



REVIEW OF ACTIVITIES AND ACHIEVEMENTS



2010-2011
20th Anniversary Edition





20th Anniversary IPOPI

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A MESSAGE FROM THE CHAIRPERSON

As 2012 marks the 20th anniversary of the International Patient Organisation for Primary Immunodeficiencies (IPOPI), it is a great pleasure to report on the numerous achievements and activities carried out in the last two years.

IPOPI was formally established as an organisation in Lugano, Switzerland in 1992. It is quite amazing to see how IPOPI has grown over the years into the professional organisation we know today.

IPOPI has continuously grown over the last few years and significantly increased its actions since 2010 through an ambitious yet achievable new strategic plan streamlined around four key strategic priorities. Under this new plan IPOPI has focused its activities around access to diagnosis and care, the strengthening of its network of National Member Organisations (NMOs), enhanced visibility and more efficient governance.

The last two years have witnessed important structural and organisational changes for us. These have not been devoid of emotions as David Watters who led the organisation for about a decade stepped down from his position of Executive Director. I wanted to express our gratitude to David without whose leadership IPOPI would not be where it is today. We are delighted to work with our new Executive Director, Johan Prevot, who has been with IPOPI since 2010 and whose contribution and strategy-focused approach to the work of IPOPI has already enabled us to further increase our overall efficiency.

At the time of writing these lines, IPOPI counts 42 NMOs among its membership, this is a 50%+ increase since 2009. This could not have been achieved without the dedication of our staff and Board members.

I am proud of the fantastic achievements of IPOPI and I hope that you will agree with me when reading through this review. We will build on this momentum to continue to optimize IPOPI's impact on the lives of people living with Primary Immunodeficiencies. Because this has always been and will remain the ultimate focus of our work.

It has been my pleasure to serve as IPOPI's chairperson since 2008 and I look forward to IPOPI's continuing success in the future.



Jose Drabwell

EXECUTIVE COMMITTEE, OFFICERS AND STAFF

EXECUTIVE COMMITTEE

Jose Drabwell, Chair (United Kingdom)
Sven Fandrup, Vice-Chair and Treasurer (Denmark)
Marcia Boyle (USA)
Dragana Koruga (Serbia)
Vicky Modell (USA)
Roberta Pena (Argentina)
Martine Pergent (France)
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Johan Prevot, Executive Director
Magda Lourenço, Executive Assistant
Carol Tavener, Bookkeeping & Administration
Clare Glynn, Financial consultant
David Watters, Consultant - Projects

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Prof. Luigi Notarangelo (Italy/USA)
Prof. Alessandro Plebani (Italy)
Prof. Surjit Singh (India)
Dr. Klaus Warnatz (Germany)



Board members, Executive Director and Medical Advisory Panel Chairperson

IPOPI STRATEGIC PLAN

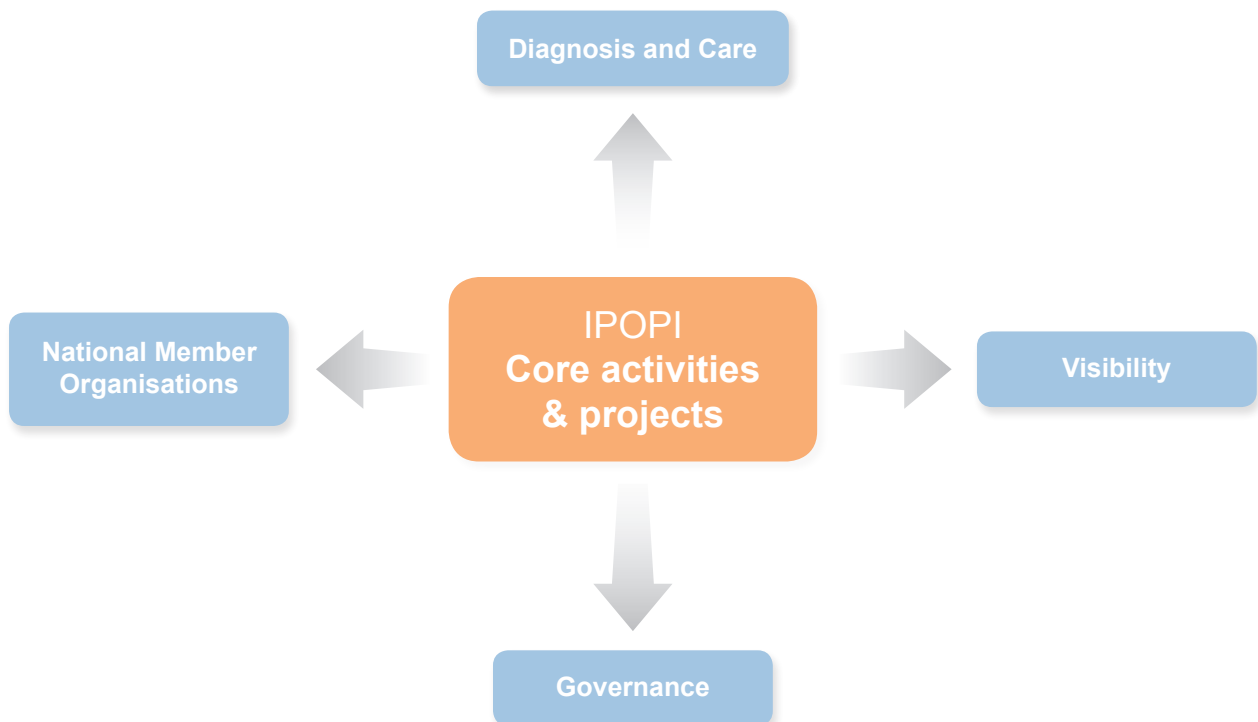
MISSION STATEMENT

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 4 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 4 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) refer to 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 can be profoundly impacted by their condition.

PIDs are caused by genetic defects of the immune system most of them hereditary. The immune system normally helps the body fight off infections by germs (or 'micro-organisms') such as bacteria, viruses, fungi and protozoa. As 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 compromised, 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 tests, PIDs remain widely underdiagnosed on a global scale. Varying treatment levels and inappropriate treatment focusing on the symptoms rather than on the cause are another challenge facing people living with a PID.

This is why IPOPI is committed to continue its work towards better access to early diagnosis and treatment for all patients living with a PID.



Picture from PIO, Swedish NMO

KEY ACHIEVEMENTS AND ACTIVITIES, 2010-2011

STRATEGIC OBJECTIVE 1 – ENSURE OPTIMAL ACCESS TO DIAGNOSIS & CARE

EU PID Expert Meeting

In 2010, IPOPI co-organised a European Parliament expert meeting on Primary Immunodeficiencies at the European Parliament. The meeting was a true success and led to the publication of an EU set of expert recommendations which has provided an excellent advocacy tool to make advances on issues relating pertaining to patient access to diagnosis and care in the region. These can be accessed on the IPOPI website.

IPOPI PID Forums

In 2011 work continued in Europe and IPOPI launched its PID Forum programme. Under this programme, two events were held at the European Parliament focussing on SCID newborn screening and the impact of Health Technology Assessments (HTAs). We were fortunate to have the active support of Glenis Willmott, a member of the European Parliament (MEP) who has worked tirelessly for the interests of PID patients in Europe. Each event led to an official parliamentary question being submitted to the EU Commission and a set of recommendations. In addition to substantial political support to those events we also benefited from the support of other key stakeholders including leading clinicians from across Europe.

IPOPI SCID Newborn Screening Programme

IPOPI's work to promote the implementation of Severe Combined Immunodeficiency (SCID) newborn screening in the European Union started with IPOPI's PID forum in 2011 and a subsequent Parliamentary Question to the European Commission. This led to further discussions with the relevant Commission services and the EU Health Commissioner. IPOPI also sponsored a follow up meeting in the UK focussing on SCID newborn screening, which further built on the political momentum started at EU level and benefited from national media coverage. IPOPI is currently working on an advocacy campaign at EU level to build on these results with the aim to obtain political endorsement for the swift need of implementing SCID newborn screening in Europe.



SCID newborn screening meeting, UK, 2011



PID EU Forum - SCID Newborn screening Dr. Bobby Gaspar, Johan Prevot, Glenis Willmott and Jose Drabwell



PID EU Forum - Johan Prevot talking about the impact of Health Technology Assessments

Regional Outreach

Advocacy and the promotion of patient interests are key to our role around the world and we are proud of our achievements in improving awareness, diagnosis and the introduction of appropriate therapies at regional level. In 2010-2011, IPOPI supported regional patient meetings and campaigns in Latin America through the LASID/IPOPI meeting in Mexico City and the LATAM High-Level meeting which led to the launch of a regional call to action and triggered political momentum around issues of access to diagnosis and treatment. Similarly a first ever African patient meeting was held on the occasion of the ASID/IPOPI meeting. Eastern Europe was also a focus of IPOPI's regional campaign with the first ever Eastern European IPOPI meeting bringing patients, doctors and stakeholder from the region. All of these meetings and campaigns have allowed IPOPI to provide direct regional impact and help with the creation of new National Member Organisations in these target regions. IPOPI has also established connections and held initial meetings in countries in Asia. Among other meetings, IPOPI was pleased to participate in the first Indian International conference on Primary Immunodeficiencies (PIDs) in New Dehli. The congress marked an important step in the wider dissemination of information on PID's in India and called for improved diagnosis and care through increased support from the health authorities.



LASID Meeting 2011



LATAM High-Level Meeting 2011

IPOPI List of Immunoglobulins

IPOPI, through extremely conscientious work by Board member Martine Pergent, works hard to maintain a list of all intravenous and subcutaneous immunoglobulins available in countries around the world. It is important that informed patients have a knowledge of all the immunoglobulins licenced for use in their country. For this we do depend entirely on the information we receive from participating manufacturers. We are grateful to those pharmaceutical companies who help to keep our listings up to date. The list can be viewed on the IPOPI website (www.ipopi.org) and is a valuable resource to all PID stakeholders.

Global Leaders Meeting 2011

The first Global Leaders Meeting was held in 2009 and we were able to bring experts from around the world together again in London for a successful meeting in November 2011. The purpose of those meetings was to bring together the thinking of researchers, healthcare professionals, patients and industry (both commercial



Global Leaders Meeting 2011

and not-for-profit) as a ‘think tank’. This is important as there is no single place where those disciplines meet under one roof and around one table to discuss the significant issues facing our shared communities. IPOPI’s aspiration is to take these meetings to the next level and hold them on a wider scale and on a biennial basis to promote the exchange of best practice, discuss latest key scientific, policy, awareness and regulatory developments and help establishing priorities in a multi-disciplinary setting.



Johan Prevot, EU Commissioner John Dali and Brian O’Mahony

Platform of Plasma Protein Users

IPOPI has worked tirelessly with other patient groups representing rare plasma related disorders under the umbrella of PLUS. Since its inception IPOPI has been represented on the Steering Committee and we believe that this has been a mutually beneficial situation. Membership of PLUS opens doors to areas where, acting alone, it would have been much harder to successfully influence policy and access high EU officials such as health Commissioners. In addition we have played a leading role in the annual ‘Dublin Consensus meetings’ where we have worked to bring together the commercial and not for profit sectors with an emphasis on mutual regard and recognition. In 2011 Johan Prevot and Brian O’Mahony from PLUS met Commissioner Dali.

The main topics for discussion were the outcomes of the PLUS 2011 Dublin Consensus meeting and the subsequent publication of 2ndPLUS Consensus Statement on “Vital issues relating to the collection and provision of blood components and plasma-derived medicinal products” and its relevance to the last Blood Directive report. IPOPI’s campaign for the implementation of SCID newborn screening in the EU was also discussed. Other topics discussed included the inclusion of patient groups in Health Technology Assessment processes in relation to the EU Cross-Border Directive. The Commissioner highlighted the importance of those issues to the Commission and will be followed up. He also re-emphasized the commitment of the European Commission to continue the consultation process with PLUS in the future.



PLUS-Dublin Consensus Meeting



IPPC 2011 in Lisbon

Other Stakeholder Collaborations

Any individual or organisation that works in isolation and for oneself loses out very greatly on the wealth of accumulated experience available. IPOPI works closely, as this Review demonstrates, with a plethora of other organisations interested in the well-being of people with PIDs, rare disorders and the political ramifications of the complex conditions that fall within our remit. Each year IPOPI attends conferences organised by the Plasma Protein Therapeutics Association (PPTA) and the scientific meetings organised by the International Plasma Fractionation Association (IPFA) – those meetings have allowed us to contribute towards the significant issues evolving in the sector. We are also active participants on European Medicines Agency (EMA) committees where we hold a permanent seat, thereby ensuring that the needs of PID patients are at the forefront of the European regulatory authority. We also take part in the meetings and programmes of the European Platform for Patient Organisations, Science and Industry (EPPOSI). IPOPI participates in World Health Organisation meetings and in coming years we hope to increase our role in presenting PID needs at this level. IPOPI is a member of Eurordis, the Europe wide organisation for rare disorders and is also represented on the European Commission’s EUCERD by Bianca Pizzera from Italy and a past Chair of IPOPI. IPOPI has also been involved in meetings at the International Society for Blood Transfusion (ISBT) – amongst other international platform and organisations.

STRATEGIC OBJECTIVE 2 - TO DEVELOP, STRENGTHEN AND SUPPORT NMOS

IPOPI Surveys

In 2010 IPOPI undertook its first international NMO survey. The survey was conducted between February 2010 and August 2010 to establish a mapping of several criteria amongst IPOPI's national member organisations including estimated number of patients in each country, known diagnosed PID cases, patient demographics, presence of registries, collaborations with international registries, provision of care, availability of treatment, funding of care, presence of national Medical Advisory Panels and communication tools. It offered a first international overview of these criteria from the patient perspective and identified positive developments, recommendations and areas where improvement is needed. We are grateful to the Immune Deficiency Foundation in the US for their practical input to the survey. The outcomes were presented at the 2010 biennial meeting in Istanbul and the full survey can be accessed on IPOPI's website.

A second survey was conducted in 2011 to establish the views of patients around the world. For this survey we were able to engage the services of a professional survey company and offer an incentive to NMOs to encourage their members to take part. Around 300 completed questionnaires were received and the final analysis will be made available shortly.

Countries providing the highest number of replies were France, Germany, Italy, Portugal, Spain and the UK. This survey did not apply to the US where patients are surveyed regularly by IDF.

PID Awareness Programme

One of IPOPI's prime aims is that of equipping its national member organisations with tools that will empower them and allow them to develop realistic and achievable campaigns to raise the awareness of PID and key access to diagnosis and treatment issues in their national setting. In 2011, IPOPI held a first successful pilot event in Belgium, which led to the elaboration of a national campaign and the launch of an NMO toolkit. The latter is available to all IPOPI NMOs and includes guidelines on media and broadcasting; facts about PID for Governments; corporate sponsorship; government outreach; family and school; and PID facts for the medical profession.



NMO Support Programme

Without NMOs, there is no IPOPI. Effective NMOs have a key role to play in IPOPI's global mission. To encourage NMOs in their activities IPOPI has a support programme which enables start up or developing NMOs to claim grant support for projects that would not go ahead without financial input. The grant applications undergo a selection process overviewed by IPOPI's Board and decisions are made speedily so that good ideas can become an effective reality. In 2010-2011, several national projects were supported through the programme including an awareness building event in Belgium, the first national PID patient meeting in Lisbon, Portugal; a regional Nordic patient meeting in Norway, a PR campaign in Cyprus, a patient access project in Venezuela; a patient meeting in South Africa, and various national patient information publications among others.



IPOPI XIth Biennial Meeting, Istanbul

IPOPI XIth Biennial Meeting, Istanbul

In October 2010, IPOPI met in Istanbul. We met alongside INGID and of course ESID with whose precious support we have been able to share this meeting now for many years. The meeting was a great success with IPOPI delegates able to enjoy a variety of presentations ranging from medical issues to political lobbying workshops. As always an added value of the meeting was the interaction between our NMOs and the sharing of experiences. The meeting notably featured an excellent session of IPOPI's Medical Advisory Panel on the last day.

IPOPI World PI Week NMO Programme

In 2011 and to coincide with the first ever World Primary Immunodeficiency Week (WPIW - see section on World PI Week for more information) IPOPI launched its WPIW NMO programme, available to its membership. Under the programme which is specifically tailored for starting or developing NMOs IPOPI offers the opportunity to its membership to obtain support in developing campaigns and projects that will raise awareness under the umbrella of World PI Week. Among the many national patient events and projects which took place in 2011, IPOPI was pleased to support 13 different national campaigns. Visit www.worldpiweek.org to discover details of what happened in 2011!

NMO Twinning Programme

We can all benefit from the experience of others and this is certainly the case in the realm of national patient organisations. While informal 'twinning' is always possible, formal twinning arrangements are available within IPOPI that offer a structured approach and some financial support as well.

NMO Professionalisation Programme

Under this programme IPOPI identifies and helps countries to develop a new NMO. IPOPI sponsored a significant workshop in Russia that brought over 60 patients and stakeholders together and contributed towards the launch of a patient organisation which became an IPOPI member in Russia.



First Russian Workshop

New NMOs in 2010-2011

When IPOPI met in General Assembly during the Istanbul Congress in 2010, we were proud to welcome a record number of 9 new national patient organisations into IPOPI membership. The following organisations had met the criteria for IPOPI membership and followed the process to become full members – Austria, Belgium, Brazil, Colombia, Greece, Japan, Mexico, Portugal and Turkey.

There is also the current list of Associate members – those countries that have been accepted by the Board and await approval by the General Assembly in Florence in 2012 – Belarus, Chile, Romania, Russia and Venezuela, bringing IPOPI's number of NMOs to 42.

STRATEGIC OBJECTIVE 3 - TO ENHANCE IPOPI AND PID VISIBILITY GLOBALLY

New website and communication tools

Over the past two years and as part of its new communications strategy, IPOPI is proud to have achieved a new website, a new version of its newsletter 'E-News' and a brand new Facebook page. Our new website is easier to maintain and update, informative and more user friendly and has enabled us since its launch to continuously increase the number of visitors. We monitor use of the site and are able to identify levels of usage in different countries around the world.

The format of IPOPI's E-News was significantly improved in 2011. E-News is circulated to a growing number of stakeholders in HTML email format and is also available online on IPOPI's website. A content management and statistics tool system has also been integrated to help us monitor trends and implement any necessary improvement. This has been warmly welcomed by our NMOs and stakeholders.

IPOPI is now also able to offer its members an IPOPI Facebook page – easily accessible from the home page of the IPOPI website, this recently launched social media tool has enabled us to enhance communication with and between our members.

As a further development IPOPI has devised a model website toolkit for NMOs.

This new tool will enable NMOs which do not yet have a website to create one and launch it easily without having to spend significant resources. The tool will also be available to NMOs with existing websites which would like to renew their website's design. This will be released very soon and will enable NMOs to adapt the model to their own national identity, while retaining something of the IPOPI image within that framework.



New IPOPI Publications

IPOPI continues to create new publications and work in collaboration with others so that we have the best material available to our NMOs.

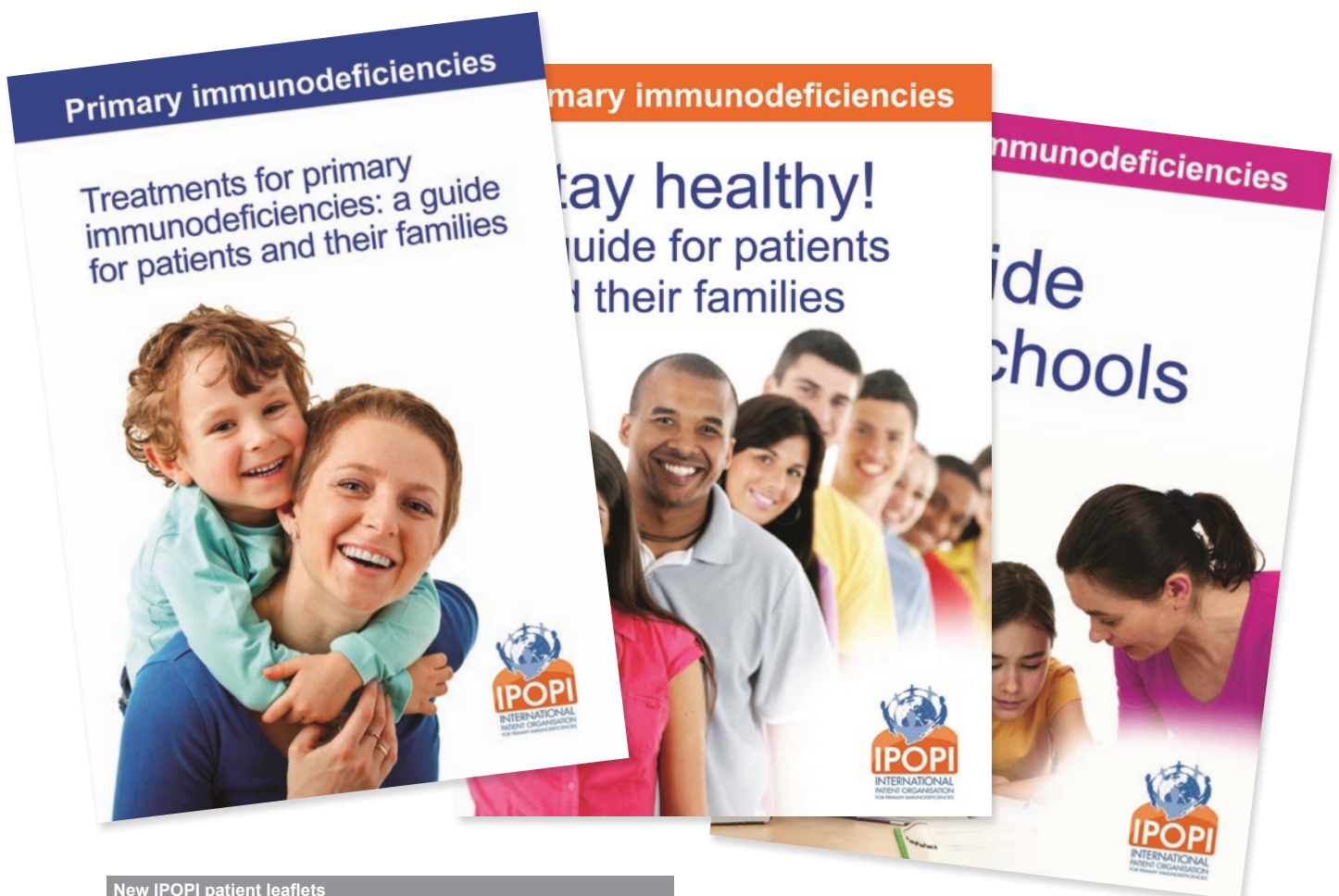
Among the notable publications produced in 2010-2011 were a guide entitled Safety and Efficacy of Immunoglobulin: A Guide for Users, Assessors and Funders. This online publication offers a helpful technical guide to national regulatory agencies and others who are responsible for the selection of immunoglobulin therapies for primary immunodeficiencies within their respective national healthcare systems. We are indebted to Professor Albert Farrugia for writing and gifting this valuable document to IPOPI.

In 2010 – for the first time – we produced an online report of the ESID scientific sessions written for a lay audience. In the past IPOPI participants were not always able to benefit from the evolving scientific knowledge presented at the ESID meeting. We are indebted to Professor Peter Spaeth for his work in preparing this document for IPOPI.

Importantly, Johan Prevot co-authored a publication with Professor Valverde on HTAs and Rare Diseases. This is a significant publication in the Pharmaceuticals Policy and Law series. The publication will be formally launched in Florence in October 2012.

Most recently, IPOPI produced three patient information leaflets on treatment, general healthcare issues and a guide for schools. These leaflets have had an instantaneous success and IPOPI is currently coordinating with its NMOs to provide translated versions in several languages.

Reference has been made elsewhere to other IPOPI publications.



New IPOPI patient leaflets

- Primary immunodeficiencies — A guide for schools
- Primary immunodeficiencies — Stay healthy! A guide for patients and their families
- Primary immunodeficiencies — Treatments for primary immunodeficiencies: a guide for patients and their families

World Primary Immunodeficiency Week

World PI Week (WPIW) arose from the need to raise awareness of primary immunodeficiency around the world through a multi stakeholder approach thereby creating a 'global' movement around PIDs and a central platform around which all local and national players can build. As such, WPIW includes a partnership of the main stakeholder organisations in the field. The WPIW steering committee comprises IPOPI and key regional organisations for clinical immunologists such as the European (ESID), African (ASID), Latin American (LASID) associations for doctors as well as the Clinical Immunology Society (CIS) and the European Federation of Immunological Societies (EFIS); the worldwide organisation for nurses (INGID); the Jeffrey Modell Foundation; and most recently the Plasma Protein Therapeutics Association (PPTA). In greater detail the objectives and Mission of the week are:

- To drive recognition of primary immunodeficiencies (PI) as an increasingly important group of diseases.
- To increase recognition of PI amongst the medical profession as well as parents, school teachers, day care centre employees, researchers and nurses to increase the understanding of these diseases and promote early diagnosis.
- To encourage health authorities to use existing awareness materials produced by JMF, IPOPI and other stakeholders to promote the timely diagnosis and treatment of people living with PI.
- To promote the model of combining physician education and global awareness with the infrastructure to diagnose and treat PI worldwide
- To stimulate efforts to improve the recognition, diagnosis, treatment and quality of life of people with PI world-wide

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

IPOPI significantly improved its 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 focused approach to its core activities and ad-hoc projects has enabled IPOPI to enhance its overall efficiency and make significant advances as reported above. IPOPI also opened two representational offices in Belgium and Portugal.

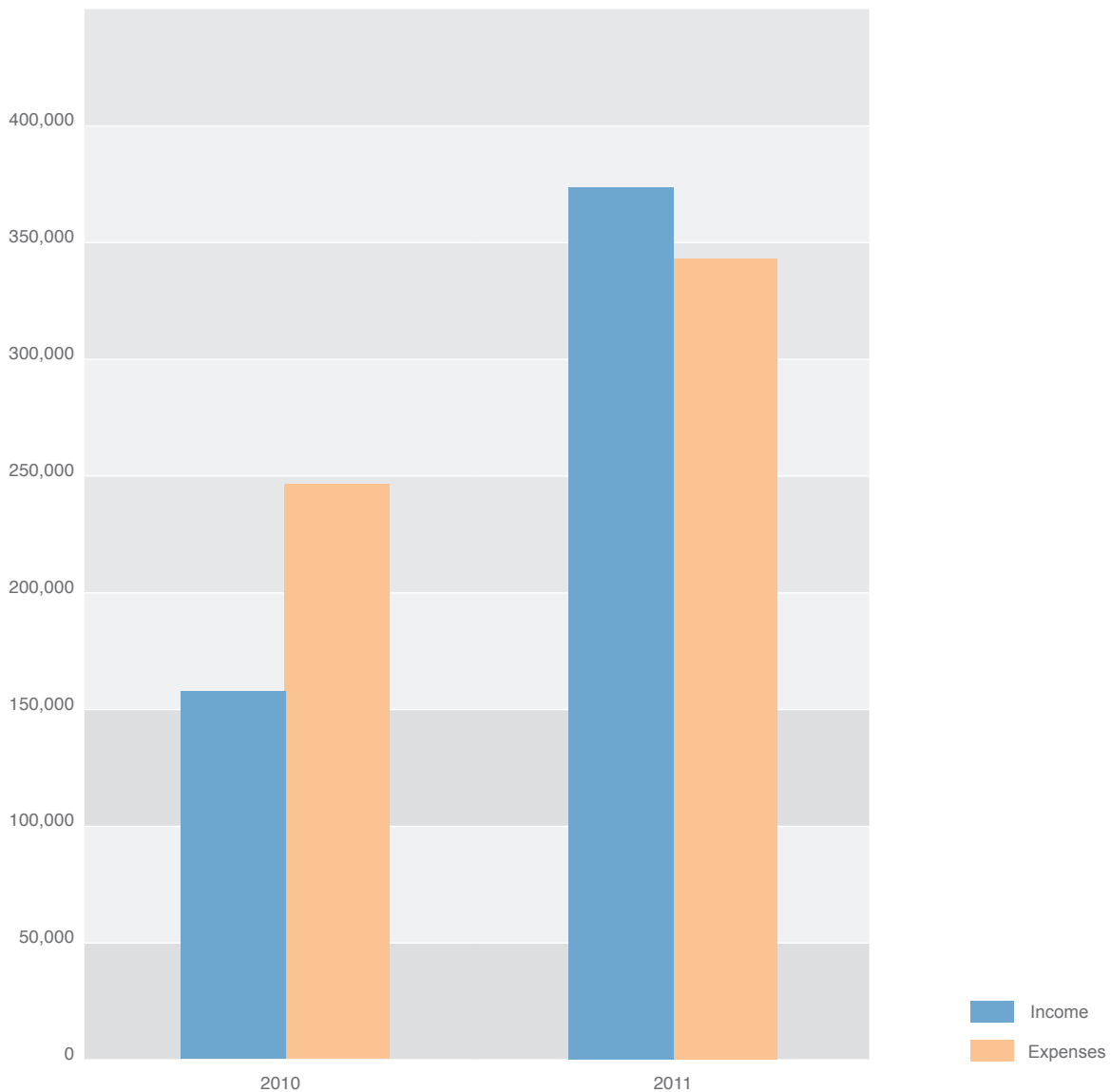


FINANCIAL REPORT 2010-2011

Financially, the years 2010 and 2011 were marked by a significant rise in IPOPI's activities enabled by increased incoming resources. Several changes were made to IPOPI's operational management including improvements in the accounting system of the organisation. As of 2011, revenue received for a given year during the previous year is carried forward to more accurately represent "in year" activities. The charts below reflect this change for 2011 but not for 2010 as this new practise had not been implemented, which explains the gap between income and revenue reported for 2010.

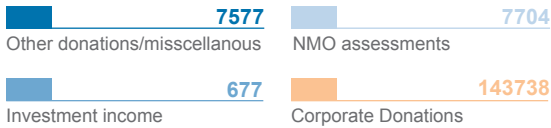
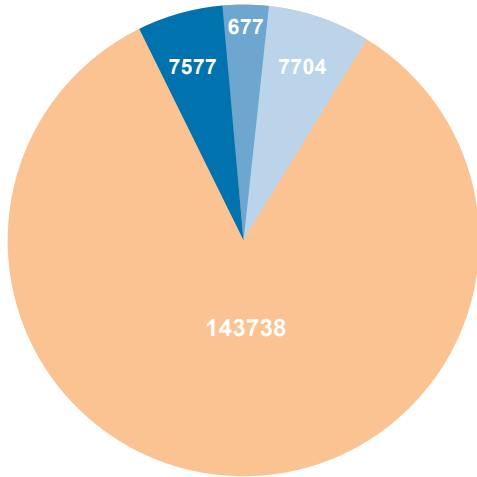
IPOPI is a charity registered in the United Kingdom and under UK Charity Law. As such, we are required to have our accounts audited every year by qualified accountants and submitted to the Charity Commission for approval. These charts provide key aspects of our financial accounts in 2010-2011. Our full audited accounts are available on request.

Income/Expenses (GBP)

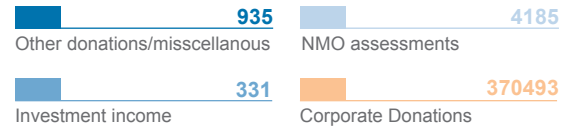
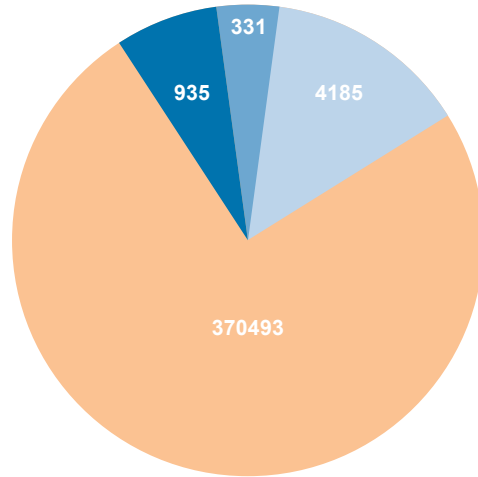


FINANCIAL REPORT 2010-2011

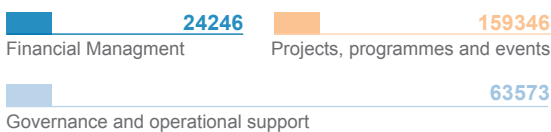
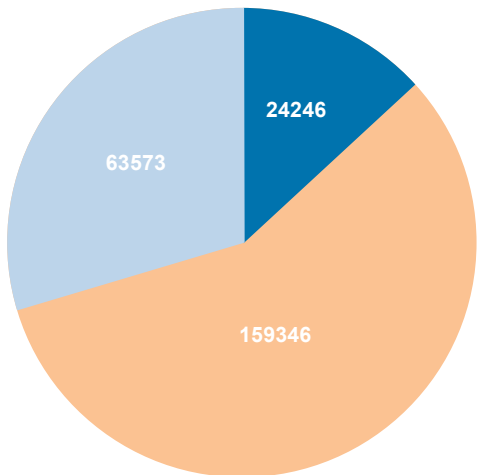
Incoming Resources 2010 (GBP)



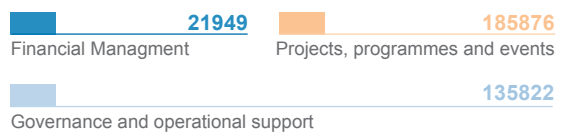
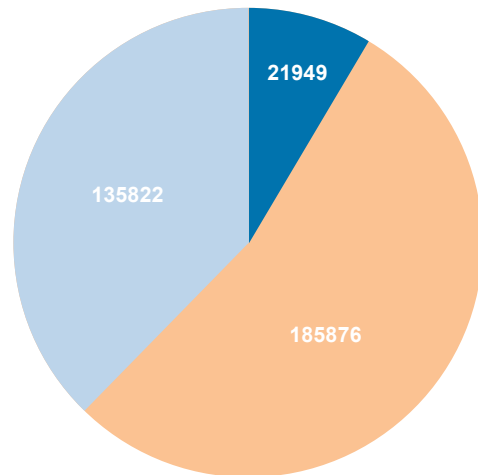
Incoming Resources 2011 (GBP)



Resources expended 2010 (GBP)



Resources expended 2011 (GBP)



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 express our special gratitude to our 42 National Member Organisations which dedicate so much time and effort in their respective countries 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 2010 and 2011 helped IPOPI implement its mission and improve awareness, access to early diagnosis and optimal treatments for primary immunodeficiency (PID) patients worldwide:

Core sponsors

In 2010 and 2011, the following corporate sponsors provided unrestricted grants towards IPOPI's core awareness, advocacy, communications and representational activities, meetings and projects:



Project sponsors

In 2010 and 2011, 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 (incl Talecris in 2010)

Kedrion Biopharma

LFB

Octapharma

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 2010 and 2011 including but not limited to: European Medicines Agency (EMA), 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 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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