

Health policy & advocacy activities

Leire Solis

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 - Regional advocacy training workshops (*)
- At national level
 - SCID NBS national campaigns
 - Advocacy & policy support to NMOs (*)
- Stakeholder collaboration:
 - PLUS - Platform of Plasma Protein Users
 - European Reference Network RITA (*)
 - Rare Disease International
- Advocacy materials (*)
- Publications (*)

International level

- Advocacy towards WHO
 - WHO Model List of Essential In Vitro Diagnostics
- 2 stage consultation for update
 - Successful 1st stage
 - Joint application with IUIS
 - Support of 8 scientific organisations & 2 pharma platforms & other stakeholders
 - Working on 2nd stage
 - Deadline 15 November



**World Health Organization Model List of
Essential In Vitro Diagnostics**
First edition (2018)

16 May 2018

At regional level

- PID Forums (*)
 - Different relevant topics for EU
 - Development of policy documents
 - Upcoming 12th PID Forum – 27th November, Brussels
 - Open to all European NMOs wishing to come
 - 2 grants available to NMOs per Forum
- Regional advocacy training workshops (*)
 - Support development of advocacy & media skills
 - Help implementing realistic & actionable advocacy plans
 - Identification of regional priorities
 - Promote cooperation amongst national representatives



At national level

- SCID NBS national campaigns
 - So far, IPOPI has supported 4 national campaigns
 - Currently supporting a campaign in Spain
- Advocacy & policy support to NMOs (*)
 - On the basis of NMO needs
 - Different tools:
 - Letters of support
 - Letters to policy makers
 - Feedback on campaign and/or materials



Advocacy materials & publications

- Advocacy materials
 - No need to reinvent the wheel – check IPOPI's website
 - On different topics
- Publications



IPOPI Position Statement Zika Virus

Zika virus was first identified in Uganda in 1947 and the first human infections were reported in the early 1950s. In recent months significant outbreaks of Zika virus in different regions and particularly in Central and South America have caught the attention of health authorities worldwide. Zika virus has been declared a public health emergency of international concern (PHEIC) by the World Health Organisation (WHO) after a substantial spike of cases of microcephaly in newborns and Guillain-Barre Syndrome (GBS) in the Americas. WHO defines a PHEIC as "an extraordinary event which is to constitute a public health risk to other states through the international spread of disease and to potentially require a coordinated international response".

Symptoms

It should be noted that only 20% of individuals infected with Zika virus become symptomatic.¹ The main symptoms of Zika virus disease are usually mild fever, skin rash and conjunctivitis, lasting for 2-7 days. Following the recent outbreak in Brazil (2015), clusters of GBS and pregnant women giving birth to babies with microcephaly (unusually small heads and abnormally developed brains) have been temporally associated with Zika virus transmission in some settings. Whilst a causative link between Zika virus and microcephaly / GBS remains to be firmly established, due to the absence of another explanation for these clusters and in the context of aggressive and women of

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Growing older with a PID: transition of care and ageing

Recommendations of the International Patient Organisation for Primary Immunodeficiencies (IPOPI)

July 2017

Introduction

The International Patient Organisation for Primary Immunodeficiencies (IPOPI) is the association of national patient organisations, dedicated to improving awareness, access to early diagnosis and optimal treatments for people with primary immunodeficiencies (PIDs) worldwide.

PIDs are a group of more than 300 genetic rare disorders in which the immune system does not work adequately or at all. PIDs are often regarded as a group of conditions typically observed in paediatric age. However, PIDs affect patients throughout their life, and with increasingly more knowledge and awareness about rare diseases, more attention should be paid to specific stages in life where support is key in ensuring the well-being and the quality of care of the patient, such as during adolescence, early adulthood and at later stages in life. Moreover, improved medical care, scientific developments and increased knowledge about PIDs have led to greater survival in paediatric patients, so that the cohort of patients entering the adult age is now increasing, with all the repercussions this may entail in terms of services and support needed.

The IPOPI Recommendations on transition of care and ageing with a PID are aimed at providing an overview of the key issues faced by PID patients when entering adulthood and at a later stage in their life, as well as supporting patient representatives in their advocacy efforts, healthcare professionals in their practice and encouraging policymakers to implement a patient-centred approach in the decision-making.

The Recommendations are based on the outcomes of the IPOPI 6th PID Forum on "Growing older with a PID: transition of care and ageing", chaired by the Member of the European Parliament Dr Elena Gentile (S&D, Italy) and supported by Mr Carlos Zorinho (S&D, Portugal) in June 2017 at the European Parliament (Brussels, Belgium).

Patient Preference and Adherence

Improving current immunoglobulin therapy for patients with primary immunodeficiency: quality of life and views on treatment

Background: Subcutaneous or intravenous immunoglobulin replacement is the mainstay of treatment for most patients with primary immunodeficiency disease (PID). The purpose of this study was to gain an understanding of how existing PID therapies affect patient lives and to identify desired improvements to immunoglobulin treatments.

Methods: An online questionnaire was made available through the International Patient Organisation for Primary Immunodeficiencies to patients with PID and their caregivers regarding current treatment satisfaction, living with PID, and patient preferences using a conjoint approach. Health-related quality of life was measured via questionnaires using the Short Form 12 Health Survey and EuroQoL-5 Dimensions.

Results: A total of 300 responded to the survey (72% patients with PID and 28% caregivers) from across 21 countries, mostly the UK, Sweden, Canada, France, Germany, and Spain. Fifty-three percent and 45% of patients received intravenous and subcutaneous therapy, respectively. Most respondents (76%) were satisfied with their current treatment, reflecting the benefits that immunoglobulin therapy provides for patient health and well-being. However, patients remained below the physical and mental well-being norms for health-related quality of life as determined by the questionnaire. All respondents expressed a desire for 4-weekly infusions, the ability to administer these at home, self-administration, shorter duration of administration, and fewer needle sticks.

Conclusion: The results of this survey highlight the importance of providing access to different treatment options and modes of administration to ensure individual patient needs are best met.

Keywords: primary immunodeficiency, immunoglobulins, quality of life, patient needs, patient satisfaction, conjoint analysis

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What Is the Burden of Immunoglobulin Replacement Therapy in Adult Patients With Primary Immunodeficiencies? A Systematic Review

Georgina L. Jones*, Katharina S. Vogt¹, Duncan Chambers², Mark Clowes³ and Anna Shrimpton³

Front. Immunol. 02 July 2018 | <https://doi.org/10.3389/fimmu.2018.01308>

Check for updates

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IPOPI NMO Programmes

Saara Kiema
NMO Programmes Officer

24 October 2018
Lisbon



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- In the pipeline
 - Clinical Care Webinars
 - PIDetect

NMO events

- Global Patients' Meetings
- Regional Patients' Meetings
 - Back to back with regional societies: ASID, LASID, SEAPID, APSID
- National Patients' Meetings
- NMO Launch Meetings
- Regional and National Clinical Care Meetings
 - Next one in Bangkok, 10-11 November 2018



NMO online resources



IMPROVING PID PATIENTS' LIVES. WORLDWIDE.

Search IPOPI website

Home About IPOPI Our Work PIDs NMOs Publications IPOPI PID Map Media e-News IPOPI TV

NMO Toolbox

Communications and media

Media Guidelines (PDF)

Checklist for an Effective Press Conference (PDF)

Broadcast Guidelines - TV and Radio (PDF)

Celebrity Guidelines (PDF)

NMO Event Checklist (PDF)

Fundraising

Guidelines on Corporate Sponsorship (PDF)

Overview of Crowdfunding and Online Fundraising Tools (PDF)

NMO Skills Manual (PDF)

Policy and advocacy

Guide to Government Relations (PDF)

PID Principles of Care



IMPROVING PID PATIENTS' LIVES. WORLDWIDE.

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Leaflets



23RD MARCH 2018

New series of IPOPI PID information leaflets published

IPOPI has since 2011 been producing primary immunodeficiencies (PID) information and a new series has just been published. This last series comprises 3 leaflets...



29TH APRIL 2016

Immunoglobulin replacement therapy. A guide for general practitioners, How are primary immunodeficiencies classified?

The first leaflet 'Immunoglobulin replacement therapy - One size does not fit all' explains the variety of factors that patients with PIDs should consider, and...



16TH JANUARY 2015

When to give IG replacement therapy, PID and respiratory disorders, PID and gastrointestinal disorders, and more!

Two of this series' leaflets focus on PIDs and specific related conditions: PIDs and Gastrointestinal disorders and PIDs and Respiratory Disorders. Two others...



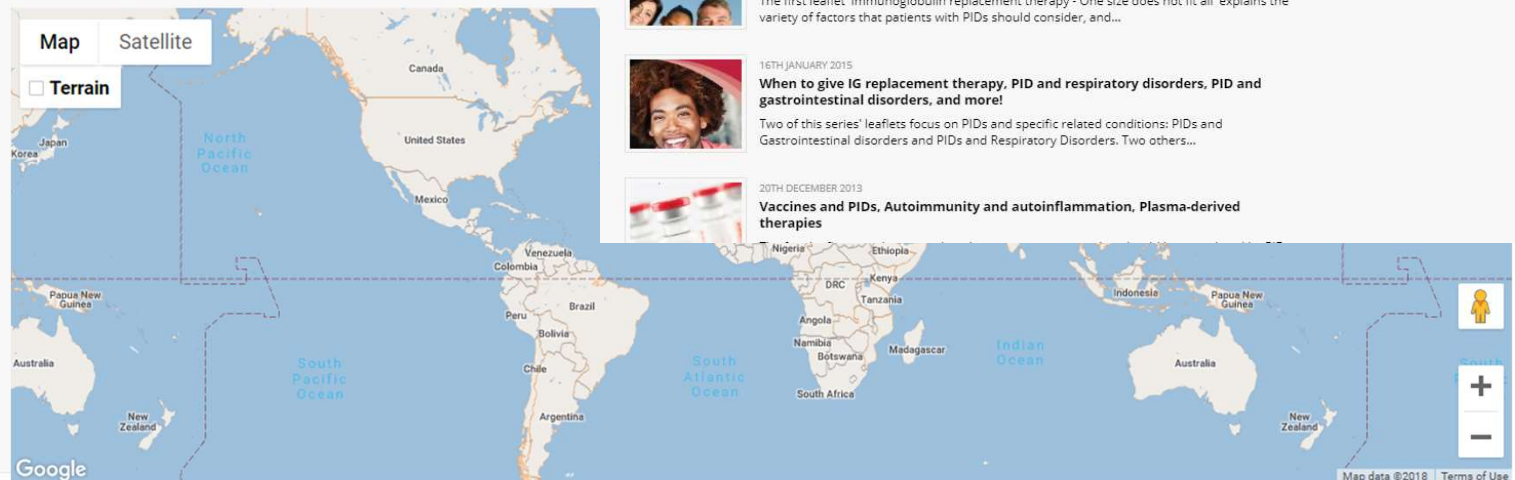
20TH DECEMBER 2013

Vaccines and PIDs, Autoimmunity and autoinflammation, Plasma-derived therapies



IPOPI PID Map

Click on a country below to find out more information about Primary Immunodeficiencies (PID) at nation



NMO grant programmes

IPOPI has two grant programmes and toolkits to support its NMOs carry out awareness and advocacy campaigns

IPOPI NMO Support Grant Programme

IPOPI WPIW Support Grant Programme





WE ARE GETTING A NEW LOOK!

TEST. DIAGNOSE. TREAT.

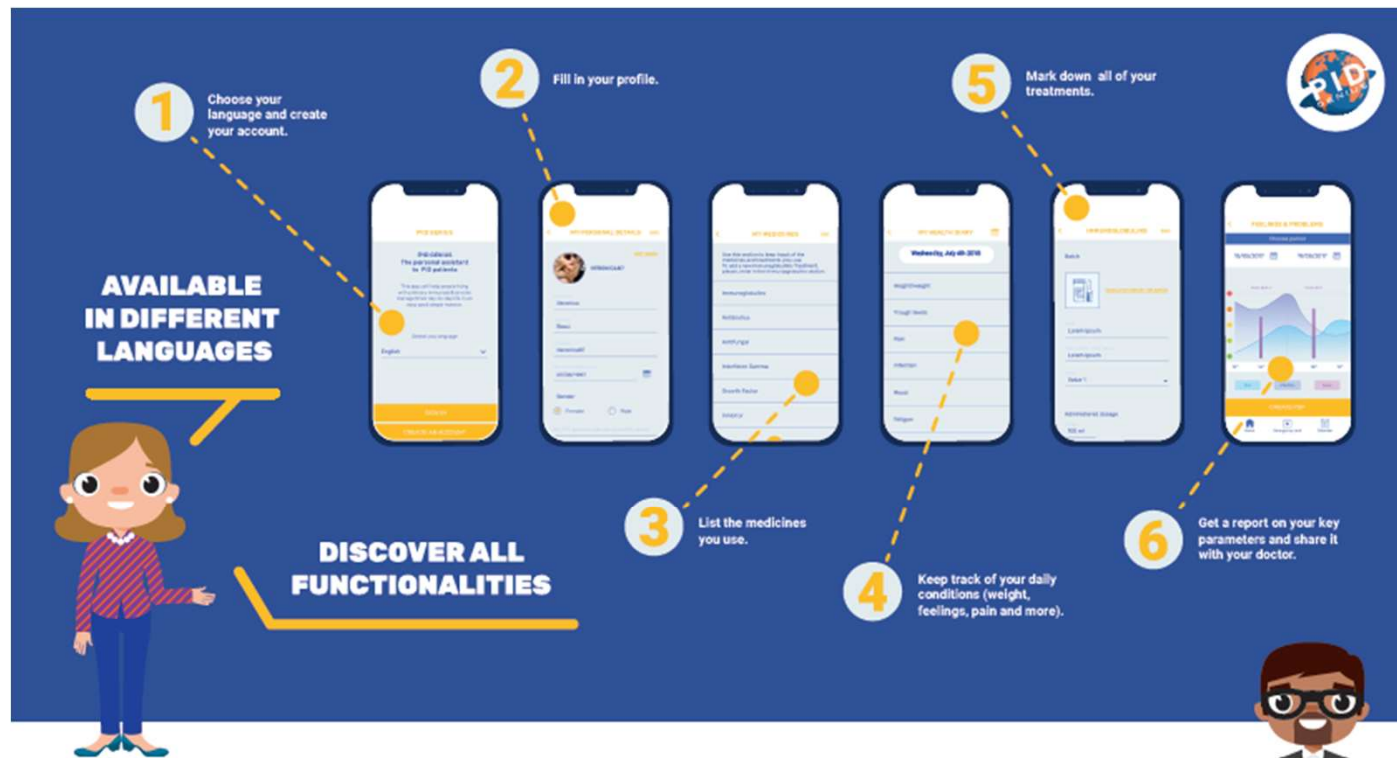


WPIW 2019 will
have a fresher look
with new innovative
materials
- stay tuned!



World PI Week

PID Genius – update 2018!



PID GENIUS HELPS YOU MANAGE YOUR CONDITION AND TREATMENT.

PID GENIUS is a dynamic app developed by IPOPI that allows people with primary immunodeficiencies to better deal with their disease. It plays the role of a personal assistant that helps them keep track of their treatments, health condition, appointments and most important documents. The recent PID GENIUS restyling introduces many innovations: more languages to choose from, better user experience and enhanced text readability.

IPOPI (the International Patient Organisation for Primary Immunodeficiencies) is the leading advocate for primary immunodeficiency (PID) patients worldwide. IPOPI is dedicated to improving awareness, access to early diagnosis and optimal treatments for people with PIDs worldwide through global collaboration.



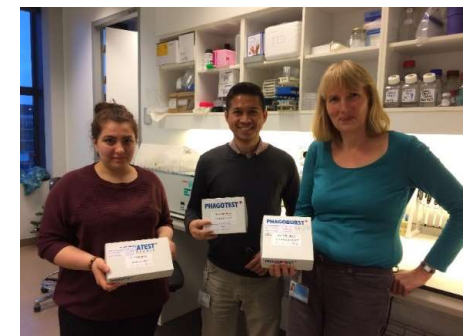
Stakeholder collaboration

- IPOPI Medical Advisory Panel Support
- Collaboration with medical societies (ASID, SEAPID, LASID)
- Research projects – RECOMB
 - Developing gene therapies for RAG1-SCID
 - Closely working with Advocacy and Health Policy Manager, Leire Solis and Communications Manager, Magda Lourenço



In the pipeline

- Clinical Care Webinars
 - first one on 14th November: *Advances in management and care of CVID*, by Prof Klaus Warnatz
 - Registration now open!
- PIDetect
 - Diagnostics training programme established by IPOPI
 - Pilot done for Indonesia in December 2017
 - Collaboration with ERASMUS University Hospital, Rotterdam
 - Goal to train doctors on PID diagnosis and have them teach the acquired knowledge in their country



Communications' update

Magda Lourenço
Communications Manager

Video – PIDs in Africa



Primary immunodeficiencies in Africa

536 visualizações

11 1 PARTILHAR ...

- Following Poster POTENTIAL FOR MANAGEMENT OF PIDs IN AFRICA (ASID 2017meeting)
- To raise awareness of PIDs by sharing statistics and simple means of diagnostic.



Video - RECOMB



RECOMB - Stem-cell based gene therapy for recombination deficient SCID

- Several complicated concepts
- Novel treatment
- Reach a broad yet focused audience

Publications

Leaflets

		24,713 % of Total: 100.00% (24,713)
<input type="checkbox"/>	1. Home - IPOPI	8,002 (32.38%)
<input type="checkbox"/>	2. Page not found - IPOPI	1,548 (6.26%)
<input type="checkbox"/>	3. Leaflets - IPOPI	971 (3.93%)
<input type="checkbox"/>	4. IPOPI PID Map - IPOPI	899 (3.64%)
<input type="checkbox"/>	5. Member organisations - IPOPI	873 (3.53%)
<input type="checkbox"/>	6. New series of IPOPI PID information leaflets published - IPOPI	676 (2.74%)
<input type="checkbox"/>	7. What are PIDs? - IPOPI	661 (2.67%)
<input type="checkbox"/>	8. List of Some Primary Immunodeficiencies - IPOPI	581 (2.35%)
<input type="checkbox"/>	9. Calendar - IPOPI	572 (2.31%)
<input type="checkbox"/>	10. Survey on Switching IG Therapies - IPOPI	484 (1.96%)



- Always amongst most read IPOPI.org pages
- Next 3: CVID, Guide for Internal medicine specialists, PIDs and HSCT

Publications

e-News Summer

Top links clicked

<https://e-news.ipopi.org/11th-ipopi-eu-pid-forum-the-case-of-pids-towards-a-revision-of-paediatic-regulation/>

<https://e-news.ipopi.org/xv-ipopi-global-pid-patients-meeting-in-lisbon/>

<https://e-news.ipopi.org/world-pi-week-2018-raising-awareness-of-pids-around-the-globe/>

<https://e-news.ipopi.org/jose-drabwell-appointed-as-officer-in-the-order-of-orange-nassau/>

<https://e-news.ipopi.org/european-conference-on-rare-diseases-in-vienna-austria/>

e-News Summer 2018

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From the Chairperson's desk

In this issue of our newsletter, we bring you news of IPOPI's actions which have taken place in the last few months in all regions of the World as IPOPI supported the organisation of 20 national NMO awareness and advocacy campaigns during World Primary Immunodeficiencies Week 2018, bringing our total number of WPMV supported campaigns well over 120 since the inception of the campaign in 2011.

[Read more](#)

IPOPI News



XV IPOPI Global PID Patients Meeting in Lisbon

IPOPI is looking forward to welcoming all National Member Organisations (NMOs) later this year in Lisbon for the XVth IPOPI Global PID Patients' Meeting taking place in on October 24-27 in the amazing city of Lisbon.



11th IPOPI EU PID Forum – towards a revision of Paediatric Regulation: the case of PIDs

IPOPI organised the 11th edition of its PID Forum, hosted by MEP José Inácio Faria (EPP Portugal), MEP Tomáš Zdechovský (EPP, Czech Republic) and MEP Elena Gentile (S&D

Social media – Twitter

Top media Tweet earned 623 impressions

#RecombEU is a project funded by the **@EuropeanCommiss**'s **#Horizon2020** that aims to develop **#GeneTherapy** for **#RAGSCID** patients. IPOPI is one of the partners and is pleased to share the newly launched project leaflet bit.ly/RecombLeaflet **#genetherapy** **#SCID** **#precisionmedicine** pic.twitter.com/pgxSwZwREX



10 12

[View Tweet activity](#)

[View all Tweet activity](#)

Top media Tweet earned 2,781 impressions

IPOPI's 11th **#PIDForumEP** is today in Brussels, 16h30! Check the programme & join the discussion on **#PIDs** & revision of the **#paediatricregulation** bit.ly/2yJ2bm4 **@EdithKlapwijk** **@PlasmaProteins** **@EU_Commission** **@JoseDrabwell** **@martinepergent** **@TomZdechovskyEP** **@elena_gentile** pic.twitter.com/mNUKK6GNgF



13 15

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Top Tweet earned 1,778 impressions

Big shout out to **#PID** patients in Africa! This **#ANPIW** IPOPI is launching an awareness video about **#primaryimmunodeficiencies** in Africa. Testing, diagnosing and treating PIDs is possible. Watch it on tv.ipopi.org and RT **@tdkdieye** **@Pinsa_ZA** pic.twitter.com/ac9Xyeb8tw



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Social media – Facebook

22/04/2018 10:00	 Today starts World Primary Immunodeficiencies Week! Learn about the campaign and let us know			1.1K	
18/05/2018 17:47	 IPOPI is running an anonymous survey on Switching Immunoglobulin Products to help us better			1K	
06/07/2018 17:24	 IPOPI is planning its XV PID Patients #GlobalMeeting taking place in Lisbon, Oct 24-27, back to back with			1.8K	
19/10/2018 16:39	 IPOPI Autumn e-News is here! Read the latest details about the Global PID Patients meeting, the			1.1K	

IPIC2019



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PROGRAMME

The congress programme will feature world-renowned experts in the field of PID. Find out more!

HOTELS

IPIC2019 has special rates with several hotels. Find the best one for you!

ABSTRACTS

Abstract submission for poster presentation will be opened in February 2019. Stay tuned!

IPIC2019 – DIAGNOSIS AND CLINICAL CARE

Thank you!

