



REVIEW
OF ACTIVITIES
AND ACHIEVEMENTS
2014



IPIC2015

INTERNATIONAL PRIMARY IMMUNODEFICIENCIES CONGRESS

FOCUS ON CLINICAL CARE
AND DIAGNOSIS

5/6 NOVEMBER 2015

BUDAPEST, HUNGARY

WWW.IPIC2015.COM



A MESSAGE FROM THE CHAIRPERSON



Jose Drabwell, IPOPI Chairperson

Dear Friends and Colleagues,

In 2014 IPOPI achieved numerous milestones, which have greatly contributed in increasing awareness of Primary Immunodeficiencies worldwide. In fact it seems that 2014 was gone in a flash. Thanks to the support of Bob LeBien, IPOPI's founding father, IPOPI continued its regional development campaign in South East Asia with new NMOs launched in Thailand, Malaysia, Hong Kong and at the time of writing these lines a new patient group has been formed in Singapore. Building on these efforts IPOPI has supported an increased dialogue between doctors and patients in this region which ultimately enabled the launch of a new PID doctors' expert group called SEAPID. Sadly however the end of 2014 was also marked by the tragic loss of Mike LeBien, the son of

Bob and Sara LeBien who have so eagerly supported IPOPI since the start of our organisation. Mike will be dearly missed by all of us at IPOPI.

IPOPI's XIII Biennial Patients' Meeting was successfully organised in collaboration with the European Society for Immunodeficiencies (ESID) and the International Nursing Group for Immunodeficiencies (INGID) in Prague, Czech Republic. The meeting was once again a unique opportunity to bring patient group representatives from all regions of the world together to share experiences, exchange information and compare activities. During the meeting we welcomed six new member organisations (NMOs) as well as four new associate member organisations which contributed to the further increase of IPOPI's NMO global network, which currently consists of 55 NMOs. Three new Board members were also elected in Prague: Mrs Dragana Koruga (Serbia), Mrs Christine Jeffery (Australia) and Mr Adrian Gorecki (Poland). In early 2015 two additional members: Mr Bruce Lim (Malaysia) and Ms Violetta Kozhereva (Russia) were co-opted to the IPOPI board.

On the advocacy front, IPOPI held its successful 5th IPOPI PID Forum at the European Parliament in Brussels which focused on the need for a comprehensive framework for care and policy for PIDs. The event was attended by a wide range of stakeholders including Members of the European Parliament, representatives from patient organisations, doctors' groups, the World Health Organisation and industry. I also want to stress IPOPI's tireless work to advocate for SCID Newborn Screening (NBS) in Europe and other regions. There is now a dedicated page on the IPOPI website showing the current status of NBS in each country. Building on IPOPI's work at EU level, our 2014 high-level political meeting in France organised with the full support of our French NMO (IRIS) and the French PID reference centre (CEREDIH) resulted in political endorsement of a pilot study, which will be key to hasten the implementation process. IPOPI is currently working on a similar programme in Italy and the Netherlands have just announced that they will implement SCID newborn screening nationally. IPOPI also supported a policy meeting in Brasilia advocating for better access to diagnosis and care in Brazil.

One of our most significant achievements was the publication of the PID Principles of Care in *Frontiers Immunology Journal* in December. This important document has already become a key advocacy tool for the PID community and is currently being translated in several languages. It is therefore with much enthusiasm and energy that IPOPI will continue with its exciting projects and programmes in 2015, as well as holding the 2nd International Primary Immunodeficiency Congress (IPIC2015) in Budapest.

A handwritten signature in white ink that reads "Jose Drabwell". The signature is fluid and cursive.

Yours sincerely,
Jose Drabwell

EXECUTIVE COMMITTEE, OFFICERS AND STAFF

EXECUTIVE COMMITTEE

Jose Drabwell, Chair (United Kingdom)
Martine Pergent, Vice Chair (France)
Christine Jeffery, Treasurer (Australia)
Marcia Boyle (USA)
Roberta Pena (Argentina)
Dragana Koruga (Serbia)
Adrian Górecki (Poland)
Violetta Kozhereva (Russia)
Bruce Lim (Malaysia)

STAFF

Johan Prevot, Executive Director
Leire Solis, Health Policy and Advocacy Manager
Magda Lourenço, Project Manager, Communications and NMO Programmes
Carla Morgado, Executive Assistant
Carol Tavener, Bookkeeping & Administration
Clare Glynn, Financial consultant

MEDICAL ADVISORY PANEL

Prof. Bobby Gaspar, Chair (UK)
Dr. Nizar Mahlaoui, Vice Chair (France)
Dr. Adli Ali (Malaysia)
Dr. Tajed Avcin (Slovenia)
Prof. Aziz Bousfiha (Morocco)
Prof. Andrew Cant (United Kingdom)
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Dr. Jose Franco (Colombia)
Dr. António Condino Neto (Brazil)
Prof. Luigi Notarangelo (USA/Italy)
Prof. Surjit Singh (India)
Dr. Joanne Smart (Australia)
Prof. Martin Van Hagen
(The Netherlands)
Prof. Klaus Warnatz (Germany)



Board meeting in Rome, Italy, March 2014. In the selfie, left to right: Martine Pergent (Vice Chair), Christine Jeffery (Treasurer), Adrian Górecki, Marcia Boyle, Jose Drabwell (President), Roberta Anido de Pena.



Bruce Lim,
Malaysia



Dragana Koruga,
Serbia



Violetta Kozhereva,
Russia



Johan Prevot, IPOPI
Executive Director



Dr. Nizar Mahlaoui,
IPOPI MAP Vice Chair



Prof. Bobby Gaspar,
IPOPI MAP President

IPOPI STRATEGIC PLAN

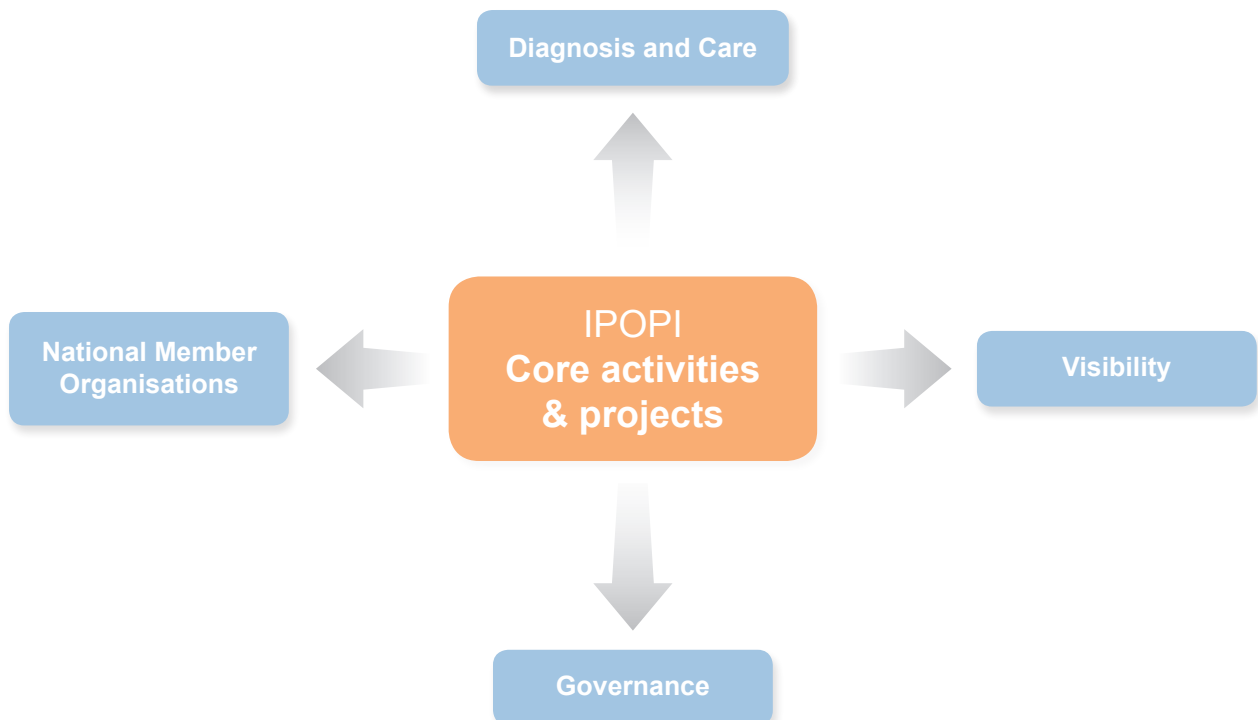
MISSION STATEMENT

IPOPI is the association of national patient organisations dedicated to improving awareness, access to early diagnosis and optimal treatments for primary immunodeficiency (PID) patients worldwide.

Strategic Objectives

IPOPI's current four year strategic plan to 2015 builds on IPOPI's significant growth over the last couple of years as well as on lessons and outcomes learnt through the course of our various activities. In designing this plan, IPOPI streamlined its strategy around four key strategic objectives with the aim to guide IPOPI's actions and activities in the four years to come, but with a clear vision to the long term future:

1. To ensure optimal access to early diagnosis & care
2. To develop, strengthen and support National Member Organisations (NMOs)
3. To enhance IPOPI and PID visibility globally
4. To increase efficient governance of a well resourced developing organisation



WHAT ARE PIDS?

Primary Immunodeficiencies (PIDs) are a large and growing group of over 250 different disorders caused when some components of the immune system (mainly cells and proteins) do not work properly. Whilst PIDs are generally recognised as rare disorders, some are more common than others and taken as a whole they represent an important group of people whose lives are profoundly impacted by their condition.

PIDs are caused by genetic defects of the immune system which are hereditary. The immune system normally helps the body fight off infections by germs (or 'micro-organisms') such as bacteria, viruses, fungi and protozoa. Because their immune systems do not work properly, people with PIDs are more prone than other people to infections. When PIDs are left underdiagnosed or misdiagnosed, the immune system remains defective, often leading to illness, disability, permanent organ damage or even death.

PIDs are currently classified into nine groups: predominantly antibody deficiencies; combined immunodeficiencies; combined immunodeficiencies with associated or syndromic features; diseases of immune regulation; congenital defects of phagocyte number or function, or both; defects of innate immunity; auto-inflammatory disorders; complement deficiencies, based on the main immunological defects; and phenocopies of Primary Immunodeficiencies.

Whilst it is estimated that around 60% of PIDs can be easily diagnosed with a simple and inexpensive blood test, **many PIDs remain underdiagnosed on a global scale.** Hopefully, as the technical ability to identify gene defects improves, more and more genetic causes of PID will be identified. Screening for some of the most severe forms of immunodeficiency will also diagnose more individuals and improve treatment outcomes. Medicine is advancing very rapidly and novel therapies that target the specific cause of the disease are becoming available. These may have significant advantages for PID patients and it is important that patients throughout the world have access to these treatment possibilities.

With appropriate access to the different and very effective therapies (such as Immunoglobulin replacement therapy and Bone Marrow Transplantation among others) which can only happen if early and correct diagnosis is made, many sequelae will be avoided and **lives of patients will be saved.**

This is why IPOPI is committed to continue to disseminate information to patients, their relatives and doctors and work towards better access to early diagnosis and treatment for all patients living with a PID.



KEY ACHIEVEMENTS AND ACTIVITIES, 2014

STRATEGIC OBJECTIVE 1 – ENSURE OPTIMAL ACCESS TO DIAGNOSIS & CARE

Publication of PIDs Principles of Care

Over a period of two years, IPOPI combined its efforts with a worldwide multi-disciplinary team of 28 medical experts representing the five continents to develop the “Primary Immunodeficiencies Principles of Care”. These efforts were rewarded in December 2014 with the publication in the *Frontiers in Immunology* Journal (<http://journal.frontiersin.org>)

This landmark publication outlines the key necessary elements and policies that should be in place to provide a “gold standard” framework of diagnosis and care for primary immunodeficiencies.

It aims at providing guidance to decision-makers and healthcare professionals throughout the world on the different aspects affecting PIDs. The PIDs Principles of Care cover the role of specialised centres, importance of registries, the need for international collaborations for scientific research, the role of patients groups, management and treatment options for PIDs, and management of PID diagnosis and care throughout the world.

IPOPI would like to express its most sincere thanks to all the co-authors of the PIDs Principles of Care with special thanks to Professor Helen Chapel, IPOPI’s Honorary Vice President, whose coordination and input were pivotal in getting the document published.



IPOPI 5th PID Forum at the European Parliament

The 5th PID Forum at the European Parliament focused on the need for a comprehensive framework for care and policy for PIDs.

This important event was held on the 4th of December and co-chaired by two Members of the European Parliament, Dr Cristian Busoi and Dr Boreslaw Piecha. IPOPI, together with representatives from three European IPOPI NMOs - ARPID, BOPPI, Immunoprotect, respectively from Romania, Belgium and Poland - and other relevant stakeholders including the European Haemophilia Consortium, Health First Europe, WHO Europe, other MEPs and representatives of the pharmaceutical industry discussed how to involve Primary Immunodeficiency (PID) patients in the development of policies that would have an impact on their lives: from SCID newborn screening, to the Blood Directive, European Reference Networks and Health Technology Assessments (HTAs).



Johan Prevot, Dr Artemiza Baldea, Dr Cristian Busoi, Dr Boreslaw Piecha and Jose Drabwell at the 5th IPOPI EU PID Forum

The 5th PID Forum provided a comprehensive set of conclusions that will pave the way for IPOPI’s upcoming activities at the EU level. Dr Busoi and Dr Piecha encouraged the participants to continue working in this coordinated way to ensure that the voice of patients with PIDs is taken into account in decision-making and promoted personally the set of endorsed concrete conclusions identified during the event with all MEPs.

IPOPI SCID Newborn Screening programme

IPOPI strives to ensure that babies born with Severe Combined Immunodeficiency (SCID) can have access to the earliest diagnosis possible. The IPOPI SCID Newborn screening advocacy campaign was initiated in the last decade to raise awareness of this paediatric emergency. In partnership with the European Parliament IPOPI called for EU Recommendations on newborn screening (NBS) for rare diseases such as SCID.

IPOPI has been combining efforts at European level with its National Member Organisations (NMOs) to organise national political and awareness campaigns. The first IPOPI SCID NBS **National Parliamentary Event** was held at the National Assembly in Paris, France, on 22 October 2014. Marie-Françoise Clergeau, Member of the French Parliament and Senator Michelle Meunier chaired the event co-organized by IPOPI, IRIS (IPOPI's French NMO) and CEREDIH (French National Reference Centre for PIDs).

The event was pivotal to get political endorsement of SCID newborn screening in France. One of the key messages was the need to secure the implementation of SCID NBS in France. Follow up meetings with the authorities are taking place to ensure this will be done.

A new **website page** was created pooling together all the latest information on SCID newborn screening at the international level as well as IPOPI's activities on the topic. For the first time, an interactive world map enables visitors to view information on the status of newborn screening in different countries.



IPOPI International Patient Organisation for Primary Immunodeficiencies

HOME ABOUT IPOPI ABOUT PIDS PUBLICATIONS EVENTS SPONSORS RESOURCES CONTACT US e-News

IPOPI SCID Newborn screening campaign

IPOPI initiated in the late 2000s an advocacy campaign to raise awareness of SCID newborn screening and, in partnership with the European Parliament, called for EU Recommendations on newborn screening for rare diseases such as SCID (Severe Combined Immunodeficiency).

IPOPI is currently combining efforts at European level with its National Member Organisations (NMOs) to organise national political and awareness campaigns.

IPOPI strives to ensure that babies born with SCID can have access to the earliest diagnosis possible.

Click on a country below to find out more information about SCID NBS at national level
This page requires your contribution! If have any updates please inform [Leire Solis](#).

Map Country List

JS map by amCharts

Activities at European level

Support to NMOs with national campaigns

Reasons for SCID newborn screening

SCID News

Marketing application for new ALIX-SCID gene therapy submitted to EMA

French Parliament PID Event

Call for SCID Newborn Screening in the UK

View all

Gallery

IPOPI is a charity registered in the UK.
Registration No. 1058005

About IPOPI About PIDS Member Organisations News Leaflets Calendar Sponsors Immunoglobulin list Contact Us

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Importance of working with stakeholders

IPOPI has always valued the benefits of working together with its stakeholders. 2014 was a great year of joint-stakeholder collaborations with other patient organisations, medical societies, key opinion leaders, industry stakeholders and many others.

IPOPI attended in March the 20th edition of the **International Plasma Protein Congress Internacional Congress (IPPC)** organised by the Plasma Proteins Therapeutics Association (PPTA) in Vienna, Austria. The meeting programme was designed around the theme of “patient centeredness in the plasma protein therapeutics industry”. Johan Prevot, IPOPI’s Executive Director, spoke at the meeting and stressed the importance of recognizing immunoglobulin therapies as the only life-saving treatment for a majority of PID patients calling out for patient involvement in the reimbursement assessment processes of these treatments.

IPOPI also became a member of Health First Europe (HFE), an alliance of patients, healthcare workers and specialists, academics, and the medical technology industry. HFE’s mission is to ensure that equitable access to modern, innovative and reliable medical technology and healthcare is regarded as a vital investment in the future of Europe.

Their 10th Annual General Assembly in March was a great opportunity to discuss EU developments around health technology assessments and the need to ensure stakeholder engagement. The Blood Directive but also newborn screening were some of the other priorities discussed and brought forward by IPOPI and the European Haemophilia Consortium (EHC). Later in the year, in December, IPOPI also participated in the launch of a new European Parliament Interest Group on Innovation in Health and Social Care in the European Parliament in Brussels.



Johan Prevot presenting at the 2014 IPPC congress in Vienna



PLUS/ ABO Meeting in London

PLUS, the Platform of Plasma Protein Users, organised a meeting in collaboration with the Alliance of Blood Operators (ABO) in London in June. The meeting was held as part of the ABO risk-based decision making (RBDM) framework project which seeks to provide an overall risk framework with health economics and outcomes tools stakeholder engagement guidelines and a web portal. Designed specifically for blood safety risk assessment, the framework aims to provide a structured and systematic process for considering all relevant factors in decisions on blood safety and ensuring that finite resources are allocated to the most significant blood safety risks.

The Framework consists of a structured approach to blood safety risk management—a systematic methodology for setting the best course of action under uncertainty by identifying, assessing, acting on and communicating risk. IPOPI as one of PLUS’ founding organisations participated actively with input from its President, Jose Drabwel, and Executive Director, Johan Prevot, and from its Medical advisory Panel Vice President, Dr Nizar Mahlaoui.

The meeting was followed by PLUS’ general assembly where Brian O’Mahony (EHC), Johan Prevot (IPOPI) and Larry Warren (Alpha 1) were re-elected as Members of the PLUS Steering Committee.

EMA



IPOPI regularly participates in meetings organised by the European Medicines Agency (EMA) and is an active member of the Patients' and Consumers' Organisations Working Party (PCWP). Jose Drabwell, IPOPI President, has held a seat on the PCWP and has for a number of years played a key role for the PID community, voicing the perspective of PID patients related to pharmacovigilance, patient involvement in clinical trials, data transparency, among others. IPOPI's participation has increased in 2014 as Leire Solis, Health Policy and Advocacy Manager supports Jose in this representative role. Patients, as the end-users of the medicines, are considered as key stakeholders by EMA.

IPOPI also attended and participated in, among other, the following events:

- Eurordis council of federations Meeting, Paris, October 2014
- 13th Annual Partnerships in Clinical Trials Congress, Barcelona, November 2014
- EMA PCWP meetings, London, all year
- EMA Clinical Trials Meeting, London, June 2014
- Eurordis General Assembly, Berlin, May 2014
- Rare Diseases Day Meeting and Gala Dinner, Brussels, February 2014
- International Plasma Protein Congress – Vienna, March 2014
- European Parliament MEP liaison Programme, all year
- European Parliament SCID NBS follow up campaign
- European Haemophilia Consortium events and round tables
- IPFA-PEI International Workshop (Rome, May 2014)
- EPPOSI workshops and meetings in Brussels
- Health First Europe General Assembly Meeting, Brussels (May 2014)
- Health First Europe launch of MEP Interest Group Meeting, Brussels (October 2014)
- 5th World Orphan Drugs Congress, November 2014

Medical Advisory Panel

2014 marked some changes among the IPOPI Medical Advisory Panel. Six new members were welcomed: Prof Aziz Bousfiha (Morocco), Prof António Condino Neto (Brazil), Dr Adli Ali (Malaysia), Dr Tajed Avcin (Slovenia), Dr Joanne Smart (Australia) and Prof Martin Van-Hagen (Netherlands).

IPOPI is greatly thankful to Prof Ewa Bernatowska (Poland), Prof Alessandro Plebani (Italy), Prof Esther de Vries (Netherlands) and Prof Alain Fischer (France) who ended their mandates in 2014 for all their work and dedication for the long years they served as MAP members.



Bob LeBien Asian Development Plan

In 2012 Bob LeBien, IPOPI's Honorary President was awarded with the first IPOPI Bob LeBien Award created in his honour for taking the initiative to create IPOPI and for the commitment to serve as IPOPI's Founding Chairman. Since then Bob has personally supported the launch of an IPOPI outreach campaign in the South-East Asian region and several actions took place in 2014. The IPOPI meeting in Hong Kong and Singapore were made possible thanks to the Bob LeBien Asian Development Plan.

IPOPI PID patients' workshop in Hong Kong and Singapore

The first Hong Kong PID National Patients meeting was held in December 2013, at the Hong Kong Academy of Medicine with the support of the Department of Paediatrics & Adolescent Medicine, LKS Faculty of Medicine of the University of Hong Kong. This was an excellent opportunity to meet together with the local patients and doctors to discuss the importance of starting a patient organisation in China. All doctors and patients present at the meeting agreed that a national patient organisation should be launched.

In 2014, the NMO PID League was created as a direct result of this First PID Patients Meeting in Hong Kong.

IPOPI organised a PID National Patients meeting Singapore in September 2014 as part of the 3rd Singapore Annual Paediatric and Prenatal annual congress in collaboration with the Singapore Paediatric Society. The IPOPI meeting brought together 70 participants including patients, family members and doctors from the region. After the medical and awareness lectures several patients shared their experiences, shedding some light over the bone marrow transplant procedure, the specific issues faced by those with a chronic condition and of coping with loss.

The patients and the doctors unanimously agreed that a national patient organisation should be launched as soon as possible. IPOPI is in close contact to guide this process and ensure that a Singaporean NMO is launched in the near future.



Eastern European Regional Meeting in Antalya, Turkey

The IPOPI Eastern European Regional Patients Meeting in Antalya was organised in the framework of the 100th J Project meeting and brought together representatives from Turkey, Poland, Hungary, Iran, Serbia, Romania, Austria, Slovenia, Bosnia and Herzegovina, Russia and Belarus. Together with physicians, stakeholders and IPOPI staff they looked into the adaptation of the Antalya declaration to country-specific situations. Patient representatives discussed the five priorities identified by experts and healthcare professionals in the "Antalya declaration" on the basis of the situation of PID patients in the different countries. As such, a prioritisation of the five targets of the "Antalya Declaration" was agreed enabling NMOs in the region to utilize this advocacy tool to advance PID diagnosis and care in their countries.



Patient and doctor representatives at the Brazilian Federal Parliament

PID Political Event in Brazil

On 11th November 2014, IPOPI organised in collaboration with ABRI and ANPIC, the two patient organisations in Brasil, a High Level Political Event on PIDs in Brasilia. The meeting was organized as a session of the Commission on Social Security and Family of the Brazilian Federal Parliament and was chaired by Congressman Saraiva Felipe. The event aimed at raising awareness about PIDs amongst Brazilian policy makers and promote better access to early diagnosis and, appropriate treatment for PID patients in Brazil. Another request made at the meeting was to initiate

an update of the Ministry of Health's guidelines to acquire IG therapies for PIDs.

Congressman Luiz Henrique Mandetta attended the meeting and expressed his willingness to collaborate with patients organisations and experts so as to ensure that patients and their families can lead normal lives.

World Primary Immunodeficiency Week (WPIW) – an increasing success!

IPOPI as a founding partner of the WPIW initiative, has witnessed a growing interest from its National Member Organisations to partake in the campaign. IPOPI was pleased to be able to support the implementation of WPIW national campaigns in 18 countries. Numerous projects, programmes, events and a number of media outreach efforts were organised during the week. These included physicians' meetings to increase medical awareness, patients and family gatherings, TV and radio appearances, newspaper articles, advocacy campaigns and online and social media- campaigns.

New campaign materials including advocacy toolkits, campaign materials or scientific and policy documents were made available in different languages to help spreading the word about PIDs. More than 50 countries joined across the world to raise awareness about PIDs and call for better recognition of the PID community's priorities.



To get involved please visit www.worldpiweek.org

IPOPI XIIIth Biennial meeting in Prague

IPOPI held its Biennial Meeting in Prague, Czech Republic on 28 October - 1st November 2014, in conjunction with the ESID and INGID Congresses. This edition featured many stimulating interactive workshops tailored for our patient group representatives. Strategies for fundraising, importance of data collection and maximizing collaboration between MNOs and national organisations for rare diseases were some of the favourite topics approached in this edition.

During the meeting IPOPI's NMOs were invited to share their achievements which were subsequently compiled into an animation video called 'NMO Miracle Book' which can be viewed on IPOPI's Youtube channel. The programme also included several scientific lectures specifically designed for patients on an array of topics, from the functioning of the immune system to Gene Therapy advances and Bone Marrow Transplantation. Presentations from the meeting can be viewed on the IPOPI website. The XIIIth edition increased interaction between participants and the moderators, allowing for very interesting discussions and exchange of best practices.



NMO representatives at the XIII Biennial Meeting

IPOPI's General Assembly took place on 31 October 2014 and 6 new National Member Organisations were welcomed: United Kingdom (PID UK, succeeding to PIA), Bosnia & Herzegovina, Bulgaria, Malaysia, Peru and Slovenia. During the General Assembly Dragana Koruga, from Supporting Persons with Primary ImmunoDeficiencies (SPwPID/POsPID) in Serbia, was re-elected as a Board member for a second mandate and Christine Jeffery, from the Immune Deficiency Foundation of Australia, who had been co-opted on the IPOPI Board for the past two years, was elected for her first mandate. Adrian Górecki, President of Immunoprotect in Poland, was elected as Board member for the first time.

IPOPI NMO Support Programme 2014

Through its core funding IPOPI was able to support the following national member organisation programmes in 2014.

- Awareness and advocacy campaign in Poland
- Communications campaign including distribution of posters, leaflets and other education materials in Brazil
- Awareness campaign in Italy
- Advocacy campaign in Ireland including liaison with Irish MoH
- Awareness programme for schools and general public in Austria
- Printing of patient information leaflets in the UK
- IPOPI's support towards advocacy Campaign in Spain
- IPOPI's support towards Indian PID patients awareness campaign
- IPOPI's support towards Slovenian PID patients awareness campaign

STRATEGIC OBJECTIVE 3 – TO ENHANCE IPOPI AND PID VISIBILITY GLOBALLY

Patient testimonial videos

During the last Biennial Meeting IPOPI interviewed patients, family members, physicians and nurses to produce 15 short (1/2 min) Patient Testimonial videos that were released in the Spring of 2015.

The videos tackled three main topics: Benefits of early diagnosis and treatment for PIDs, Importance of individualized treatment and Burden of treatment. Some testimonials featured patient/parent stories, others medical expertise and calls for more political awareness of PIDs.

Jose Drabwell (IPOPI President and PID patient), Prof Helen Chapel (one of IPOPI's Founders), Gaby Rosário (PID patient and advocate) and Sarita Workman (clinical nurse specialist) are some of those who so willingly agreed to take part in the project. IPOPI would like to thank all interviewees for their kind cooperation.



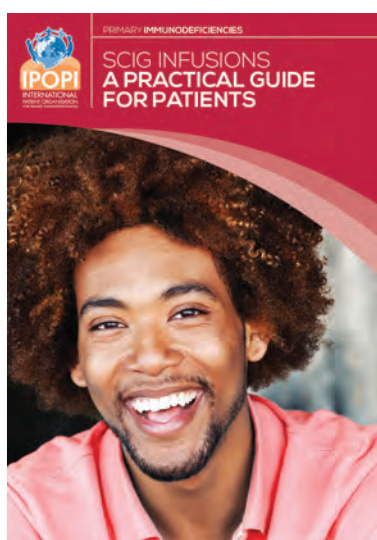
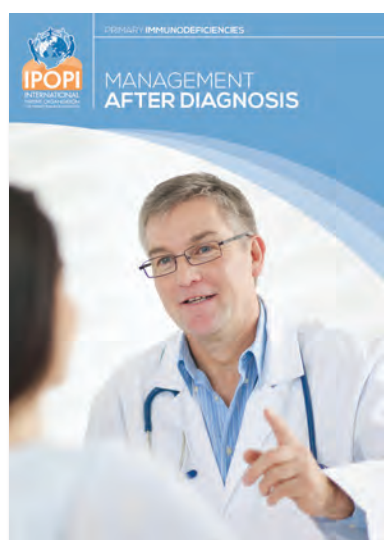
New Patient Information Leaflets

In 2014 IPOPI issued another series of Patient Information Leaflets on five brand new topics with helpful information and guidance for patients, their families and other interested stakeholders of the PID community. The 2014 leaflets are: PIDs and Gastrointestinal disorders and PIDs, PIDs and, Respiratory Disorders, When to give Immunoglobulin replacement therapy, Management after diagnosis, SCIG infusions – a practical guide for patients.

Two of these leaflets focus on PIDs and specific related conditions: PIDs and Gastrointestinal disorders and PIDs and Respiratory Disorders. Two others help patients and their families understand routine medical exams and the medical considerations behind treatment decisions: Management after diagnosis and When to give Immunoglobulin replacement therapy. The fifth leaflet is a step by step guide for the administration of Subcutaneous Immunoglobulin in a safe and informed way: SCIG infusions – a practical guide for patients.

At the time of writing these lines the 2014 series of leaflets had already been translated into two languages – Spanish and Polish.

To view and download please go to www.ipopi.org



New IPOPI patient leaflets

- PIDs and Gastrointestinal disorders
- PIDs and Respiratory Disorders
- When to give Immunoglobulin replacement therapy
- Management after diagnosis
- SCIG infusions – a practical guide for patients

Social Media

IPOPI's social media presence has grown significantly since 2013 clearly showing the engagement of the community and increasing public awareness.

Our **Twitter** followers tripled as we gained the attention of other umbrella organisations, health related organisations and political institutions. Our **Facebook** presence is growing steadily and this platform remains a favourite for member organisations to share their events and achievements.

Check and follow our social media pages!

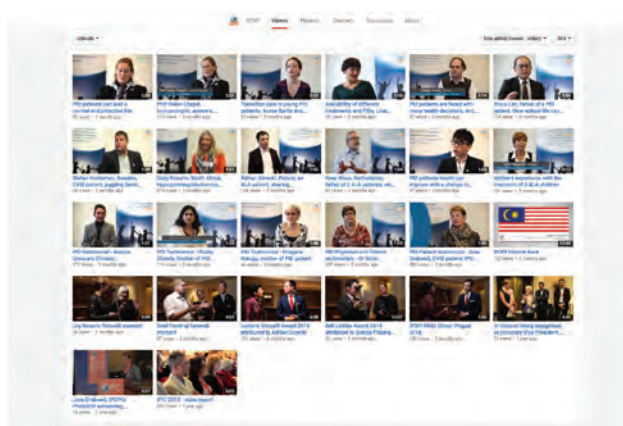
 [twitter/ipopi_info](https://twitter.com/ipopi_info)



 facebook.com/ipopid



 youtube.com/user/IPOPIPID/videos



STRATEGIC OBJECTIVE 4 – TO INCREASE EFFICIENT GOVERNANCE OF A WELL-RESOURCED DEVELOPING ORGANISATION

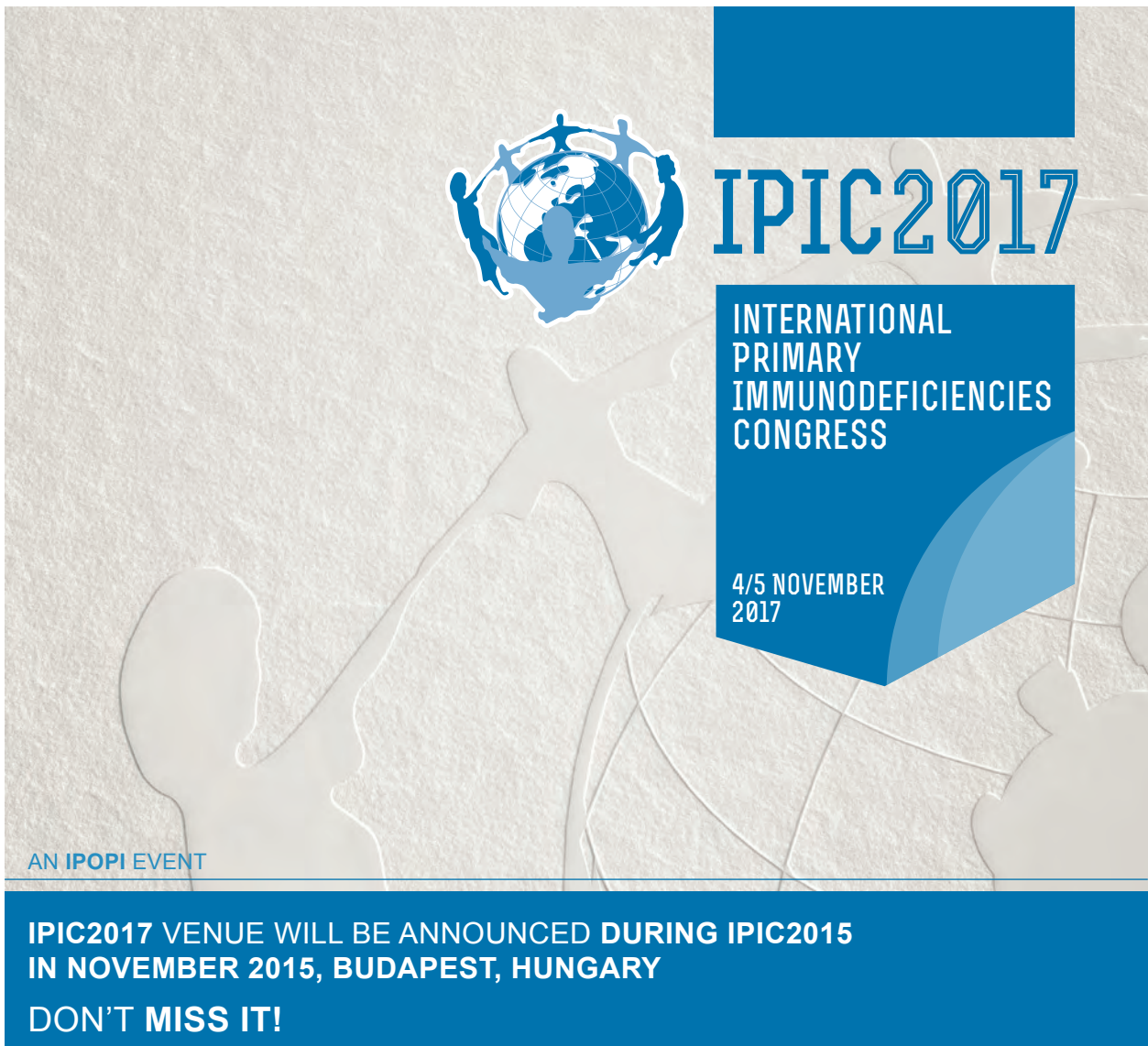
In 2014 IPOPI further optimized its overall governance to carry out a wide range of successful projects, events and programmes as outlined in this report. New stakeholder collaborations were started and regional programmes were extended, demonstrating IPOPI's presence at the forefront of the PID community. IPOPI staff also grew with Leire Solis who joined our team as Health Policy and Advocacy Manager. With a revived Medical Advisory Panel and new regional representation on our Board, IPOPI looks at the future with much enthusiasm and sheer conviction to serve the PID community worldwide.

Looking Ahead – 2015 and beyond

IPOPI looks forward to continuing its advocacy work internationally. New and continuing programmes such as IPOPI's SCID National Parliamentary Events, national advocacy campaigns and the EU PID Forums will ensure the PID patients community is included in important policy-making decisions. The launch of new projects and NMO programmes including national and regional meetings and workshops will undoubtedly strengthen PID patient organisations around the world.

The second edition of the International Primary Immunodeficiencies Congress (IPIC2015) in the beautiful city of Budapest is just around the corner!

Looking even further ahead, we hope to see you at IPIC2017!



The poster features a central graphic of a globe held by silhouettes of people, set against a background of faint human silhouettes. A blue banner on the right contains the event title and dates. A dark blue footer contains the venue announcement.

IPIC2017
INTERNATIONAL
PRIMARY
IMMUNODEFICIENCIES
CONGRESS
4/5 NOVEMBER
2017

AN IPOPI EVENT

**IPIC2017 VENUE WILL BE ANNOUNCED DURING IPIC2015
IN NOVEMBER 2015, BUDAPEST, HUNGARY
DON'T MISS IT!**

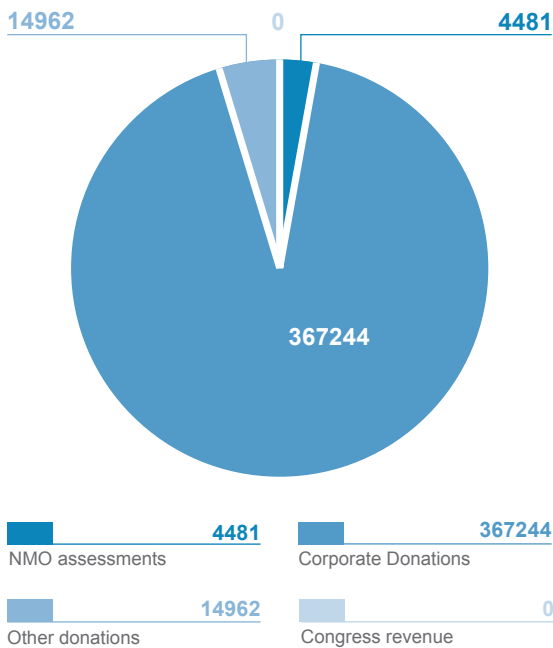
FINANCIAL REPORT 2014

2014 was a year of financial stability for IPOPI. As a 'gap' year with no congress, IPOPI focused its resources on its awareness and advocacy programmes as well as regional meetings. IPOPI focused on continuing to diversify its sponsors base (for details see page 19). At year end IPOPI had a surplus of 13,947 GBP. This has contributed to further secure IPOPI's reserve in line with UK Charity Commission recommendations as well as to support costs towards our regional meeting in Africa in 2015. IPOPI actually increased expenditure compared to 2013 towards its core activities and ad-hoc projects as well as support programmes to its NMOs enabling us to organize among other events the best attended IPOPI Biennial Meeting to date with the widest geographical representation.

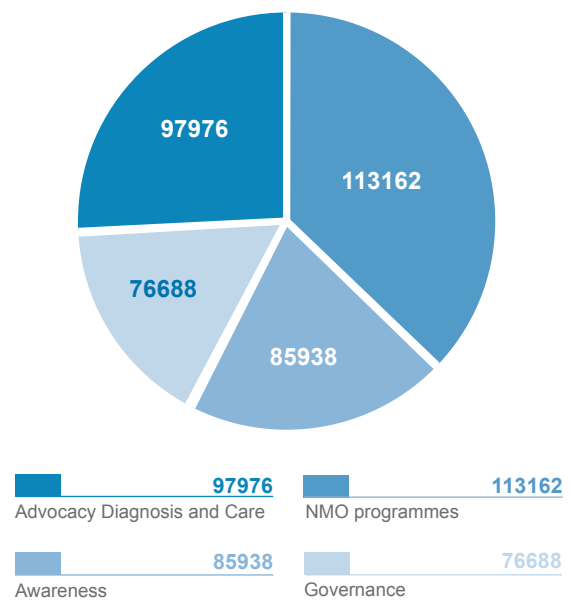
IPOPI is a charity registered in the United Kingdom and under UK Charity Law. As such, we are required to have our accounts audited every year by qualified accountants and submitted to the Charity Commission for approval. These charts provide a summary of key aspects of our financial accounts in 2014. Our full audited accounts are available on the Charity Commission website and on request.

In 2014, IPOPI estimated the economic valorisation of the work carried out by its volunteers to be 64,756 GBP.

Income 2014



Resources expended 2014 (GBP)



Income and expenses 2014 (GBP)

INCOME	2014
Corporate Donations	367,244
NMO assessment fees	4,481
Congress registration revenue	0
Other income	14,962
Total	386,687

RESOURCES EXPENDED	2013
Advocacy, Diagnosis & Care	97,976
NMO programmes	113,162
Awareness	85,938
Governance	76,688
Total	373,764
Excess towards Reserve & regional patient meetings	13,947

IPOPI is grateful to a large number of people and stakeholder organisations who support our work through personal effort, shared objectives, alliances or financial support. These collaborations help IPOPI achieve more year after year for people living with a primary immunodeficiency worldwide.

We also express our gratitude to our 55 National Member Organisations whose important activities and efforts in their respective countries are vital to improve the conditions for people living with a PID. Our NMOs are key stakeholders who contribute towards the global mission of IPOPI.

We would like to extend our warmest thanks to Bob LeBien and his family for their generosity and continued support towards our Asian regional activities.

Lastly, IPOPI expresses its gratitude to the following corporate sponsors whose contributions in 2014 helped us implement our mission and improve awareness, access to early diagnosis and optimal treatments for primary immunodeficiency (PID) patients worldwide:

Core sponsors

In 2014, the following corporate sponsors provided unrestricted grants towards IPOPI's core awareness, advocacy, communications and representational activities, meetings and projects:

PLATINUM



SILVER



Project sponsors

In 2014, the following corporate sponsors provided unrestricted grants towards various IPOPI ad-hoc projects that enhance our awareness, advocacy, communications and representational activities

Baxter Healthcare Corporation

Biotest

CSL Behring

Grifols

GSK

Kedrion

LFB

Octapharma

Sigma Tau

IPOPI's corporate relations with the above mentioned sponsors are subjected to IPOPI's corporate relations guiding principles available on IPOPI's website.

Key Stakeholders

Stakeholder collaboration is very important for IPOPI therefore we would like to express our most sincere thanks to a number of stakeholder organisations for their partnership and collaboration in 2014 including but not limited to: African Society for Immunodeficiencies (ASID), Asociación Espanola de Pediatría (AEP), Asia Pacific Society for Immunodeficiency (APSID), British Society for Immunology (BSI), Clinical Immunology Society (CIS), European Federation of Immunology Societies (EFIS), European Medicines Agency (EMA), the European Haemophilia Consortium (EHC), European Platform for Patient Organisations, Science and Industry (EPPOSI), Eurordis, European Society for Immunodeficiencies (ESID), Food and Drug Administration (FDA-US), Grupo Português de Imunodeficiências Primárias (GPIP), Health First Europe (HFE), Hungarian Paediatrics Society, Hungarian Society for Allergology and Immunology, Infecciologia pediatria International Alliance for Patient Organizations (IAPO), International Nursing Group for Immunodeficiencies (INGID), International Immunocompromised Host Society (ICHS), International Plasma Fractionation Association (IPFA), International Society for Blood Transfusion (ISBT), International Society for Neonatal Screening (ISNS), International Union of Immunological Societies (IUIS), Latin American Society for Immunodeficiencies (LASID), Le Centre de Référence Déficits Immunitaires Héritaires (CEREDITH-FR), MSAI (Malaysian Society for Allergy and Immunology), Plasma Protein Therapeutics Association (PPTA), Platform of Plasma Protein Users (PLUS) and its member organisations, Sociedad Española de Inmología (SEI), SEAPID (South East Asia Primary Immunodeficiencies Network), Sociedade Portuguesa Alergologia Imunologia Clínica, Sociedade Portuguesa de Pediatria, World Health Organisation (WHO), World PI Week and its member organisations.



INTERNATIONAL PATIENT ORGANISATION FOR PRIMARY IMMUNODEFICIENCIES

IPOPI is a charity registered in the UK. Registration No. 1058005.

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