

# What is WPIW and NMO examples

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12 April

IPOPI



# World PI Week, 22-29 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

# World PI Week, 22-29 April

- IPOPI is a member of the WPIW steering committee which provides materials and means for local campaigning and raising awareness activities.
- IPOPI Supports local implementation of WPIW through IPOPI NMO Support programme.
- Dissemination of IPOPI Patient Information Materials and WPIW support materials through network of NMOs.
- Promotion of World PI Week through IPOPI's Social Media channels including Facebook and Twitter.
- Participation of IPOPI Staff, Board Members and Medical Advisory Panel in selected events.
- Since the inception of the campaign IPOPI has supported 103 NMO national campaigns

# World PI Week, 22-29 April

## Steering Committee



Asian Pacific Society for  
Immunodeficiencies



Arab Society for Primary  
Immunodeficiencies



African Society for  
Immunodeficiencies



Immunodeficiency Canada



Clinical Immunology Society



European Federation of  
Immunological Societies



European Society  
for Immunodeficiencies



Immune Deficiency Foundation



International Nursing Group for  
Immunodeficiencies



International Patient Organisation  
for Primary Immunodeficiencies



Jeffrey Modell  
Foundation  
Jeffrey Modell Foundation



Latin American Society for  
Immunodeficiencies



Plasma Protein Therapeutics  
Association



South East Asia Primary  
Immunodeficiency Network



# IPOPI activities during WPIW

## Awareness and joint actions

- New leaflet series
- PID awareness video for Africa
- WPIW photo contest participation
- Participation in the members activities (Ireland, UK, Netherlands)
- NMO WPIW support grants (31 NMOs in 2019)
- WPIW EU event (2017)



# NMO Campaign Examples

## Success stories





# Colombia – 2018

Joining forces with the medical professionals

**WHO:** Foundation FIP in collaboration with Astma, Allergy and Immunology Association (ACAAI)

**WHAT:**

- the 8th national PID symposium for healthcare professionals in Medellin, on the theme of “advances in diagnosis and treatment”
- Academic seminars on quality of clinical tests to diagnose PID genetic defects
- Flow Cytometry School
- Gathering of PID patients and families, balloon launch



# Portugal – 2018

## Making friends in policy making

**WHO:** Portuguese Association for Patients with Primary Immunodeficiencies APDIP

**WHAT:**

- meeting with Member of the European Parliament Jose Inacio Faria to discuss national objectives: newborn screening, European Reference Networks for Rare Diseases, eHealth & mHealth, PID diagnosis & treatment
- 7th Family Day
- Press coverage in national health magazine





# Puerto Rico – 2018

Patient education, physical activities and awareness among general practitioners

**WHO:** Association of Patients with PID APIP Puerto Rico

**WHAT:**

- Educational family day with lectures on healthy diets by a nutritionist, and lectures on treatment and health insurance by specialist doctors, immunologists and an insurance expert
- Physical activity class (yoga)
- Lecturing at Annual Congress of Family Doctors in Puerto Rico, with case studies of patients



## Public awareness and fundraising through sports

## WHAT:

- 
- The logo for the DIP MARATHON INDOOR CYCLING event. It features the text "DIP" in a large, stylized font at the top, with "MARATHON" in a smaller font below it. The words "INDOOR CYCLING" are written in a curved path along the bottom left. A stylized graphic of a person on a bicycle is positioned on the right side, partially enclosed by a large circular arc.



 2ÈME ÉDITION DU  
**DIP MARATHON**  
D'INDOOR CYCLING

**SAMEDI 14 OCTOBRE 2017**  
**SALLE OMNISPORTS D'ELOUGES**

**12H DE MARATHON**  
**MIDI - MINUIT**

AU PROFIT DE L'ASBL BOPPI  
(DÉFICITE IMMUNITAIRE PRIMAIRE)

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[WWW.DIPMARATHON.BE](http://WWW.DIPMARATHON.BE)

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

 DIP MARATHON

EN PRÉSENCE DU GROUPE  
**TIME LINE**

Mon Bon Logis SPRL

dour coffee

Wallonie

SPW Université de Polésie

JL J-L LEKEU Houtcoeur

Del'fante

Compta Wapi Stéphanie Flawegica Expert Comptable Conseil Fiscal ICI

BNP PARIBAS FORTIS

colruyt

Fit Move

Power MAX

Droit de la Santé

Bravo Lefevre

Telitures Depard Barthélémy

Key-S Consulting

Panor

CYCLE GABRIEL

Gj CYCLING SHOP

Diôle

ULTIMATE SPORT

MyEco

PRIMO

COIFFURE DIMITRI

calm

RST

DECATHLON

Belfius

GSM AVENUE

ESPACE

Tel : 0692 490976 37 73 gromagnon\_et\_brodel@hotmail.be



# Romania – 2017

## Public awareness and fundraising through running



**WHO:** ARPID – Romanian Association for Patients with PID

### WHAT:

- Timotion is a charitable national running contest where charities can raise funds and awareness for their cause
- The competitors will also raise awareness and serve as “champions” for their chosen cause, to encourage the public to donate
- ARPID received donations worth of 1000€ going towards psychological and social counselling for the families
- Taking part since 2016





# Spain – 2018

## Medical and political awareness

**WHO:** AEDIP, the Spanish Association for PID Patients

**WHAT:**

- medical education day on PID with collaboration with the Spanish society for Immunology
- They grant study credits for medical students
- They invited a regional government rep to inaugurate the meeting and hear about PIDs
- They organise a similar meeting each year in a different region to raise medical awareness throughout the country



**Outcome:** one regional government provided funds for 2 professionals to take care of PID patients (adults / children) in a reference centre



# What can my NMO do?

- Come up with an idea and start planning!
  - To get ideas, you can visit [www.worldpiweek.com](http://www.worldpiweek.com) and read the annual reports that outline all national activities
  - reach out to IPOPI or its NMOs
- Use existing materials from the website
  - You can reach out to IPOPI on how to adjust and translate existing WPIW materials to national use
- Join forces with others
  - Medical professionals, events, other charities, interest groups, rare diseases
- Join the social media buzz during the week by sharing the posts and tweets, or create your own content
  - Twitter: @WorldPIWeek, Facebook: @WorldPIWeekcampaign
  - #WorldPIWeek #WPIW2018 #PID #Plawereness
- Invite everyone to join!

# Thank you!

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



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**[Youtube.com/worldpiweek](https://youtube.com/worldpiweek)**