

# Summary of IPOPI NMO campaigns

## World PI Week 2019



# Argentina

## AAPIDP (Asociación Ayuda al Paciente con Inmunodeficiencia Primaria)

### Actions:

- National patients' meeting with medical talks, psychological workshop, art workshop and recreational activities
- Regional patients' meeting with a recreational afternoon outdoors with patients and families





# ÖSPID (Österreichische Selbsthilfegruppe primärer Immundefekte)

## Actions:

- Cycling for a good cause
- Release of film about a PID patient meeting her doctor
- Movie from a PID patient's life
- PID-balloon challenge
- Life-saving folders to all plasma centers in Austria



# Belgium



## ASBL BOPPI

### Actions:

28/04/2019:

WPIW: Family day « Technopolis »

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



02/11/2019:

DIP MARATHON Indoor cycling

[www.dipmarathon.be](http://www.dipmarathon.be)



Recipient of IPOPI grant

# Brazil

**ANPIC** (Associação nacional dos portadores de imunodeficiência primária)

## **Actions:**

- PI Week Brazil
- Public hearing at the Ministry of Health
- Regional event to create regional association

# Canada

**CIPO** (Canadian Immunodeficiencies Patient Organization)

## **Actions:**

- Digital education and social media campaign: “Life of PI”
- Profiling a new person (patient/parent/carer/healthcare worker) one day throughout WPIW



## PID Care China

### Actions:

- Psychology lecture for PID patients and caregivers with psychologist Ms. Jiang Qian Li, 20 April 2019
- Group counselling for patients and their families





# Ecuador

## Fundación PIDE

### Actions:

- National Meeting of patients with PIDs
- Training workshops
- Support material





# Finland

## Immuunipuutospotilaiden yhdistys ry

### Actions:

- Awareness day and patient's event
- Lectures on “how to diagnose PID genes” and “when PID is overwhelming

# France

## IRIS (Immuno-Deficiency Primitive: Recherche, Information, Soutien)

### Actions:

- Online PID quiz
- Dissiminated through facebook, IRIS website, mail to trustees and board members
- 104 participants : 85 women & 19 men



#### QUIZZ Semaine mondiale des DIP

Postée le : 22/04/2019  
Actu DIP



Pour cette semaine mondiale des DIP, l'association organise un quizz sur les DIP du 22 avril au 29 avril 2019 avec plusieurs lots à gagner :

- 1er gagnant: Visite de l'Institut Imagine avec une nuit à Paris pour deux personnes
- 2ème et 3ème gagnants : Goodies (t-shirt + sac + mascotte peluche + livre gourmandises de blogueurs + clé USB)
- 4ème et 5ème gagnants : Goodies (t-shirt + clé USB + bloc-note + stylo)

Les personnes ayant eu le meilleur score seront tirées au sort pour le premier lot. Ensuite un autre tirage au sort sera réalisé pour choisir les gagnants des lots 2 à 5. Ils seront choisis parmi les participants ayant le plus haut score.

Envie de participer ? Cliquez sur ce lien :  
<https://associationiris.typeform.com/to/T67INJ>

Recherche... Rechercher

Ensemble pour agir, informer, aider et protéger !

Vous pouvez envoyer un chèque à l'ordre de Association IRIS. Un reçu fiscal vous sera envoyé dans les plus brefs délais.

Pour donner, n'hésitez pas à remplir un bulletin d'adhésion. En plus du soutien financier que cela représente, chaque adhésion donne un peu plus de poids à l'association.

[Télécharger notre bulletin d'adhésion](#)  
[adhérer en ligne](#) [faire un don en ligne](#)

→ Suivez-nous !  
[sur YouTube](#) [sur Facebook](#)  
→ Contactez-nous

#### Documents officiels :

[Plan stratégique 2018-2020.pdf](#) 259.38 Ko  
[Rapport Général CAC2017 IRIS signé.pdf](#) 170.69 Ko  
[Rapports IRIS 2017.pdf](#) 779.48 Ko

Association IRIS a partagé une publication.  
Admin · Publié par Marion Schaefer [?] · 25 avril, 10:16 · Ajouter des sujets

Participez au quizz spécial semaine mondiale des DIP, et tentez de remporter une visite à l'Institut imagine !

Association IRIS  
Publié par Marion Schaefer [?] · 22 avril, 08:32

Pour cette semaine mondiale des DIP, l'association IRIS organise un quizz sur les DIP du 22 avril au 29 avril 2019 avec plusieurs lots à gagner :

1er gagnant : ...

Afficher la suite





# Greece

## APMONIA (Association of Greek Friends for Paediatric Immunology - Primary Immunodeficiencies)

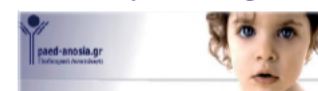
### Actions:

- Awareness events in central square of Athens. Desks and banners
- Open day for patients, doctors and parents



Department of Immunology - Histocompatibility  
Specialized Center & Referral Center for  
Primary Immunodeficiencies -  
Paediatric Immunology  
"Aghia Sophia" Children's Hospital, Athens, Greece

[www.paed-anosia.gr](http://www.paed-anosia.gr)



Scientific Meeting  
on Primary Immunodeficiencies  
Paediatric Immunology



NIKOLAS EVGENIOS  
SCULPTURE CELESTIAL GAME, 2015

**20<sup>th</sup> April 2019**

"Kostis Palamas", UoA  
Athens - Greece



Recipient of IPOPI grant

# Iceland

## Lind (Icelandic Immune Deficiency)

### Actions:

- Educational seminar for new parents and families at Children's hospital
- Conference for grown-ups about SUBCUT, NBS, health anxiety and life long treatments

**Fræðslufundur Lindar**  
Félag fólks með meðfædda ónæmisgalla/mótefnaskort

Fræðslufundur verður haldinn mánudaginn 29. apríl 2019  
kl. 16:15 í Hringssal Barnaspítala Hringssins 1. hæð.  
Fundurinn er ætlaður sjúklingum, aðstandendum,  
heilbrigðisstarfshópnum og þeim sem hafa áhuga á málefnum.

**Dagskrá**

**16:15 - 16:45**  
Ónæmisgallar og íslensk mólíkúla Ásgeir Haraldsson, læknir.

**16:45 - 17:00**  
Heilsukviði Hildur Ey, hjúkrunarfræðingur

**17:00 - 17:15**  
Nýburaskimun Björn Rúnar Lúðvíksson, læknir.

**17:15 - 18:00**  
Anita Berg Product Manager Nordicinfu Care AB

**18:00 - 18:15**  
Kaffiveitingar

**18:15 - 19:15**  
Being a parent to a teenager with chronic disease - Transition and transfer.  
Lotte Vosmar Denning, læknir

**19:15 - 20:00**  
Pallborðsumræður, heilbrigðisstarfsmenn og stjórnarmenn úr Lind svara spurningum úr sal

FRÆDSLUFUNDUR



**Apríl**  
16:15 - 20:00

**29**  
Apríl

  
Staðsetning  
Hringssalur Barnaspítala  
Hringssins

**1H**  
Fyrsta hæð  
Klukkan 16:15 - 20:00

  
Veitingar  
Kaffiveitingar kl 18:00

Allir hjartanlega velkomnir  
Við hvetjum fólk til að afta sér þekkingar um sjúkdóm  
sem lítið hefur verið fjallað um á Íslandi.

 Facebook/lindistland  
 [www.lindistland.net](http://www.lindistland.net)





# India

## IPSPI (Indian Patients Society for Primary Immunodeficiency)

### Actions:

- Seminar on PID in Maulana Azad Medical College, LN Hospital, New Delhi
- Walk for Awareness on PID in collaboration with AMSA India at Jantar Mantar, New Delhi to mark the Launch of WPIW 2019





# Indonesia

## IPIPS (Perhimpunan Pasien Immunodefisiensi Primer Indonesia)

### Actions:

- Online social media campaign
- Family day (50 attendees)
- Pediatric residents and (60 attendees) fellowship trainees session
- <https://www.youtube.com/watch?v=w9xGvszyNPE>





# Italy

## A.I.P. (Associazione Immunodeficienze Primitive)

### Actions:

- Dedicated event to promote knowledge and procedures to doctors regarding PIDs
- Launch of balloons to give more relevance to PIDs
- Shared experiences from patients and insights from AIP about the efforts made to support them during their life
- Perspectives from some medical fields involved such as vaccinations, gastroenterology, pneumology, hematology, dermatology, endocrinology
- Social media activity

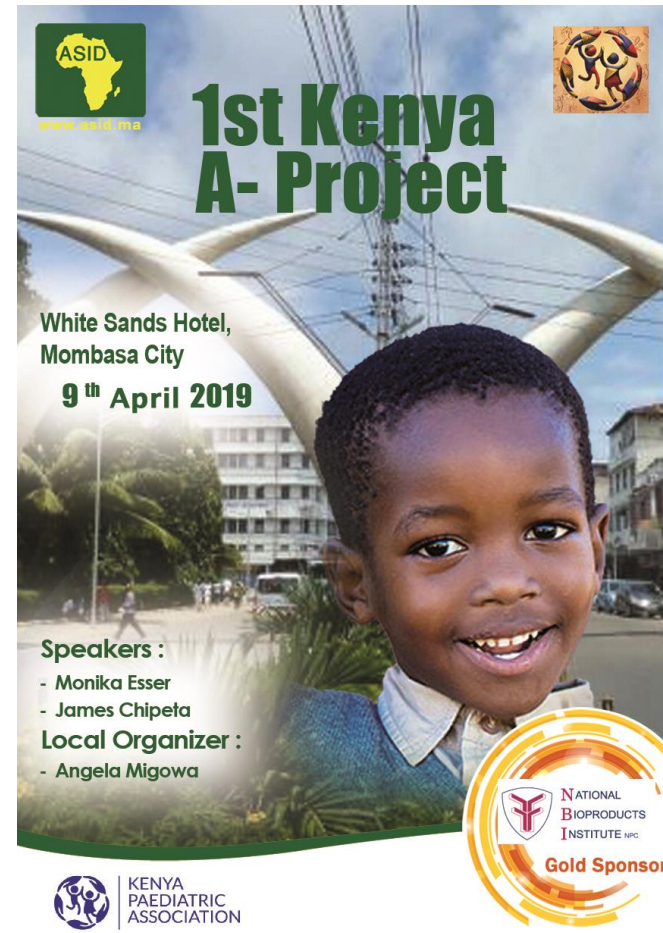


# Kenya

## PIDs Kenya (The Primary Immunodeficiencies Association Kenya)

### Actions:

- Held presentation during the first A Project in Kenya, raising awareness on PIDs from a patient perspective
- Establishment of a PID working group
- The PID working group comprises both patient support groups (PIDs Kenya and the Rare Diseases Society of Kenya) as well as medical doctors.





# Malaysia

## MyPOPI (Malaysia Patient Organization of Primary Immunodeficiencies)

### Actions:

- National WalkAbout 2019, in 7 states (Kelantan, Penang, Perak, Selangor, Kuala Lumpur, Malacca and Sabah). Collaboration with medical universities of Asian Medical Students' Association (AMSA) Malaysia.
- A grand total of 117 medical students participated in this walkabout.





# Morocco

## Association Hajar de Soutien aux patients atteints de deficits immunitaires Primitifs

### Actions:

- Day of blood donation (more than 400 blood donors)
- Day trip for Hajar's children to the Zoo
- Day of PID training of doctors and nurses





# Philippines

## PhilPOPI (Philippine Patient Organization for Primary Immunodeficiencies)

### Actions:

- Daily run of PID infographics video in drug store counters
- Newspaper publication on PID
- Radio and TV broadcastings on PID
- Public display of tarpaulin and distribution of brochures and promotional items on PID
- Dialogue on Universal Health Care with the Philippine Health Insurance Corporation (PhilHealth) and the Department of Health

Recipient of IPOPI grant





# Poland

## Immunoprotect (Association for Patients with Primary Immunodeficiencies)

### Actions:

- PID patient meeting
- Distribution of immunobags with IPOPI educational leaflets and Immunoprotects publication "Pełnia życia"



# Portugal

## APDIP (Associação Portuguesa de Doentes com Imunodeficiência Primária)

### Actions:

- Family Day
- Walk of Health
- Awareness Campaigns in TV Shows and Social Networks
- IDF Signs Alerts PT Version distribution





# Puerto Rico

## APIP (Puerto Rico Alliance of PID patients)

### Actions:

- Health Fair at the University of Puerto Rico
- Community events in schools
- Attending medical congresses, with information table and flyer distribution
- Health Fair in Culebra
- Facebook campaign promoting family meeting
- Press announcement
- 10 digital billboards
- Radio ad in 12 stations
- Family meeting, 125 participants





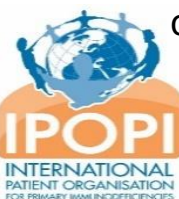
# Romania



## ARPID (Romanian Association for Patients with Primary Immunodeficiencies)

### Actions:

- Timotion – Fundraising Marathon for PID children's summer camp
- Patient stories at NoRo –radio show dedicated for rare diseases  
<http://radionoro.ro/ro/povestea-saptamanii-stela-parvu?fbclid=IwAR3BLbP4tXlboEf6LB2K4rRopfi9vtWdNii6vQl27uJkACKoCDQ6fbALfUw>
- Press release regarding WPIW: <https://www.hotnews.ro/stiri-sanatate-23112789-saptamana-mondiala-imunodeficientelor-primare-accesul-pacientilor-romani-tratament-partial-pentru-unele-tipuri-ale-bolii-iar-pentru-altele-lipseste-complet.htm>
- Organizing the national PID Conference and patient meeting in Zarnesti
- Public survey on the willingness of plasma donation and a press conference about the necessity of plasma donation in Romania



Recipient of IPOPI grant



# Senegal

## ASDIP (Association sénégalaise des déficients immunitaires primitifs)

### Actions:

- A scientific meeting in partnership with the African Center of Excellence for Maternal and Child Health (CEA-SAMEF, the Senegalese Society of Pediatricians (SOSEPED) and the Senegalese Society of Immunology (SSI)
- 50 participants
- Covered by local media

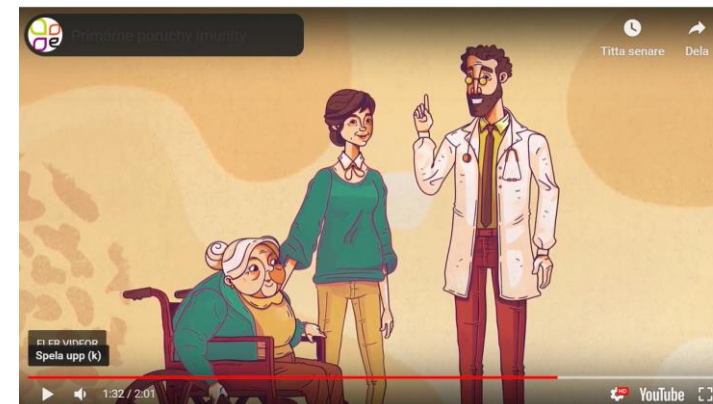
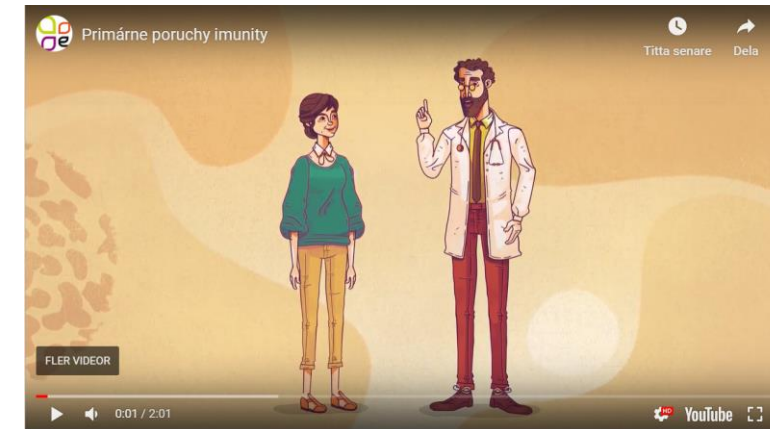


# Slovakia

## Slovakian Association of Patients with Primary Immunodeficiency

### Actions:

- Animated video on patient's rights to educate patients and the general public
- A follow up to the animated video “Warning signs of PI in adults” from 2018
- The video was presented during WPIW as a part of a wider campaign on raising awareness on patient's rights





# South Africa

## PINSA (Primary Immunodeficiency Network of South Africa)

### Actions:

- Radio interviews
- Collaborative press release on WPIW with Allergy Society of South Africa and Allergy Foundation South Africa
- PiNSA's poster advertised in the Child Mag
- PID seminar
- Patient meetings
- Doctors collaboration
- Patient support group collaboration



# Spain

## AEDIP (Asociación española de deficits inmunitarios primarios)

### Actions:

- One-day meeting in León 26/04/2019 with the goal to improve awareness amongst pediatricians, pneumologists and internal medicine doctors
- Distribution of IPOPI leaflets in Spanish

#### CONVOCATORIA ASAMBLEA GENERAL ORDINARIA 2019

Publicada en *abril 24, 2019*



#### CONVOCATORIA ASAMBLEA GENERAL ORDINARIA 2019

Día: 26 de Abril de 2019.

Lugar: Salón de actos Hospital Universitario de León

Hora: 17:00 H. En primera convocatoria y 17:30 H. en segunda convocatoria.



# Korea

## PID Korea

### Actions:

- Lunch time with the family of patient
- PID Korea Lecture (Prof. Kim & parents of patient Lee Seong Young)
- Speaking about real barriers and practical solutions
- Giving gifts





# Thailand

## ThaiPOPI

### Actions:

- Blood donation project in collaboration with the Thai Red Cross Society
- Thai culture show to encourage donation
- Information booth
- Free lunch and snacks





# Uganda

## PIPO (PRIMARY IMMUNODEFICIENCIES PATIENT ORGANISATION)

### Actions:

- PIDs Seminar with case presentation at Kabale University Medical School, South Western Uganda. Participants included three senior staff from the Department of Pediatrics and all the Pioneer Junior Clerks.
- PIDs Seminar at Gulu University Medical School, Northern Uganda. Participants included one senior staff member from the Department of Pediatrics and students from the clinical years.



# Ukraine

## RID (Rare Immune Diseases)

### Actions:

- Creation and distribution of short animated video, highlighting the main concepts of PID



# Venezuela

## IDP Venezuela (Inmunodeficiencias Primarias Venezuela)

### Actions:

- Psychiatrist meeting for PID patients, families and friends about daily life for PID patients
- Visits to different medical services: pediatrics health services, pediatrics emergency, family medicine, general practitioner, nurse and students, internal medicine specialist, pneumologist and otholaryngologist



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