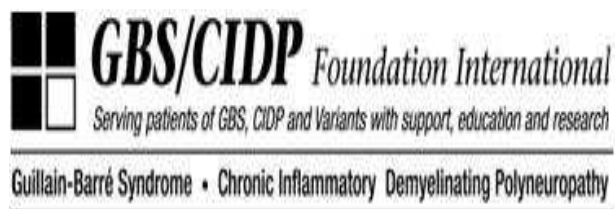
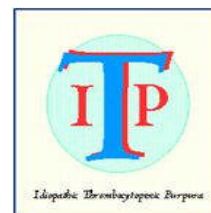
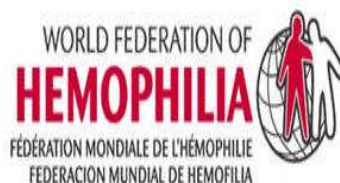
The core list presents a list of minimum medicine needs for a basic health care system, listing the most efficacious, safe and cost-effective medicines for priority conditions. Priority conditions are selected on the basis of current and estimated future public health relevance, and potential for safe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

The complementary list presents essential medicines for priority diseases, for which specialized diagnostic or monitoring facilities, and/or specialist medical care, and/or specialist training are needed. In case of doubt medicines may also be listed as complementary on the basis of consistent higher costs or less attractive cost-effectiveness in a variety of settings.



Working with others....

- IPOPI works with other patient organisations representing rare plasma related disorders under a coalition group :



Working with others....



- Activities undertaken by



- Meeting with EU Health Commissioner
- In 2011 and 2008



Policy Meetings 2010 at EU Parliament

- Plasma Protein Therapies in the Treatment of Rare Diseases,
Chair: Miroslav Mikolasik
- Improving Care for Rare Plasma Related Disorders, Chairs:
Jorgo Chatzimarkakis / Miroslav Mikolasik

Working with others....



PLUS Call to Action:

- Better diagnosis rates for plasma related disorders
- Equal treatment levels
- Recognition of unique nature of plasma protein therapies in national policies
- Value of strong patient groups
- Patient registries
- Reference Centres
- Value of national Rare Diseases plans
- Supply of human plasma
- MEP Interest Group



CO-AUTHORS



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SUPPORTING MEPs (Current Term)



Working with others....



- **IPOPI actively participates in PLUS Stakeholders Consensus Meetings, Dublin**
- **Dublin Consensus statements published in Vox Sanguinis (2010-11) and Blood Transfusion (2012)**
- **EU Parliament Fly-In meetings and meeting with Commission services (2011), Blood Directive Report**
- **Active participation in EU Commission survey of the blood, blood components and plasma derivatives market**

Working with others....

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





International Alliance of
Patients' Organizations

A global voice for patients

Working with others....



30 October 2013

Patient Solidarity Day



- 30 October 2013: Patient Solidarity Day in Africa
- Patients to come together and call for patient-centred healthcare in Africa
- Patient-centred healthcare = healthcare system designed & delivered to address the healthcare needs and preferences of patients so that healthcare is appropriate and cost-effective
- Opportunity for PID community in Africa to join this campaign
- More information on the Day and how to participate:
<http://www.patientsorganizations.org>

CONCLUSIONS....



- Support tools and support programmes are available
- You and your NMO implement awareness campaigns
- 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.**





**Thank you for your
attention!**