



# REVIEW OF ACTIVITIES AND ACHIEVEMENTS

2012

**ANNOUNCING**



**IPIIC** 2013 International Primary  
Immunodeficiencies  
Congress

## FIRST INTERNATIONAL PRIMARY IMMUNODEFICIENCIES CONGRESS

FOCUS ON CLINICAL CARE  
AND DIAGNOSIS

**ESTORIL (LISBON), PORTUGAL**

**7/8**  
**NOVEMBER 2013**  
**PORTUGAL**

**HOTEL**  
**ESTORIL PALÁCIO**

[www.ipic2013.com](http://www.ipic2013.com)



## A MESSAGE FROM THE CHAIRPERSON



Jose Drabwell, IPOPI Chairperson

Dear Friends and Colleagues,

In 2012, IPOPI celebrated its 20<sup>th</sup> year during the Congress in Florence, Italy. A high point of this celebration was marking the significant contribution made by Bob LeBien, our founding Honorary Life President. Together with Helen Chapel he was responsible for the formation of IPOPI in 1992 and Bob was an active board member and chair during the early growth years of the organisation. Elsewhere in this report there is mention of the Bob LeBien Award which was the centrepiece of the 20<sup>th</sup> Anniversary celebrations.

**Honorary Life President's Message** – *'I believe that every organisation should have a knowledge of its past, because it gives a better sense of the present and a possible direction for the future'.*

*Mr Bob LeBien (IPOPI Biennial Meeting, Florence, Italy, 4 October 2012.)*

2012 brought the best gift it could have given IPOPI, a truly successful year filled with new activities and exciting projects. So much in fact that starting with this edition we have decided to produce annual reports rather than on a biennial basis as was done in the past. As you will realise when reading this report, there were many positive outcomes that came out of our work in 2012.

We are fortunate that we can now count as well on the support of two additional Board members to help us build on these achievements as Christine Jeffery (Australia) and Maria Michelfelder (Sweden) were co-opted on IPOPI's Board of Directors during the Florence meeting. Christine and Maria bring an additional set of skills and extended regional representativeness to IPOPI. The IPOPI staff has also continued to grow and so has our membership which at the time of writing these lines counts 45 NMOs.

All of our work is focused on ensuring we optimize the lives of people living with Primary Immunodeficiencies. It is with this clear remit that we carry out our projects, programmes and activities. I hope that you will agree with me that in 2012 significant steps were made by IPOPI to increase awareness of primary immunodeficiencies and improve access to care and diagnosis of this important group of rare disorders.

I would like to thank all of our Board and Staff members, NMOs, MAP members, stakeholders and our sponsors for believing in IPOPI and helping us make it the organisation it is today.

It was both an honour and a pleasure to be re-elected as IPOPI's chairperson in 2012 and I look forward to IPOPI's continuing success in the future.

A handwritten signature of Jose Drabwell in white ink. The signature is stylized and cursive, with the first letters of the first and last names being large and prominent.

Jose Drabwell



## EXECUTIVE COMMITTEE, OFFICERS AND STAFF

### EXECUTIVE COMMITTEE

**Jose Drabwell**, Chair (United Kingdom)  
**Martine Pergent**, Vice Chair (France)  
**Sven Fandrup**, Treasurer (Denmark)  
**Marcia Boyle** (USA)  
**Christine Jeffery** (Australia)  
**Dragana Koruga** (Serbia)  
**Maria Michelfelder** (Sweden)  
**Vicki Modell** (USA)  
**Roberta Pena** (Argentina)  
**Joy Rosario** (South Africa)

### STAFF

**Johan Prevot**, Executive Director  
**Magda Lourenço**, Communications and NMO  
Programme Officer  
**Carla Morgado**, Executive Assistant  
**Carol Tavener**, Bookkeeping & Administration  
**David Watters**, Consultant - Projects  
**Clare Glynn**, Financial consultant

### MEDICAL ADVISORY PANEL

**Dr. Teresa Español**, Chair (Spain)  
**Dr. Ewa Bernatowska** (Poland)  
**Prof. Andrew Cant** (UK)  
**Dr. Esther de Vries** (Netherlands)  
**Prof. Bobby Gaspar** (UK)  
**Dr. Monika Esser** (South Africa)  
**Prof. Amos Etzioni** (Israel)  
**Prof. Alain Fischer** (France)  
**Dr. Jose Franco** (Colombia)  
**Dr. Nizar Mahlaoui** (France)  
**Prof. Luigi Notarangelo** (Italy/USA)  
**Prof. Alessandro Plebani** (Italy)  
**Prof. Surjit Singh** (India)  
**Dr. Klaus Warnatz** (Germany)



IPOPI's Board Members, Executive Director and Medical Advisory Panel Chairperson

# IPOPI STRATEGIC PLAN

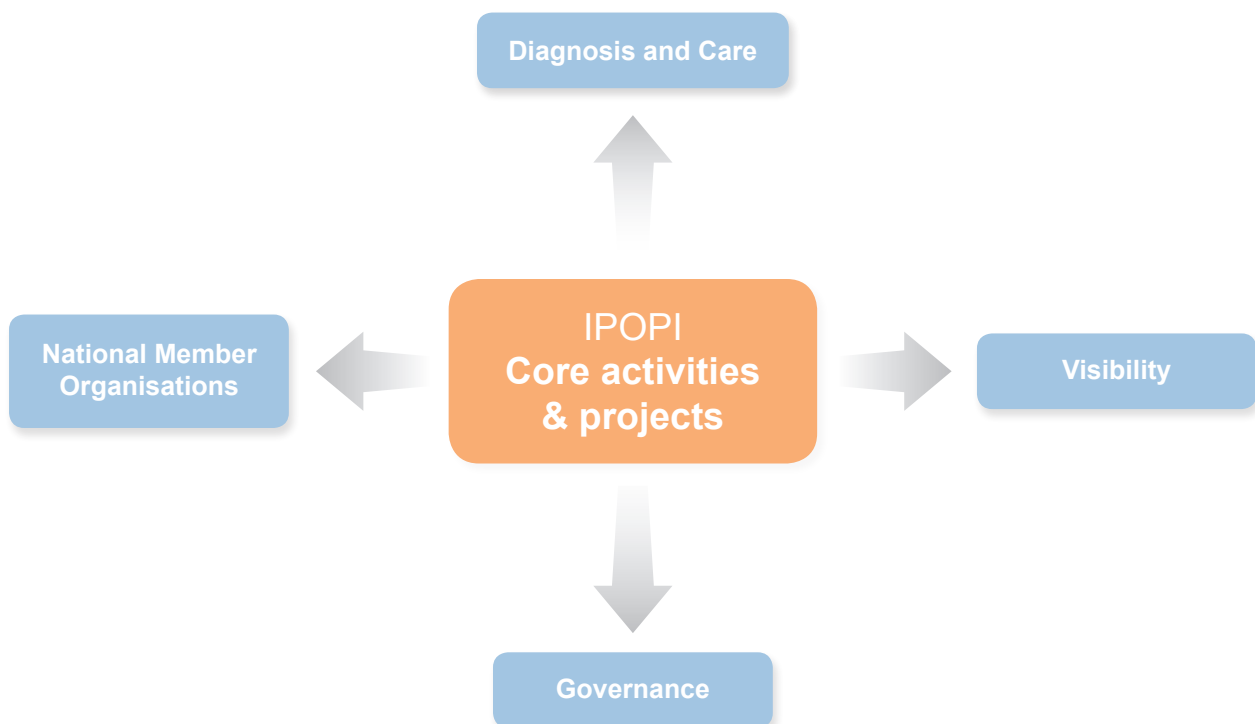
## MISSION STATEMENT

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 new 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



## PRIMARY IMMUNODEFICIENCIES SOME KEY BACKGROUND INFORMATION

Primary Immunodeficiencies (PIDs) are a large and growing group of over 200 different disorders caused when some components of the immune system (mainly cells and proteins) do not work properly. Whilst PIDs are generally recognized 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.

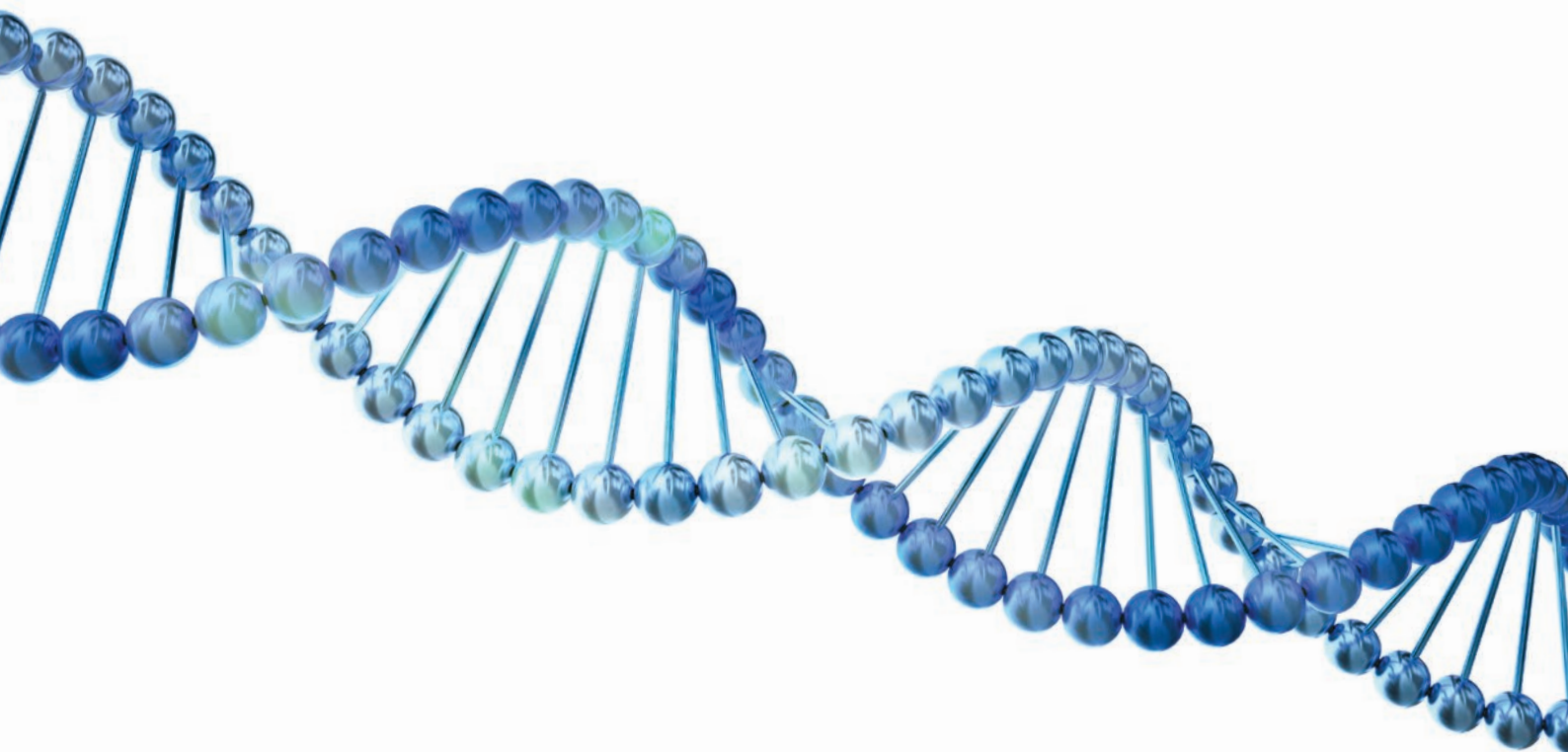
PIDs are currently classified into eight groups: predominantly antibody deficiencies; combined T- and B cell deficiencies; other well-defined syndromes; diseases of immune regulation; congenital defects of phagocyte number or function, or both; defects of innate immunity; auto-inflammatory diseases; and complement deficiencies, based on the main immunological defects.

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, 2012

## STRATEGIC OBJECTIVE 1 – ENSURE OPTIMAL ACCESS TO DIAGNOSIS & CARE

### IPOPI EU PID Policy Forum

This significant event was held in Brussels, Belgium, in September 2012 and was chaired by MEP Mrs Nessa Childers (S&D Ireland) at the European Parliament. Twenty-five experts representing patients, academics, physicians and industry discussed with Members of the European Parliament the benefits afforded to patients by national plans for rare diseases and the need for Member States to fully implement and finance their national plans including the setting up of patient registries and designate centres of reference. Seven Members of the European Parliament were in attendance. After careful discussions a list of 13 recommendations were framed and while some related to rare diseases as a generality, others referred to PID specifically:

- National and European policymakers should support the development of PID centres of reference so as to ensure high quality information to patients and the care they need to live normal lives
- Reference centres for PID should be encouraged as a means of tackling under diagnosis, and improving knowledge among the medical community about the condition
- Member States should set up national centres of reference for PID to improve the information to patients and training of medical professionals and to support the enrolment of patients into PID registries
- Member States should set up PID patient registries where there are none, and support the development of the ones already established
- The EU should help Member States with less experience in managing PID to invest in appropriate frameworks for care for patients leaving with a PID.

Started by IPOPI in 2011, the IPOPI PID Forum events aim to gather political endorsement to the PID patient community's priorities in terms of access to care and diagnosis, position the patient viewpoint in relevant policy discussions and dossiers whilst strengthening IPOPI's network of supporting EU policy makers.



IPOPI, MEP Nessa Childers and Irish patient group representative Ivonne Rooney

### IPOPI SCID Newborn Screening programme

IPOPI has been involved in active campaign work for the implementation of SCID Newborn Screening (NBS) since June 2011 and this continued throughout 2012. We have been greatly encouraged in this work by Glenis Willmott, MEP and Professor Bobby Gaspar from the Institute of Child Health in London. Good progress was made through attendance at many meetings and in early 2013 the EU Parliament committee responsible for all health matters (ENVI) supported a question to the European Commission tabled by Mrs Willmott. At the time of writing, the response from the Commission is awaited. The backing by ENVI represents a victory at the European political level and provides an important tool for further advocacy campaigns.

### International Primary Immunodeficiencies Congress (IPIC)

In 2009 and 2011, IPOPI organised successful gatherings of doctors, nurses, patients and industry to look at the priorities of each stakeholder group. Those meetings were known as the Global Leaders' Meeting (GLM). One of the conclusions following the 2011 GLM was that rather than a small, hand-picked and personally invited audience the success should be marked by the introduction of a new biennial event to be known as The International Primary Immunodeficiencies Congress (IPIC). The Congress will be held on alternate years to the European Society for Immune Deficiency meetings. As a result, the first IPIC will be held in 2013 and much work has gone into the planning of this event throughout 2012. The congress website was designed and launched in 2012 at [www.ipic2013.com](http://www.ipic2013.com) and the IPOPI Board and staff look forward to welcoming all stakeholder groups to this meeting in Estoril, Portugal, on 7/8 November 2013. The focus of IPIC will be on clinical care developments and diagnosis.



Johan Prevot with Brian O'Mahony  
Chief Executive of the Irish  
Haemophilia Society at the  
Eurordis Gala

### Working with stakeholders

IPOPI is a growing organisation and this makes it important that we work closely with others. This includes most notably the Plasma Users Platform (PLUS) which is made up of patient groups representing consumers of plasma products and of which IPOPI is a founder member. Early in 2012 IPOPI was involved in the planning of the second PLUS Conference in Dublin Ireland, which brought together key stakeholder organisations to discuss issues related to the collection and provision of blood components and plasma derived medicinal products. Later in the year we attended the membership meeting in Madrid, Spain, and PLUS stakeholders also participated in the EU Study on Blood and Plasma Products. The key outcome of both meetings has been the production of landmark consensus statements on this crucial issue. Those are available on the IPOPI website at [www.ipopi.org](http://www.ipopi.org)

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

- European Haemophilia Consortium meeting in Prague, Czech Republic
- The EURORDIS Rare Diseases Gala Dinner in Brussels, Belgium
- Mrs Joy Rosario (South Africa) participated in the EURORDIS Summer School in Barcelona, Spain
- IPPC in Madrid, Spain;
- WHO Workshop 'Improving access to safe blood products in law in middle income countries'
- IPFA Budapest, EPPOSI, Brussels and; the Paul Ehrlich Institute, Germany
- PPTA 20th Birthday Celebrations, Washington, USA
- ISNS New Born Screening Meeting, Budapest, Hungary





Dr Español at the IPPC meeting in Madrid

### Medical Advisory Panel and Hilfenaus Award to Dr Español

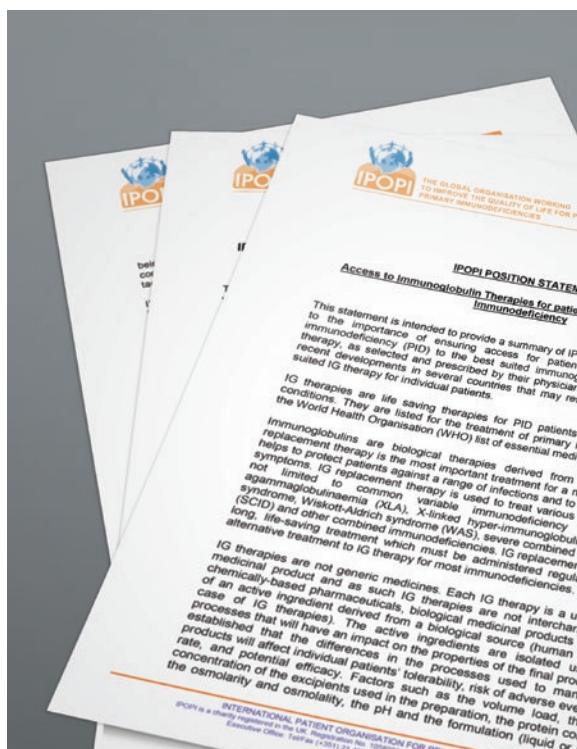
The Board of IPOPI are cognisant of the hard work of all our MAP members (see list on page 4) and most especially they are grateful to Dr Teresa Español, the Chair of the MAP for her hard work and commitment to IPOPI and the needs of people with PID around the world. It was a great delight that the 2012 Hilfenaus Award, presented by PPTA, was awarded to IPOPI's Dr Teresa Español at the IPPC Meeting in Madrid – it was a well-deserved recognition!

### European Medicines Agency – Participation in EMA consultation on core SCmPC and clinical investigation guideline for SCIg

IPOPI participated in the European Medicines Agency consultation on the Draft guideline on core Summary of Products Characteristics (SmPC) for human normal immunoglobulin for subcutaneous and intramuscular administration. IPOPI highlighted the importance of the routine use of SCIg (Sub cutaneous Immunoglobulin) in the treatment of SCID infants pre and post HSCT. In addition IPOPI is participating in the EMA consultation on the clinical investigation guideline for SCIg which is open until June 2013.

### HTAs and PID

The International Network of Agencies for Health Technology Assessment define HTAs as: the systematic evaluation of properties, effects and/or impacts of health care technology. It may address the direct, intended consequences of technologies as well as their indirect, unintended consequences. Its main purpose is to inform technology-related policymaking in health care. HTA is conducted by interdisciplinary groups using explicit analytical frameworks drawing from a variety of methods. This makes HTAs – which are in place in most major countries around the world – important to rare disorders such as PID and, indeed, all high cost therapies for rare disorders. Consequently IPOPI has been actively involved with the topic since the organisation of the IPOPI PID Forum on Health Technology Assessments and PIDs at the European Parliament in late 2011. IPOPI is participating in EP-POSI's health technology assessment advanced innovation programme and advocates for a different approach for rare diseases therapies that include the societal macro-economic benefits brought about by appropriate treatment and early diagnosis. Staff spent more than a little time watching, listening and, where possible, influencing how they may affect the therapies available to our national member organisations. In 2013 IPOPI hopes to organise a first patient survey with the collaboration of Professor Albert Farrugia.



### IPOPI Health Policy Position Statements

IPOPI position statements on Chronic Diseases and Access to therapies were issued during the year.

The first statement was submitted to the European Commission in the context of the EU public consultation regarding the "EU's reflection on Chronic Diseases". IPOPI's position statement covered several aspects linked to primary immunodeficiencies as chronic rare diseases among which the need for swift implementation of national rare diseases plan in EU Member States, the importance of specialised reference centres, the need for improved diagnosis and therapy protocols as well as the need for a different approach in discussion around the optimal financing of care and tools such as HTA assessments for rare diseases including PIDs.

The second statement was intended to provide a summary of IPOPI's position with regards to the importance of ensuring access for patients living with a primary immunodeficiency to the best suited immunoglobulin replacement therapy, as selected and prescribed by their physician. The full statements can be accessed at the IPOPI website – [www.ipopi.org](http://www.ipopi.org)

## STRATEGIC OBJECTIVE 2 - TO DEVELOP, STRENGTHEN AND SUPPORT NMOS



Participants at the XXIIth IPOPI Biennial Meeting in Florence, Italy

### IPOPI XIIth Biennial Meeting

The 2012 Biennial Meeting was held in Florence, Italy, in October, alongside the Biennial Meetings of ESID and INGID. It has become traditional at the Biennial meeting to observe a period of silent remembrance and this year the candle lit to mark the occasion was left burning throughout the meeting and at the end the candle and its holder were presented to the Italian NMO as a mark of the remembrance of the Florence Congress. There were many presentations and Workshops during the formal part of the

programme and, just as important, opportunities to meet old friends and make new friends. During the formal AGM six new NMOS were welcomed into full membership of IPOPI. The new member countries are Russia, Belarus, Chile, Romania, Uruguay and Venezuela. Bulgaria was also welcomed as an Associate NMO. Elections were held for the Board as a result of which Ms Jose Drabwell was re-elected as Chair, Mrs Martine Pergent as Vice-Chair and Mr Sven Fandrup as Treasurer. IPOPI also welcomed two new co-opted Board members- Mrs Jeffery from Australia and Mrs Michelfelder from Sweden

During the course of the meeting the Luciano Vassalli Award was presented to Audrey Rigault from France. Audrey, lives her life to the full despite her PID and is committed to doing everything she can to raise awareness of the conditions and help others get diagnosed and have access to proper treatment. The Award was accepted on her behalf by Mrs Martine Rembert from IRIS.

As part of the Biennial Meeting a dinner was hosted for our NMOS. At this event the first Bob LeBien Award was announced and presented to Bob LeBien himself in recognition of his outstanding commitment to IPOPI. Many people, including Bob himself, Board members, NMO delegates and former staff gave speeches applauding the Award and praising the input by Bob to bring IPOPI to where it is today.

It is important to note that all IPOPI meetings are subject to Evaluation as a means of gauging the appropriateness of programmes and speakers.

### IPOPI NMO Awareness Campaign Workshops

At the core of IPOPI's existence lies the important question of early diagnosis and access to appropriate treatment. In order to achieve this there needs to be enhanced awareness of the conditions that make up the spectrum of primary immunodeficiencies. To this end successful Workshops, attended by doctors, nurses and patients, were held in Ireland and Spain during 2012. The workshops were pivotal to identify national priorities and agree action plans moving forward.

### IPOPI NMO Regional Advocacy Workshop – Belgrade

It is vital that our national member organisations (NMOS) ensure the best possible access to treatment and diagnosis in their own countries. It follows that NMOS need to know how to approach the various statutory – governmental – agencies that make policy decisions affecting the lives of people with primary immunodeficiency (PID). IPOPI organised a two day Advocacy Workshop, in 2012 in Belgrade, Serbia, attended by delegates from Hungary, Poland, Romania, Russia, Serbia and Turkey. The workshop was moderated by



IPOPI PID Awareness Workshop in Barcelona



IPOPI NMO Regional Advocacy Workshop – Belgrade

Johan Prevot and David Watters. The programme featured several presentations on examples of successful advocacy and awareness campaigns, IPOPI's Support Programmes and Toolkits, the work of PLUS as well as interactive sessions and role play sessions. The workshop was also a good opportunity to identify specific issues in the region and among others the lack of proper adult care and treatment was considered to be a common priority. The role play sessions were focused on a government meeting and a press conference and combined a fun and constructive approach. These sessions were fine-tuned during the meeting on the basis of the discussions, to add relevance to the exercise. The outcomes of the sessions were then analysed and discussed, the pro's and con's highlighted and some principles and guidelines identified for each participant to keep in mind and apply in their local circumstances.

Following this skill-building event excellent feed-back has been received from workshop participants on progress made in the region.

## World PI Week

22nd - 29th April 2012



## Second World Primary immunodeficiencies Week

In 2012, IPOPI was able to support the campaigns of 17 National Member Organisations around the world – Argentina, Australia, Belgium, Colombia, France, Germany, Greece, Hungary, India, Japan, Morocco, Netherlands, Poland, Portugal, South Africa, Spain and Turkey. The theme for the year was 'Access to appropriate Treatment' and a total of 32 countries took part. The large number of NMOs participating highlights the growing excitement about this week in the global PID calendar and it is a wonderful way to highlight the presence of PID in any country!

### News from the NMOs

We have already reported that 32 NMOs played an active role in the World Primary Immunodeficiency Week. In addition 2012 was a year rich in NMO activities. The following list includes examples of such activities:

- In Germany DSAI have launched a new newsletter to its members and organised activities for members
- In the UK PiA encounters difficulties and closes. IPOPI is closely monitoring developments and it is hoped that a new NMO will be launched in 2013
- In the USA IDF have produced new materials for PID nurses, provided blogs, produced an eHealth Record, as well as promoting a new 'Battle of the Bands' video to promote understanding of PID to young people
- In Argentina AAPIDP have organised a regional meeting with physicians, participated in a rare diseases day plus, one suspects, much else!
- The new NMO in Venezuela has been actively promoting Forums, Workshops and Awareness meetings about the importance of early diagnosis and appropriate treatment of PIDs
- In France IRIS organised a first PID National Day
- Sweden – support for research
- Our NMO in Portugal took part in not one, not two but three celebrations of WPIW!
- In India IPSI participated in the national CME programme

.....and much more! The above is a short example of what our active NMOs can achieve in their home countries.

## IPOPI NMO Support Programme 2012

Through its core funding, IPOPI was able to support the following national member organisation programmes in 2012

- Nordic/Baltic PID Regional Patient Meeting, Helsinki, April 2012
- Communications Campaign in Argentina
- Communications Campaign in Romania
- Communications Campaign in Portugal
- Communications Campaign in Morocco
- Communications Campaign in Serbia
- South African Doctors Awareness Campaign, February 2012
- Serbian PID Patients Summer Camp, August 2012
- Advocacy and awareness campaign Ireland Q3-Q4 2012
- Advocacy and awareness campaign Spain 2012

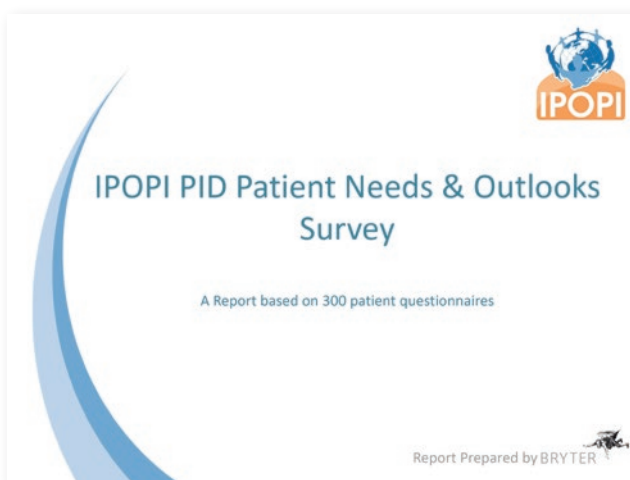


## STRATEGIC OBJECTIVE 3 - TO ENHANCE IPOPI AND PID VISIBILITY GLOBALLY

### IPOPI Survey results

This survey, started in the second half of 2011, received input from 21 countries and the final report was published in 2012. The full report of outcomes is available on the IPOPI website, but among the findings are the following:

- Sixty-six per cent of patients using intravenous Ig (IV Ig) and 70% using subcutaneous Ig (SubC Ig) report missing 10 or fewer work/school days during the past 6 months. Of these, 35% using intravenous Ig and 37% using subcutaneous Ig missed 0 days. While 39% report no pain, 50% report moderate pain; 48% report problems with daily activities. Patients' mental well-being is affected too: 61% report no anxiety/depression, while 39% identify moderate or extreme anxiety/depression (averages were below population norms across physical and mental Quality of Life elements)
- IV patients who had tried SubC were most likely to have stopped because of side effects (61%) and wanting longer time between doses (32%). SubC patients who had previously tried IV most commonly stopped because of inconvenience of going to the centre (51%), wanting to treat at home (43%) or because it was recommended they change (48%). 33% said side effects
- 34% of IV patients believe headaches are the most important area to improve. For SubC patients, pain at the infusion site and swelling at the infusion site are priorities for improvement though 19% say it is 'highly important' to focus on headaches too.
- Half of IV respondents (52%) would prefer a SubC type therapy similar to those available. This would be preferable for 91% of existing SubC respondents.



### New Patient information materials

In 2012 new publications were published with the following titles:

- Diagnosis of PID
- Moving from child to adult care
- PID in adults

During the year IPOPI was proud to make the publications listed below available in Spanish, Arabic, French, Serbian, Romanian and Portuguese – through the co-operation of our NMOs - in addition to English:

- Treatments for primary immunodeficiencies
- Stay healthy
- A Guide for Schools

### National Parliamentary events

In 2012, IPOPI started working on its new national parliamentary event programme. The programme will be used to increase the visibility of PIDs at national level and politically position PID patients priorities within the national health policy system. The first National Parliamentary Event will be held in Paris, France in 2013. The Event will be used to improve the position of IPOPI's French NMO (IRIS) politically and to advocate for better access to care and diagnosis for French patients.

### Communication tools – IPOPI NMO Website Toolkit, Facebook and new graphic image.

In 2011 IPOPI started renewing its image by developing a new website with the help of generous funding. As a follow on to that exciting development, we have developed a Facebook page which allows us to get immediate and first hand input from our NMOs on our activities.

As announced in our previous Review an IPOPI Website Toolkit was made available to all our national member organisations. This is a valuable step for new NMOs as setting up a website can be costly and this 'off the rack' site is available for free to NMOs recognised by IPOPI and offers flexibility and adaptability to national situations. Ireland and Serbia are working on developing new sites based on the IPOPI Website Toolkit, South Africa and Romania have already implemented theirs.

IPOPI has also modernized its image by renewing the graphic image and refining the colour schemes. All these improvements are present in our recent publications and promotional materials, such as 'pull-up' banners, leaflets and pens.



#### New IPOPI patient leaflets

- Primary immunodeficiencies — Diagnosis of primary immunodeficiencies
- Primary immunodeficiencies — Moving from child to adult care
- Primary immunodeficiencies — Primary immunodeficiencies in adults
- Primary immunodeficiencies — Treatments for primary immunodeficiencies: a guide for patients and their families
- Primary immunodeficiencies — Stay healthy! A guide for patients and their families
- Primary immunodeficiencies — A guide for schools

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

In 2012 IPOPI focused on further improving its overall governance and has diversified its level of funding by securing collaboration with new corporate players. Internal improvements in the way the organisation was operated and the recruitment of new staff together with a strategy focus approach to its core activities and ad-hoc projects has enabled IPOPI to enhance its overall efficiency and make significant advances as reported above. While the representational office in Lisbon remains as a hub of much activity within IPOPI, it was decided both as a matter of economics and practicality to close our Brussels facility. The IPOPI registered offices remain in the UK.

### Looking Ahead – 2013 and beyond

There are many exciting projects ahead for IPOPI – the greatest of which is the International Primary Immunodeficiency Congress (IPIC) which will take place in Estoril, Portugal in November of 2013 and which will also shape much of the future direction of the organisation and its national member organisations.

During the IPOPI Congress in Florence, Bob LeBien let it be known that he wished to support the development of IPOPI's role into Asia. As IPOPI had started its outreach in the region in 2011, this too will occupy much thought and time in the coming year as contacts are sought and nourished. IPOPI would like to thank Bob for his generous support.

There will be continuing work on Rare Diseases – 2013 sees the Year of Rare Diseases in Spain.

The work on SCID Newborn Screening will continue in Europe and will occupy time and energy.

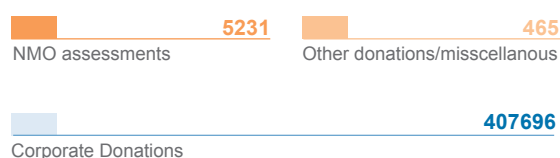
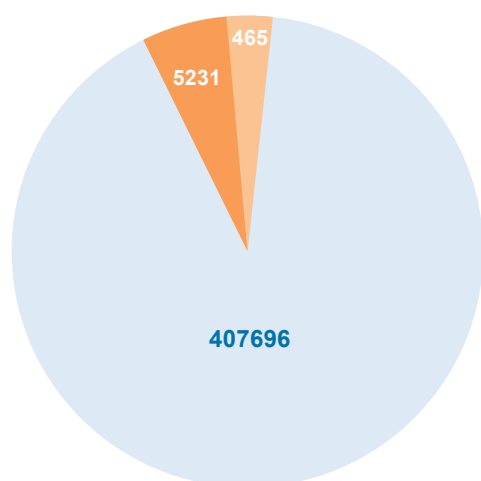
IPOPI looks forward to launching new projects and NMO programmes including regional meetings and workshops as well as the continuing development of new publications for IPOPI member organisations around the world.

# FINANCIAL REPORT 2012

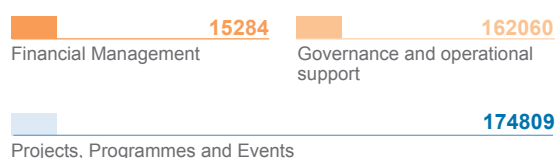
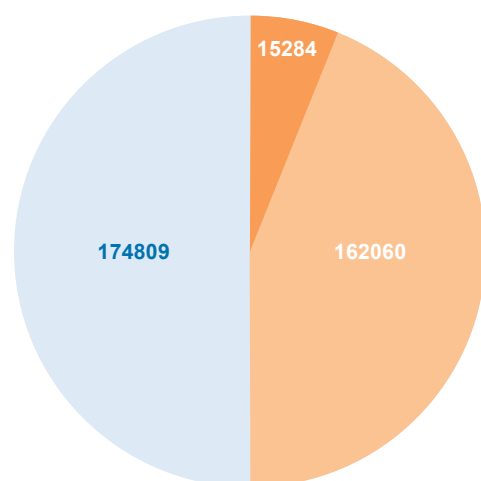
Financially 2012 was a successful year for IPOPI marked by a 10% increase in revenue compared to 2011. This was made possible thanks to increased core and project funding. IPOPI focused on strengthening existing collaborations with its sponsors but also on diversifying its sponsors base (for details see page 15). This has allowed IPOPI to make up for financial losses incurred in 2010 and contributed to building IPOPI's reserve in line with UK Charity Commission recommendations and with a view to provide additional support towards IPIC in 2013. IPOPI dedicated more resources towards its core activities and ad-hoc projects as well as support programmes to its NMOs which resulted in the highest number of NMO campaigns ever supported and best attended Biennial Meeting so far as described in this report. Expenditure therefore also increased compared to 2011.

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 2012. Our full audited accounts are available on request.

Income 2012 (GBP)



Resources expended 2012 (GBP)



Income and Resources Expended 2012 (GBP)

INCOME	2012
Corporate Donations	407,696
NMO assessment fees	5,231
Other income	465
<b>Total</b>	<b>413,392</b>

RESOURCES EXPENDED	2012
Projects, programmes and events	174,809
Governance and operational support	162,060
Financial management	15,284
<b>Total</b>	<b>352,153</b>
Excess towards Reserve & IPIC	(61,239)



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 45 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.

IPOPI expresses its gratitude to the following corporate sponsors whose contributions in 2012 helped IPOPI implement its mission and improve awareness, access to early diagnosis and optimal treatments for primary immunodeficiency (PID) patients worldwide:

#### **Core sponsors**

In 2012, the following corporate sponsors provided unrestricted grants towards IPOPI's core awareness, advocacy, communications and representational activities, meetings and projects:



#### **Project sponsors**

In 2012, 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

Binding Site

Biotest

BPL

CSL Behring

Grifols

Kedrion Biopharma

LFB

Octapharma

Perkin Elmar

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**

IPOPI is grateful to a number of stakeholder organisations for their partnership and collaboration in 2012 including but not limited to: European Medicines Agency (EMA), the European Haemophilia Consortium (EHC), the European Platform for Patient Organisations, Science and Industry (EPPOSI), Eurordis, the European Society for Immunodeficiencies (ESID), the US Food and Drug Administration (FDA), the International Nursing Group for Immunodeficiencies (INGID), the International Plasma Fractionation Association (IPFA), the International Society for Blood Transfusion (ISBT), the International Society for Neonatal Screening (ISNS), the Plasma Protein Therapeutics Association (PPTA), the Platform of Plasma Protein Users (PLUS) and its member organisations, the World Health Organisation (WHO), World PI Week and its member organisations.

IPOPI is a Charity registered in the UK, registration number 1058005

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**INTERNATIONAL PATIENT ORGANISATION FOR PRIMARY IMMUNODEFICIENCIES**

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