

# e-Update

## March 2007



The global organisation working to improve the quality of life for people  
with Primary Immunodeficiencies.

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

1992 - 2007  
**HAPPY 15<sup>th</sup> BIRTHDAY - IPOPI!**

**2007** sees IPOPI achieve its **15<sup>th</sup> birthday!** IPOPI was formally constituted in Lugano – and here we are 15 years on with our Italian friend Bianca Pizzera as our Chairperson and leader.

In **1992** only a handful of NMOs were present – now in **2007** we have almost 30 members and we are growing year by year.



*David Watters, Louise Carrol, Robin Fanshawe, and Maj-Lis Hellstrom at one of the very first IPOPI meetings*



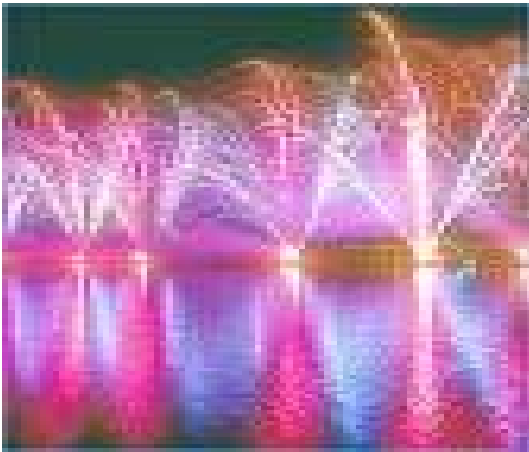
*Bob LeBien, Founder and first IPOPI Chairman*

We now have our own offices in the UK, a strident **Strategic Plan**, budgeting, and a solid reputation based on working together with all our stakeholders on projects like the **EU Consensus Conference** and the **WHO** project to secure the re-statement of immunoglobulins on their **List of Essential Medicines**.



*The first IPOPI Young Adult Group meeting*

We face our 16<sup>th</sup> year with confidence and we look forward to welcoming friends old and new when we meet in the **Netherlands in 2008.**



## US Stakeholder Meeting

**The IDF report on a US Stakeholder meeting held by PPTA in January 2007.**

Present at this meeting were representatives of many of the patient groups concerned with issues surrounding immunoglobulins and their availability.

The meeting heard an update on TSE from **Thomas Kreil**, Chair of PPTA's Pathogen Safety Steering Committee. Dr Kreil's address related to plasma derived coagulation products used in the treatment of haemophilia.

The PPTA Data Gathering Programme also featured on the programme. The programme relates to North America and is available at [www.pptaglobal.org](http://www.pptaglobal.org). This data provides the most useful indicator of total US supply of plasma derivatives. In the US in **2005** the total amount of IVIg distributed in the US was **28,000 kg** – this amount was exceeded during month 11 of **2006** when the total distribution was more than **29,500 kg.**

The **Stakeholder Toolkit** was also introduced. This toolkit was made available after repeated requests for information on plasma protein therapy manufacturing processes and available resources. It is an important educational tool and is available on-line at <http://pptaglobal.org/en/stakeholder.cfm>.

**Johan Prevot**, Senior Manager Public Affairs (Europe) gave an overview of stakeholder involvement in Europe where the Plasma Protein Users Group (**PPUG**) was formed in 2004.

There is a widespread group of patient representatives involved in the Group and significant achievements include a patient group toolkit (available at [www.patientgrouptoolkit.org](http://www.patientgrouptoolkit.org)) as a means of helping to develop NMOs and the co-ordination of a joint submission for the **reinstatement of immunoglobulins on the WHO Model List of Essential Medicines.**

The meeting discussed the state of quality of care initiatives in the US, particularly in light of the changes in the political structure following the November elections. There were presentations from a range of national patient organisations, including most particularly our good friends from **IDF – Marcia Boyle and Dr Michael Blaese**, their Medical Director – outlining various initiatives to improve the overall quality of care available to patients.

The meetings closed with proposals for specific actions in a number of States, including New York, Massachusetts, Florida, Rhode Island and Pennsylvania.

**Another excellent example of the benefits of working together with others!**

## YOUNG ADULTS

For many years now IPOPI has made special provision at bi-annual meetings for young adults.



*Presentation from the YA Group in Budapest*

The Board have recently been able to clarify their thinking on the future of Young Adults (YAs) within IPOPI and the basis of all thinking is that NMOs should be doing more to encourage YAs, defined as aged 16 – 25 years, within their own national organisations.

At IPOPI we have been surprised, delighted and enlightened by what young people have brought to the organisation.

However, IPOPI is not an organisation for individuals – it is an organisation for organisations and as such a YA ‘division’ is not a comfortable fit with the aims and purposes of IPOPI.

It was in this spirit that the Board of IPOPI wrote to the active YAs who have taken part in recent Congresses:

The IPOPI Board has had a comprehensive discussion about the future involvement of Young Adults in the “IPOPI World”. In this connection the following criteria and objectives have been formulated:

1. YAs must first and foremost be involved in the activities of their own National Member Organization.
2. It is the opinion of the IPOPI Board that a YA should be 16 – 25 years old and he/she should be a PID-patient.

3. By representing the YAs of their NMO they should bring forward proposals on:

- a. Issues and activities to be programmed into the IPOPI's biennial meetings.
- b. Establish contact to YAs in other NMOs, not only during the biennial meetings, but also in between the biennials.
- c. Formulate and forward proposals on issues and projects of importance for YAs to the IPOPI Board for further considerations and actions.

The underlying point for NMOs to note is this: the Board of IPOPI are very keen that national member organisations should encourage the active participation of young adults in the 16 – 25 age range in the organisation and running of the national organisation in such a way that international co-operation is fostered.



## Update on AAPID - Argentina February 2006

Over the past few months **AAPID** has been working on a project to be presented to our National Health Authorities that would **ensure free medical assistance and total reimbursement of all medications for patients with PID** in the province of Buenos Aires (Argentina).

A leading immunologist in our country, **Dr. Matias Oleastro**, has provided his expertise in the field to revise the document that is being prepared. We hope this will be passed as law in the course of this year. **Once this is approved, it will lay the foundation for a similar regulation in the whole country.**



**AAPID** has built a collaborative alliance with the **GEISER Foundation** (which is the group dealing with Rare Diseases in Argentina) in order to join efforts to organize **the 1<sup>st</sup> Latin American Congress of Rare Diseases and Orphan Drugs** to be held in Buenos Aires on March 22/23 2008.

Due to availability problems of immunoglobulin since September 2006, we have reached out to major pharmaceutical companies in order to ensure all patients with PID will have access to this vital treatment.

**World Immunology Day:** AAPID is evaluating different projects to celebrate World Immunology day and enhance awareness of PID's in our country. We are currently approaching different labs for sponsorship.

As from June/07 AAPID will be holding regional meetings in key strategic cities within the country to educate patients and physicians on PID.

[www.aapid.com.ar](http://www.aapid.com.ar)

## HAE – Argentina

As a rare disease patient advocacy group, we are witnessing quite an extraordinary time in the history of HAE, since there are currently 5 major pharmaceutical companies conducting clinical trials worldwide to bring new HAE treatments onto the market.

HAE Argentina is working closely with National Health authorities in trying to include "Hereditary Angioedema" within the list of chronic, life-threatening diseases which will result in free access to C1 Inhibitor Concentrate therapy for all HAE patients in our country.

We understand our commitment as a small patient community, and our patients have successfully helped complete one of the clinical trials in Buenos Aires. Our association is currently evaluating the possibility of participating in other two clinical studies during the course of 2007.

Being the only HAE Association in Latin America, we continue to encourage other countries within the region to set up their own patient groups and thus help promote awareness of this rare disorder.

HAE Argentina is closely working with HAE International in trying to promote and facilitate the availability of effective HAE diagnosis and management throughout the world.



On Monday 19 March IPOPI and IUIS (the International Union of Immunological Societies) will be making verbal representations to the World Health Organisation's Essential Medicines Committee in Geneva in our combined attempt to restore immunoglobulins to the Essential Medicines List. Speaking directly to the Committee will be Dr Surjit Singh from Chandigarh in India and Sir Christopher Mallaby, President of the PiA in the UK. Dr Helen Chapel, Bianca Pizzera and David Watters will also be there to offer support and last minute briefings in advance of the hearing. We will not be formally advised of the outcome for some months.

*Later in the year we will be producing a special 15th birthday edition of e-Update. We are anxious to hear from everyone who has an IPOPI story to tell - and especially any photographs of IPOPI events. This will also be a part of recording our history - so please contribute by sending your material to David Watters at [david@ipopi.org](mailto:david@ipopi.org)*