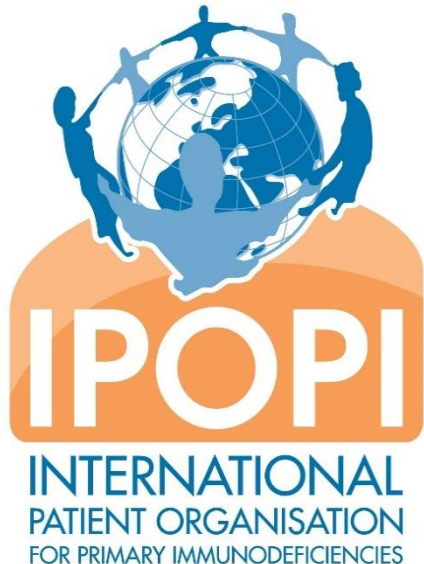


# Role of effective national patient organisations

Martine Pergent

IPOPI

12/04/2019

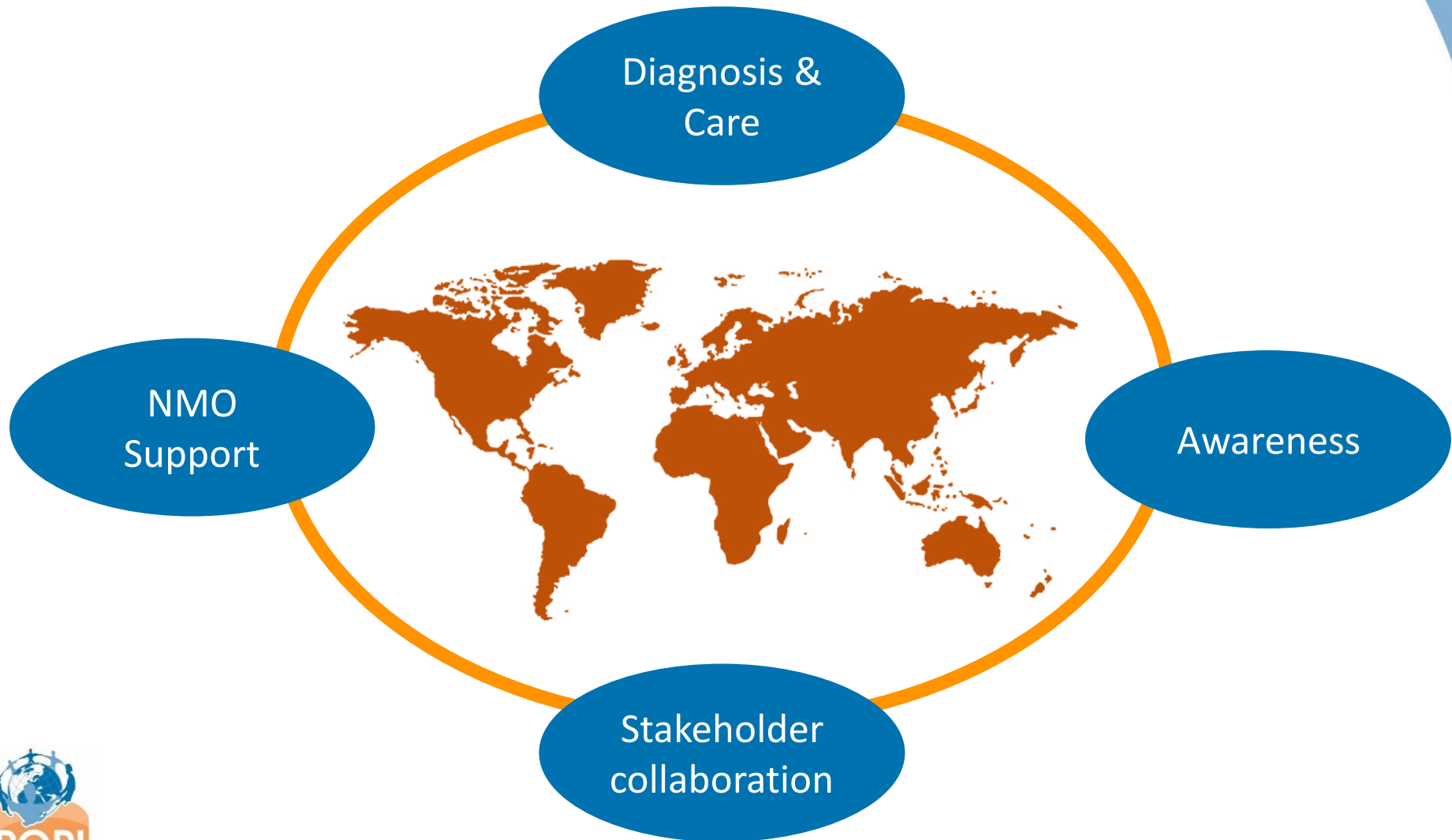


# IPOPI

- IPOPI is the association of national patient organisations dedicated to improving:
  - awareness
  - access to diagnosis and
  - optimal treatments
  - worldwide for primary immunodeficiencies
- Established in 1992



# IPOPI strategic objectives



# IPOPI achievements

- Policy actions  
Building political momentum around PID issues through
  - EU PID Forums
  - SCID NBS Campaign
  - Government Call to Actions
- Stakeholder collaboration
  - PLUS – Plasma Protein Users Network
  - European Reference Network RITA and patient involvement
- Awareness
  - Supporting National Campaigns
  - Clinical Care workshops
  - World PI Week global campaign
- Diagnosis and care
  - PID Congress IPIC (in Dubai 2017)
  - SCIDNET project – Gene therapy
  - PID Principles of Care



A roadmap to population newborn screening (NBS) for severe combined immunodeficiency (SCID)







IPOPI has 66  
National Member  
Organisations

**Latest to join:  
China – Kenya –  
Kazakhstan**

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

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



# Why are we here today?

- To help **NMOs** find strategies to improve the situation for PID patients in their countries
- To identify the key priorities for patients
- To find practical solutions to address those priorities
- To prepare a step-by-step action plan
- To bring stability and a future to the NMO

# Why do we need national PID patient organisations?(1)

- 1) To provide support to patients & families in your country
- 2) To advocate for better access to early diagnosis and treatments in an organised way:
  - 1) Working with policymakers,
  - 2) Civil servants, politicians and regulators
- 3) To raise awareness of PID patients needs and priorities

# Why do we need national PID patient organisations? (2)

4. To nurture stakeholder collaboration and work with:
  - Doctors, nurses and other healthcare professionals and other NGOs/Patient groups.
  - Other key stakeholders including industry.
5. To disseminate information
6. To collect data
7. To organise key events that bring patients and the PID community together



# 1. Advocacy – what's first?

- What is the ideal scenario?
  - E.g: Patients with PIDs receiving access to early diagnosis, treatment and care to match their needs, having these covered by the national health insurance/ free of charge!
- How do you get to this scenario?
  - define the problem
- You need to know what you want!
  - Research; Consult; Involve others!
- You need to know whose mind you need to change!
- You need to identify friends who can help!

# Advocacy – how to be successful?

... Getting your message across in such a way that you convince those who need convincing.

That means:

- The need to define the message to ensure that you are being listened to.
- The person you speak to is the right one to achieve your objective.
- What you suggest is reasonable and has benefits to society in general (not just to yourself).

Get allies to support your message.

Present yourselves as partners to the decision-makers and aim for a more efficient and optimal management of patients in the country.

# WHO Essential Medicines List

- WHO 2003 decision:
  - to remove IG from the WHO Essential Medicines List

➔ 2006:

IPOPI joins forces with stakeholders to lobby instalment of IGs in the list

## **Stakeholders included:**

- IPOPI & its NMOs
- IUIS, ESID, INGID and national societies
- Other PLUS patient groups and their NMOs
- Industry associations
- WHO Global Collaboration for Blood Safety
- International experts call to action – around 50 signatures!

- WHO 2007 decision:
  - Resintatement of immunoglobulins
  - PID listed as top two priority
  - Subcutaneous IG since then added following IPOPI & IUIS request

## **The Lesson:**

- Identify the issue
- Identify what needs to be done – from your perspective and from the institution you will advocate to
- Identify who are your supporting stakeholders
- Collect Data
- Call to Action – get as much support as you can
- Respect timelines & format
- **WORK TOGETHER & REQUEST A MEETING TO MAKE YOUR CASE!**
- Ensure contacts have been secured & follow up !

# Poland

## making treatment available for adult patients

- It all started in 2012 – in an IPOPI Advocacy & Media Training Workshop in Belgrade (Serbia).
- One of the challenges identified was the lack of treatment for adult patients officially recognised (some hospitals illegally treated adults with SCIG home therapy).
- From 2012 to 2014, the patient organisation was organised, established contacts with medical doctors, liaised with the media and presented their plan to the Ministry of Health.
- After many efforts, the Ministry of Health accepted establishing a PID treatment programme for adults on both SCIG and IVIG.



# Romania

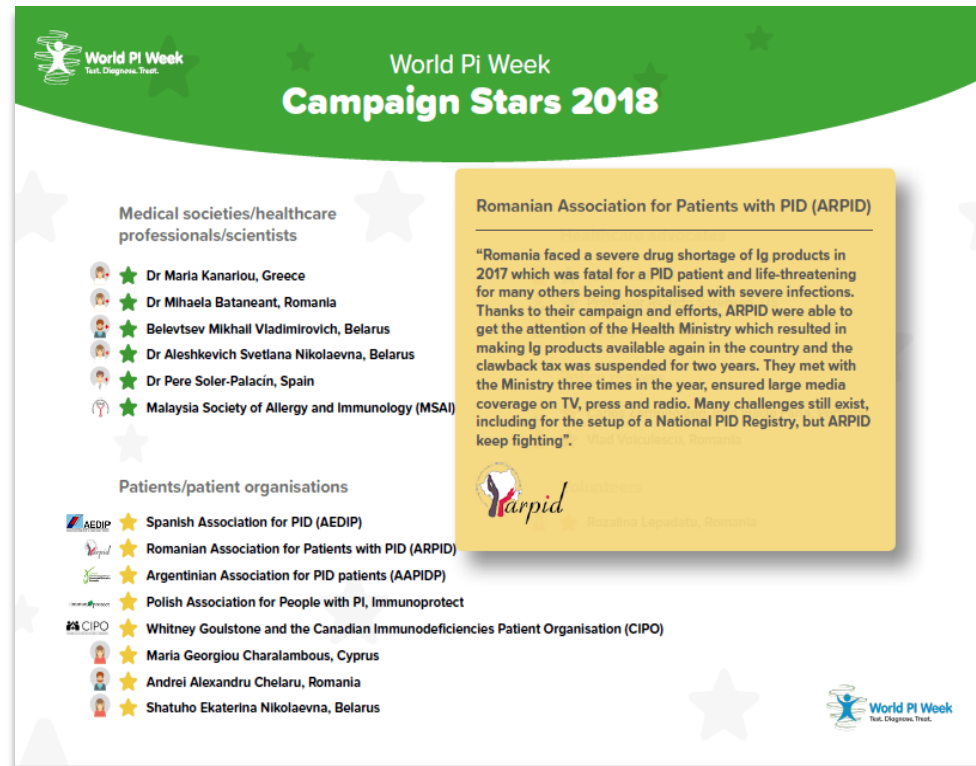
## Immunoglobulin crisis

Romania faced a severe Ig shortage in 2017 which was fatal for a PID patient and life threatening to many others being hospitalised with severe infections.

Thanks to their campaign and efforts, ARPID was able to get the attention of the Health Ministry which resulted in making Ig products available again and claw back tax being suspended for two years.

They met with the ministry 3 times in a year, ensured large media coverage on TV, press and radio.

Many challenges still exist but ARPID keeps fighting!



The poster is titled "World Pi Week Campaign Stars 2018" and features a green header with the World Pi Week logo. It lists various medical societies, patient organizations, and individuals who contributed to the campaign. A yellow box highlights the Romanian Association for Patients with PID (ARPID) and its efforts in 2017.

**World Pi Week**  
Test. Diagnose. Treat.

**World Pi Week Campaign Stars 2018**

**Medical societies/healthcare professionals/scientists**

- ★ Dr Maria Kanariou, Greece
- ★ Dr Mihaela Bataneant, Romania
- ★ Belevtsev Mikhail Vladimirovich, Belarus
- ★ Dr Aleshkevich Svetlana Nikolaevna, Belarus
- ★ Dr Pere Soler-Palacin, Spain
- ★ Malaysia Society of Allergy and Immunology (MSAI)

**Patients/patient organisations**

- ★ Spanish Association for PID (AEDIP)
- ★ Romanian Association for Patients with PID (ARPID)
- ★ Argentinian Association for PID patients (AAPIDP)
- ★ Polish Association for People with PI, Immunoprotect
- ★ Whitney Goulstone and the Canadian Immunodeficiencies Patient Organisation (CIPO)
- ★ Maria Georgiou Charalambous, Cyprus
- ★ Andrei Alexandru Chelaru, Romania
- ★ Shatuho Ekaterina Nikolaevna, Belarus

**Romanian Association for Patients with PID (ARPID)**

"Romania faced a severe drug shortage of Ig products in 2017 which was fatal for a PID patient and life-threatening for many others being hospitalised with severe infections. Thanks to their campaign and efforts, ARPID were able to get the attention of the Health Ministry which resulted in making Ig products available again in the country and the clawback tax was suspended for two years. They met with the Ministry three times in the year, ensured large media coverage on TV, press and radio. Many challenges still exist, including for the setup of a National PID Registry, but ARPID keep fighting".

**arpid**  
Romanian Association for Patients with PID

**World Pi Week**  
Test. Diagnose. Treat.

# ARPID & IPOPI collaboration

## Romania immunoglobulin crisis

- IPOPI facilitating communications between ARPID and PPTA's Romanian taskforce, Jan 2017
- IPOPI and Prof Bobby Gaspar prepare support letter to ARPID, Oct 2017
- IPOPI sends a letter and list of approved Igs to the Romanian Health Minister, Oct 2017
- A Patient dies of lack of treatment, Nov 2017
- IPOPI in talks with pharmaceutical companies to provide temporary access to Igs for Romanian patients, Dec 2017
- MEP Monica Macovei writes a letter to Commissioner Vytenis Adriukaitis urging the MoH to solve the issue
- The Romanian government suspends clawback tax for 2 years, Dec 2017
- IPOPI and ARPID urge PPTA to push companies back to Romanian market during the Stakeholders Meeting in Budapest, March 2018
- The situation improves, companies return to the Romanian market, July 2018

# Advocacy in a nutshell

These examples only show that by:

- Knowing what you want;
- Partnering with others with same objectives (look around you!); For example other plasma user groups
- Liaising with other stakeholders, introducing your challenge to them;
- Developing allies;

Many things can be achieved!



# 2. Raising awareness

## World PI Week, 22-29 of April

Test. Diagnose. Treat.



### Mission statement

World PI Week is a global movement to **raise awareness of Primary Immunodeficiency (PI)** and related challenges; promote quality of life for people with PI, early diagnosis, availability and access to treatment and care worldwide; and stimulate communication and advocacy around PI

### Objectives

- Drive recurring momentum on PI and bring together different stakeholders under an overarching umbrella for awareness and advocacy activities tailored to regional contexts, priorities and needs
- Share common messages on PI and related issues to grow awareness
- Develop template materials and resources under the World PI Week label, adaptable to regional/local missions to communicate about PI and support grassroots advocacy
- Promote scientific guidelines, materials and activities from regional patient organisations and medical societies



# Raising awareness

## World PI Week, 22-29 of April

Highlights:  
APIP Puerto Rico





# Raising awareness

## World PI Week, 22-29 of April

Highlights:  
UMAE Paediatric  
Medical Center

Mexico



# Raising awareness World PI Week, 22-29 of April

Highlights:  
IPIPS Indonesia





# Raising awareness World PI Week, 22-29 of April

Highlights:  
Fundacion FIDEP  
Bolivia





# Raising awareness

## World PI Week, 22-29 of April

Highlights:  
IDFA Australia



# 3. Stakeholder collaboration

- During WPIW 2018, MyPOPI works also in collaboration with the national blood centre, the haemophilia society of Malaysia, Malaysian medical student association and Malaysia nursing association

## Malaysia Society of Allergy and Immunology (MSAI)

"MSAI have been a great partner of MyPOPI since 2014 in the annual World PI Week until now. They have been mentoring MyPOPI since its creation to do radio and TV interviews and newspaper articles, and a joint live TV interview was made in 2017. MSAI has been a mentor for MyPOPI and a driving force alongside MyPOPI in every WPIW events. This healthcare professional association is truly a hero in Malaysia and an example for the region".



Andrei Alexandru Chelaru, Romania

Shatuba Ekaterina Nikolzevna, Belarus

Chantal Aubinow, France

# Stakeholder collaboration

## Working with policy makers – Portugal

- Policy meeting with Member of the European Parliament  
Jose Inacio Faria to discuss priorities of PID patients in Portugal



# Stakeholder collaboration

## Working with industry

- collaboration opportunities:
  - Meetings and events
  - Information materials
  - Awareness materials
  - Contacts

## How is Your Day - campaign



"THANKS TO IMMUNOGLOBULIN THERAPY, I CAN LIVE A NORMAL LIFE... AND LOOK TO MY FUTURE WITH CONFIDENCE."

Cornelia, 58, living with CVID

**HOW IS YOUR DAY?**

Making the difference with plasma proteins.

HIYDglobal HIYDglobal [www.HowIsYourDay.org](http://www.HowIsYourDay.org)



# Stakeholder collaboration

## Working with IPOPI

- IPOPI PID Clinical care national meetings
- IPOPI Regional Patients Meetings
- National and regional advocacy campaigns  
Newborn screening for SCID
- National and regional skills building workshops on awareness, advocacy, media
- Biennial Global PID Patients meetings  
(in Lisbon October 2018)



# 4. Disseminate information



## PID Principles of Care



**PRINCIPLE 1**  
The Role for Specialized Centers



**PRINCIPLE 2**  
The Importance of Registries



**PRINCIPLE 3**  
The Need for International Collaborations for Scientific Research



**PRINCIPLE 4**  
The Role of Patient Groups



**PRINCIPLE 5**  
Management and Treatment Options for PIDs



**PRINCIPLE 6**  
Managing PID Diagnosis and Care in all Countries

# 5. Collect data

- National and regional registries
  - ASID
- Patient surveys



Only a few cases of each PID are reported yearly in each country. National and regional registries help to ensure sufficient treatment supply, medical investigation and governmental policies.



## SURVEY ON SWITCHING IMMUNOGLOBULIN PRODUCTS (IG)

### Introduction

The survey seeks the input of patients living with a primary immunodeficiency and parents who are taking care of a child with a primary immunodeficiency (under the age of 18 years), using IG replacement therapy and have switched to another brand or mode of administration (intravenous, subcutaneous, facilitated subcutaneous) during the last 2 years.

Gathering this data will help IPOPI:

- develop a crucial understanding of the effects which switching from one IG product to another may have on your health and quality of life, either good or bad,
- understand your opinion on this topic.

The data we will collect will be fully anonymized and protect your privacy in accordance with EU data protection laws.

The aggregated data will be used to advocate for optimal care and conditions for PID patients worldwide.

We hope we can count on your help to develop this much needed information!

Thank you!

## Primary Immunodeficiencies (PIDs) Principles of Care implementation survey 2018

### Introduction

Welcome to this survey!

We will ask you questions along the 6 Principles of Care IPOPI has defined for PID Patients worldwide.

>When answering, you may go back to change an answer when you wish.

>If you leave the questionnaire, you can get back to the point you left by clicking on the link in the email again (when using the same device and same internet explorer).

Thank you very much for helping IPOPI  
to gather robust data on PID care  
around the world!



# 6. Bringing PID community together!



Zambia 2017



IPIC 2017 - Dubai



Lisbon 2018



Vietnam 2017





an IPOPI event



# IPIC2019

INTERNATIONAL PRIMARY  
IMMUNODEFICIENCIES  
CONGRESS

6-8 NOVEMBER  
MADRID, SPAIN

[www.ipic2019.com](http://www.ipic2019.com)

## See you at IPIC 2019 in Madrid!

# Thank you!

