



The importance of PID Awareness Campaigns: Success Stories & IPOPI Toolkits

IPOPI Awareness Campaign Workshop
11 October 2013
Hotel Ramada
Sibiu, Romania



Contents

1. Introduction and Structure of IPOPI
2. Why an awareness campaign?
3. Examples of successful awareness campaigns
4. IPOPI Support Programmes and Toolkits
5. Conclusions

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.



THE GLOBAL ORGANIZATION WORKING
TO **IMPROVE THE QUALITY OF LIFE FOR PEOPLE
WITH PRIMARY IMMUNODEFICIENCIES**



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**

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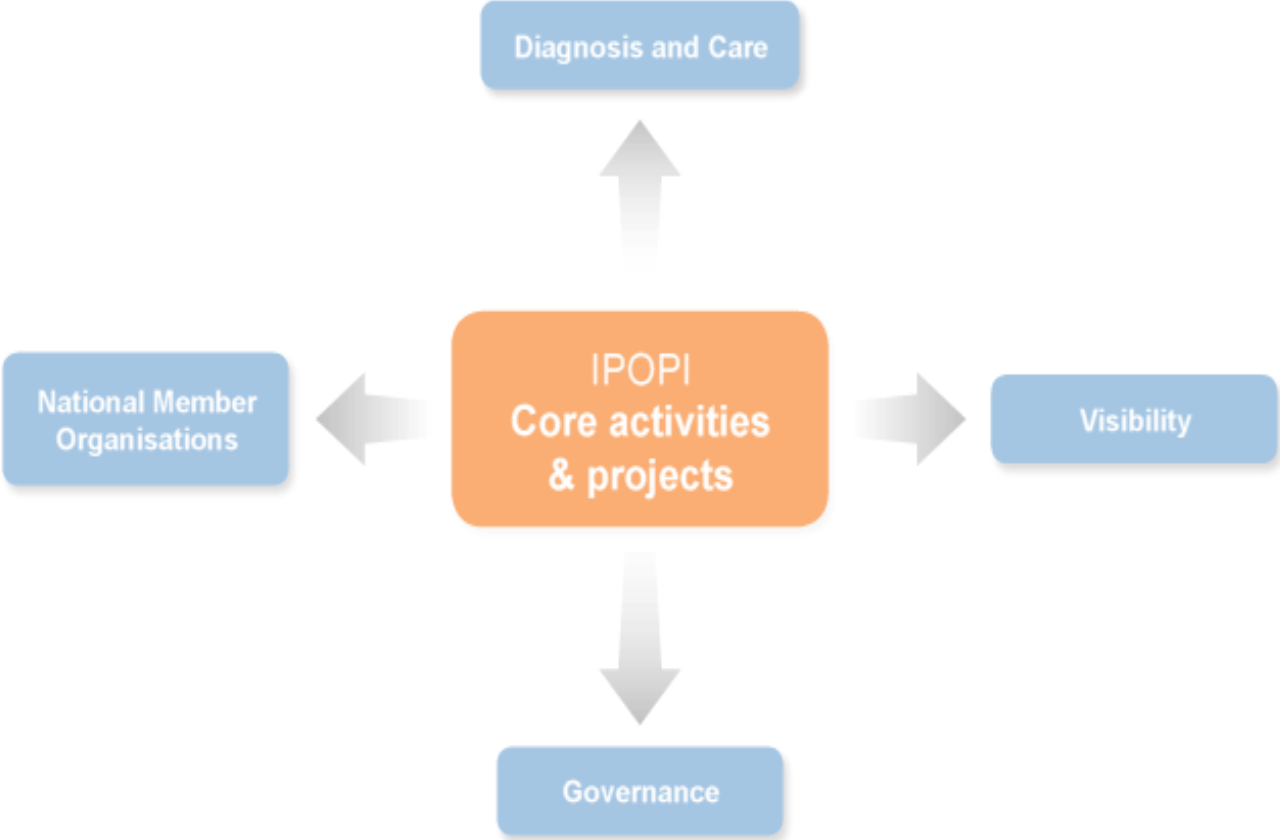
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Objectives



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)

Goals

- Raise awareness of PIDs in Romania
- Raise ARPID's Profile = Louder Voice
- Improve patients quality of life through access to early diagnosis and appropriate treatment

Goals

- **Consider potential types of awareness campaigns** based on opportunities and threats & identify target groups:
 - Public awareness campaign
 - Political awareness campaign
 - Patient/Medical awareness campaign
 - Media outreach campaign
- Consider options and **agree on type of campaign** needed
- **Identity 1-2 key priority objectives** on the basis of workshop discussion
- **Identify key target groups**
- **Identify key stakeholders** with whom to collaborate
- **Establish a stepwise plan** for an awareness campaign for PID in Romania – timelines and milestones

IPOPI WHO Awareness campaign

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, most efficacious, safe and cost-effective medicines for priority conditions selected on the basis of current and estimated future public health needs and cost-effective treatment.

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

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

Submitted by



PID Multi-stakeholder campaign

3 editions of WPIIW

- Public Awareness campaigns
- Political outreach
- Media outreach campaigns
- Educative campaigns
- Publications
- A global momentum



See worldwide events



See what's on near you, or browse events from previous campaigns. Add your own event to the map.



22nd - 29th April 2013

Primary Immunodeficiency:
Turning Hope into Action!

TEST!
DIAGNOSE!
TREAT!



Political awareness campaigns



**Building political momentum
around PID issues**



**Recommendations,
Parliamentary Questions
and EP resolutions**



**National policy & media
follow up campaigns**

IPOPI PID Awareness campaign Workshop Belgium, 2011

- BOPPI – Patient group
- BPIDG – Doctors group



Identified objectives for the dynamization of the patient group

Established an action plan for Belgium

- **IPOPI Awareness Toolkit**
First presented
- **IPOPI NMO Web Toolkit**
Posteriormente foi criado





Nieuwsblad.be

NIEUWSSITE VAN HET JAAR

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

h Primaire Immunoostörungen (PI). Om de ziekte uit de anonimiteit te halen én om patiënten de kans te geven den de BOPPI (de Belgische Organisatie voor Patiënten met Primaire Immunoostörungen) en de BPIDG (de Deficiëntie Groep van Artsen) de eerste PI familiedag ooit. De première in het Bloso domein van Hofstade werd door Europees President Herman Van Rompuy. Meer dan de helft van de patiënten is vandaag nog niet een tijdige en correcte diagnose belangrijk om de levenskwaliteit van de patiënt te bevorderen. Een grotere e 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'Immunodéficience Primaire (IP) s'est tenue le week-end passé au domaine provincial d'Hofstade (Zemst) organisée 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



Increasing awareness 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



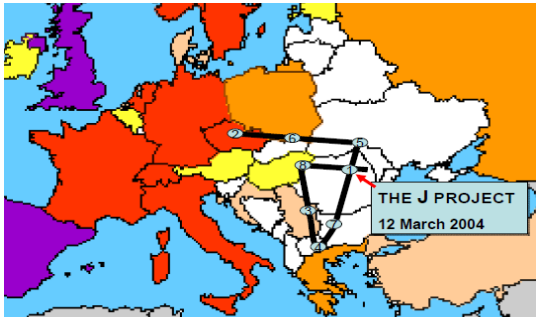
Increasing awareness in Asia

- First IPOPI Thai PID National Patients Meeting, Bangkok, October 2013
 - ✓ First ever meeting between doctors, patients and other stakeholders
 - ✓ Attendance of 50 participants
 - ✓ National priorities identified (Coverage for BMT and Wider access to IG therapies)
 - ✓ Decision to launch NMOs
 - ✓ Collaboration agreement between doctors and patients
 - ✓ Raised awareness with Medical societies for immunology and allergy



Increasing Awareness in Eastern Europe


- Belgrade workshop 2012, First Russian PID patient meeting, Moscow, November 2011 & Eastern European Stakeholders Meeting Berlin Nov 2010



Specific aims of the J Project

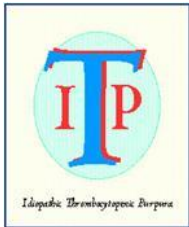
1. To organize professional meetings on PID and related diseases in several ECE countries with low number of registered PID patients.
2. To discuss diagnostic and therapeutic practices and problems, and to define specific areas to be improved and to be supported by other European groups, institutions, companies, and foundations.
3. Updating national PID registries
4. Establishing PID professional working groups
5. Establishing PID Patients' groups

Working with others.....

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



Platform of Plasma Protein Users



Meeting with Health Commissioner John Dalli

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



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SUPPORTING MEPs (Current Term)



Dublin consensus statements

Working with others....

- Doctors
- Regulators
- Nurses
- Industry
- WHO
- EU Institutions
- Stakeholder platforms:
 - **Rare Diseases Groups**
 - **Other 'plasma users'**
- Politicians
- Health Officials



How can IPOPI help?

- **IPOPI has developed several programmes and toolkits to support its NMOs carry out awareness and advocacy campaigns**
- Awareness campaign Workshops
- Advocacy and Media Workshop
- NMO Professionalization Programme
- IPOPI NMO Support Grant Programme
- IPOPI World PI Week Support Grant Programme
- IPOPI Awareness and Advocacy Toolkits / Guidelines
- NMO Website

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**

Online resources:

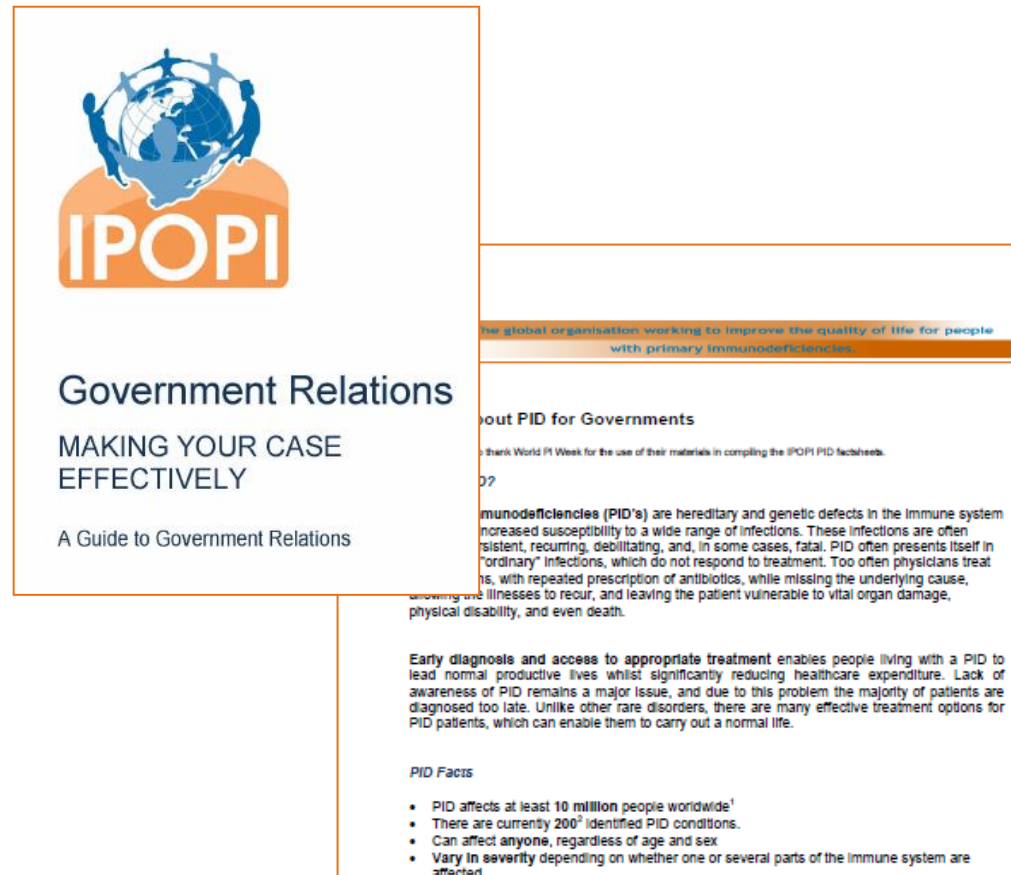
www.ipopi.org

www.worldpiweek.org

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

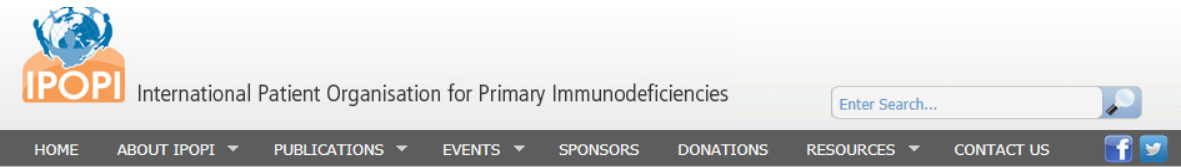
Advocacy and Media Training Toolkit

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





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.

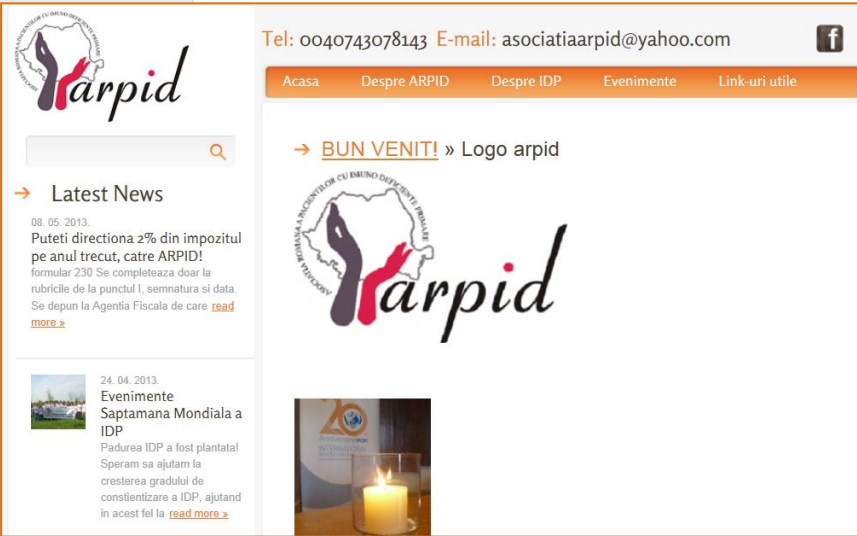
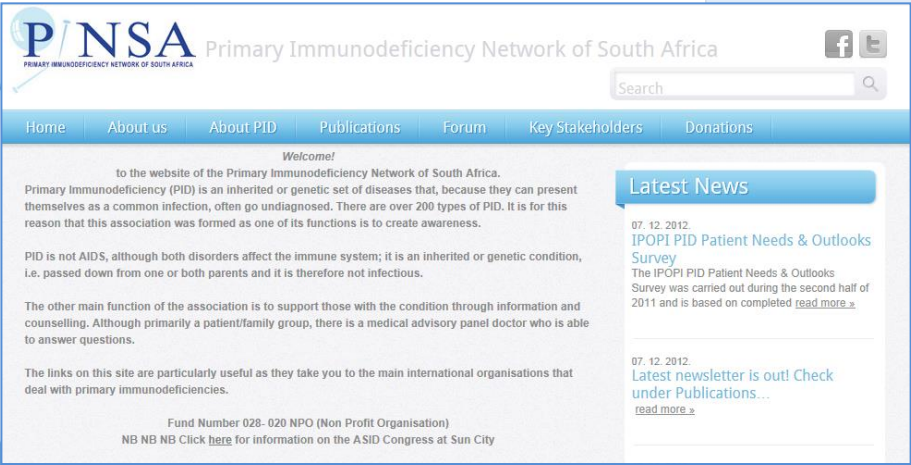
To start working on your new website and to access the User Guide, please login below:

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

Please login to see content.

Email Address:

Password:



IPOPI NMO Support Programmes

Example: WPIW

- 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




Other Available Tools

Publications



Surveys and Data

Position Statements



IPOPI POSITION STATEMENT
Access to Immunoglobulin Therapies for patients living with a Primary Immunodeficiency

8 May 2012

This statement is intended to provide a summary of IPOPI's position with regards to the importance of ensuring access for patients living with a primary immunodeficiency (PID) to the best suited immunoglobulin (IG) replacement therapy, as selected and prescribed by their physician. IPOPI is concerned by recent developments in several countries that may restrict access to the best suited IG therapy for individual patients.

IG therapies are life saving therapies for PID patients with life-long, chronic conditions. They are listed for the treatment of primary immunodeficiencies on the World Health Organisation (WHO) list of essential medicines.

Immunoglobulins are biological therapies derived from human plasma. IG replacement therapy is the most important treatment for a majority of PIDs, as it helps to protect patients against a range of infections and to reduce autoimmune symptoms. IG replacement therapy is used to treat various PIDs, including but not limited to common variable immunodeficiency (CVID), X-linked agammaglobulinemia (XLA), X-linked hyper-immunoglobulin M (hyper-IgM) syndrome, Wiskott-Aldrich syndrome (WAS), severe combined immunodeficiency (SCID) and other combined immunodeficiencies. IG replacement therapy is a life-long, life-saving treatment which must be administered regularly. There is no alternative treatment to IG therapy for most immunodeficiencies.

IG therapies are not generic medicines. Each IG therapy is a unique biological medicinal product and as such IG therapies are not interchangeable. Unlike chemically-based pharmaceuticals, biological medicinal products are composed of an active ingredient derived from a biological source (human plasma in the case of IG therapies). The active ingredients are isolated using complex processes that will have an impact on the properties of the final product. It is well established that the differences in the processes used to manufacture the products will affect individual patients' tolerability, risk of adverse events, infusion rate, and potential efficacy. Factors such as the volume load, the type and concentration of the excipients used in the preparation, the protein concentration, the osmolality and conductivity, the pH and the formulation (liquid or lyophilised)

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Immunoglobulin List

Companies

Countries

Click on company name to view company products

Baxter

Biotech

CSL Behring
Biotherapies for Life®

GRIFOLS

Afghanistan
Albania
Andorra
Argentina
Australia
Austria
Azerbaijan
Bahrain
Barbados
Belarus
Belgium
Bolivia
Bosnia and Herzegovina
Brazil
Bulgaria
Canada

Available products in

KIOVIG

SUBCUVIA

Gammagard S/D

Endobulin S/D

Intratec®

Privigen

Flebogamma

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

Unscheduled visits in relation to PID in last 12 months

| Setting | 0 | 1 | 2 | 3 | 4 | 5+ | Ave |
|--------------------------------|-----|----|-----|----|----|-----|-----|
| Regional general hospital | 72% | 7% | 7% | 4% | 3% | 9% | 1.2 |
| Local general hospital | 72% | 6% | 6% | 3% | 4% | 6% | 1.0 |
| Specialist clinic | 69% | 7% | 9% | 4% | 4% | 8% | 1.3 |
| Doctor's surgery/health centre | 43% | 9% | 11% | 6% | 6% | 25% | 3.6 |

Days missed at work/education due to ill health in last 6 months

| Days missed | Intravenous | Subcutaneous |
|--------------|-------------|--------------|
| 0 | 15% | 17% |
| Less than 11 | 11% | 11% |
| 11 - 15 | 11% | 11% |
| 16 - 30 | 11% | 11% |
| 31 - 60 | 11% | 11% |
| 61+ | 11% | 11% |

PID Patient Needs & Quality Study 2012
Received 05/06/12

Conclusions

- Patient-led awareness and advocacy activities are **key** to ensure PID are better known and that patient priorities are taken into account by decision-makers – Your view matters!!
- In an environment of healthcare budget restrictions, increasing need to raise awareness of PIDs as an increasingly important sub-group of rare diseases
- Patient organisations play a key role in raising awareness of their condition, the importance of early diagnosis and appropriate treatment

- Identify key priorities, opportunities and threats in Romania & establish a step wise awareness campaign
- Put ARPID on the (political) MAP and increase PID patients

visibility in Romania:

- **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.**
- **It can be done and IPOPI is here to support you!!!**

IPOPI wishes to thank:

octapharma

For the safe and optimal use of human proteins

IPOPI Platinum Core Sponsor

For their support to this event!

A decorative blue curved graphic element located in the bottom-left corner of the slide.



**Thank you for your
attention!**