



# **IPOPI EASTERN EUROPEAN PATIENTS WORKSHOP**

**IPOPI AWARENESS CAMPAIGN  
&  
ADVOCACY CAMPAIGN EXAMPLES**

**Jose Drabwell  
President**

## 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:**



**Nieuwsblad.be**  
NIEUWSITE VAN HET JAAR

### 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.



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

- ✓ Improved NMO's skills set
- ✓ Elaboration of national PID awareness & advocacy campaign action plans in Ireland and Spain
- ✓ 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 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 -Awareness Campaign Workshop Sibiu in Romania – October 2013**

**8 patients, 5 doctors**

**Empowerment of both patients and doctors through future  
collaboration**

**Action plan – Patient Registry**

**Political agenda-National Plan for RD**

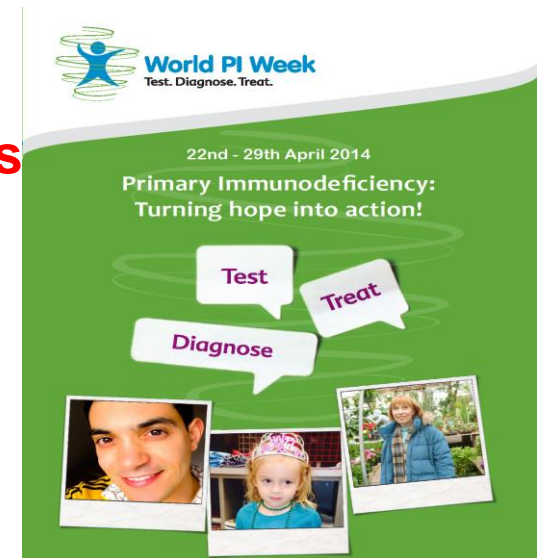


# IPOPI World Primary Immunodeficiency Week NMO Programme



- Launched in 2011
- Over 4 years, IPOPI has supported 49 national World PI Week campaigns so far including:
  - Media outreach campaigns
  - Medical & public awareness campaigns
  - Advocacy campaigns
  - Targeted events
  - Publications

[www.worldpiweek.org](http://www.worldpiweek.org)







## **IPOPI NMO Regional Advocacy and Media Training Workshop – Eastern Europe -2012**

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







**ADVOCATING AT EU LEVEL**



**EU PID FORUM – SCID Newborn Screening 2011**

**EU PID FORUM – HTA assessments 2011**

**EU PID FORUM – National Plans for Rare Diseases 2012**

**EU PID FORUM – Crossborder Healthcare and PIDs 2014**



## **ADVOCATING AT DIFFERENT LEVELS**

**WHO Expert Committee on biological standardisation**

**WHO ROME DECLARATION**

**Rare Disease Day – awareness and advocacy**

**Wilbad Kreuth – Council of Europe**

**PLUS – Dublin Consensus**

**Survey outcome**



## **Antalya Declaration**

**Education – Medical Students and Healthcare Professionals**

**Public Awareness**

**PID Genetic Diagnostics – free in J Project countries**

**PID Register – National and International data bases**

**Personalised Immunoglobulin and Stem Cell Transplantation  
(no restriction on funding or infrastructure constraints)**



## **Online resources:**

### **NMO Support Programmes and Toolkits**

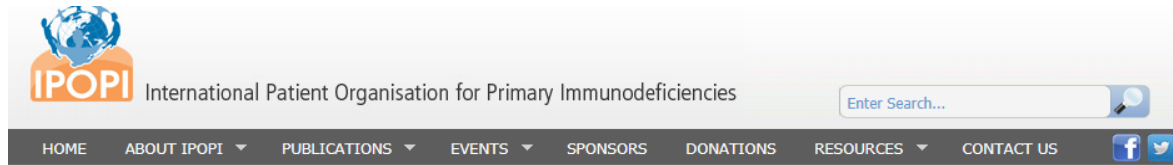
**IPOPI website contains a wealth of other resources (publications, position statements, latest news, IG database..)**

**[www.ipopi.org](http://www.ipopi.org)**

**A gift from IPOPI to our NMOs – a Website Toolkit**



# 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.

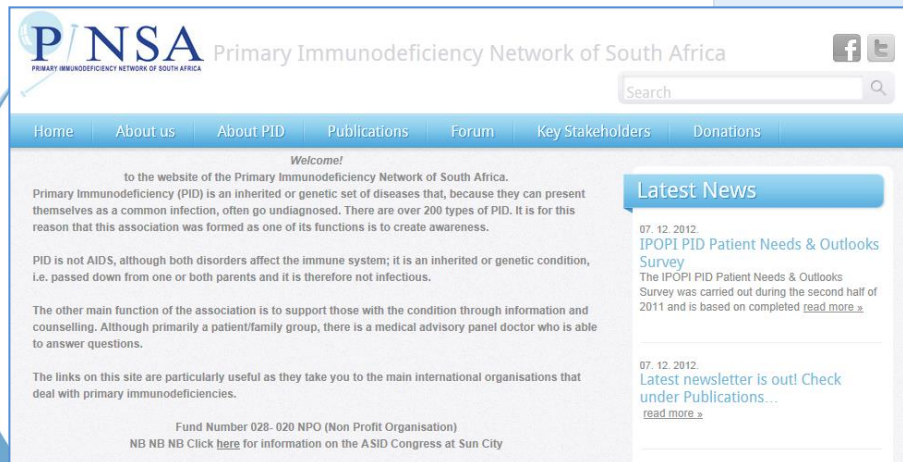
To start working on your new website and to access the User Guide, please login below:

To apply for a password please send a request to [magda@ipopi.org](mailto:magda@ipopi.org).

**Please login to see content.**

Email Address:

Password:





# Thank you

