

e-Update

April 2006



In this issue of *e-update* you will read about:

The IPOPI meeting in Budapest in October.

The EU Consensus meeting in Frankfurt in June

The work we need to do to make sure immunoglobulins get back onto the WHO list of essential medicines

Our revised Strategic Plan

THE EU CONSENSUS CONFERENCE

As we have reported previously, this landmark event will take place in Frankfurt, at the Paul Ehrlich Institute, on June 19-20 2006.

Attendance will be by invitation only and a team is working hard to make sure we have successful outcomes by having efficient planning and smooth organisation. This week we have issued invitations to tender for event management, media and publicity, website, production and branding. You will find a version of the *draft programme* attached to this e-mail.

BUDAPEST 2006

We do hope that you are making your bookings for Budapest. We have distributed financial assistance forms and there is a deadline for the return of those applications. Do not miss the closing date we have a busy schedule right now!

We repeat our programme as it currently stands – there will be one or two worthwhile small changes still to come!

We look forward to seeing you in Budapest between

OCTOBER 4 – 7 2006

For fuller details and registration forms, etc, visit ESID at their website address www.esid2006.com

If you want to be sure of getting the reservation you want, and early booking discounts, do not put off booking – do it today!!

THE WHO ESSENTIAL MEDICINES LIST

'The decision of WHO to remove immunoglobulins from their list of Essential Medicines creates a very major task for IPOPI and other patient groups who rely on this important plasma derivative for their health and well-being,' was what we wrote in the last e-update. Considerable progress has been made since then and we will be going to Geneva to visit WHO during May to discuss what is needed in a successful application for re-instatement of Igs on the list! We have also established a helpful rapport with the officials who are now looking after this area of concern – we hope it is helpful anyway!! We have been asked to make sure there is ONE solid application that is lodged with WHO, supported by all those who share our concern. We also plan to be represented and have an opportunity to present our case at WHO when they meet in 2007. **So, watch this space – we will be seeking your support!** We are delight to report the support of PPTA and IPFA in this vital piece of work.

Young Adults at Budapest!

We hope that many NMOs will actively encourage a few Young Adults (aged 18 - 25) to come along to Budapest and meet their peers and share the experience of primary immunodeficiencies around the world. This helps to promote understanding – it is not only our health providers who need education on how treatments are essential for the quality of life of our people! They will have some programme time to themselves and share others with the main IPOPI conference.

The IPOPI Strategic Plan

It is always important to realize that a Strategic Plan – or any other plan for that matter – is not a static document cast in concrete but a living and changing document.

In the year that has just gone by there have certainly been many changes in life for IPOPI with the EU Consensus Conference, the WHO issue – so you not be surprised to learn that your Board members – Trustees – have also spent a fair amount of time looking again at the Plan. We fortunate to have outside help to help us with this exercise and it has certainly helped us to have 'a fresh look'. Some of this will carry itself over to the formal adoption of a new document 'Rules of Procedure' at the Congress in Budapest – you will learn more about this very soon! **Note – this is why it is very important that NMOs select their delegates for Budapest sooner rather than later!**

Perhaps the biggest single change come with the new Vision of IPOPI. This now reads:

The global organisation working to improve early diagnosis and treatment of primary immunodeficiencies.

It is true to say that we have retained the same three objectives – but we now have 17 actions and some 71 tactics to achieve our objectives. And so far – touch wood! – we are on target with our deadlines!

We must also express our grateful thanks to Baxter, ZLB Behring, Talecris, Grifols and Octapharma for their generous support of our work during 2006 – not forgetting our friends at the Immune Deficiency Foundation and the Jeffrey Modell Foundation. Thank you all.

IPPC – Prague

IPOPI was well represented at the International Plasma Protein Conference in Prague in March! Indeed it was possible for the entire Board, apart from Vicki Modell, to be present and we were able to have two formal Board meetings! It was all work!!

Speakers included Board members Stephen Baxter from IDFNZ and Anneli Larsson for PIO in Sweden. The BIG ISSUE affecting all Ig users is REIMBURSEMENT!

This meeting is significant because of the wide range of people who are brought together to share experiences and it is an excellent venue for networking.

During the meeting in Prague it was also possible for PPUG – the Plasma Protein Users Group – to meet. This used to be haemophilia and primary immunodeficiency but now it includes many others – Alpha1, GBS, ITP, and as users of Ig we all work together to make sure that WHO re-instate this onto their List of Essential Medicines.



The PPUG members

This column is empty – because no one sent us any articles!! We do want to help you to share your experiences with other NMOs!!



COMMISSION OF THE EUROPEAN COMMUNITIES



EU CONSENSUS CONFERENCE FOR PRIMARY IMMUNODEFICIENCIES

DRAFT AGENDA

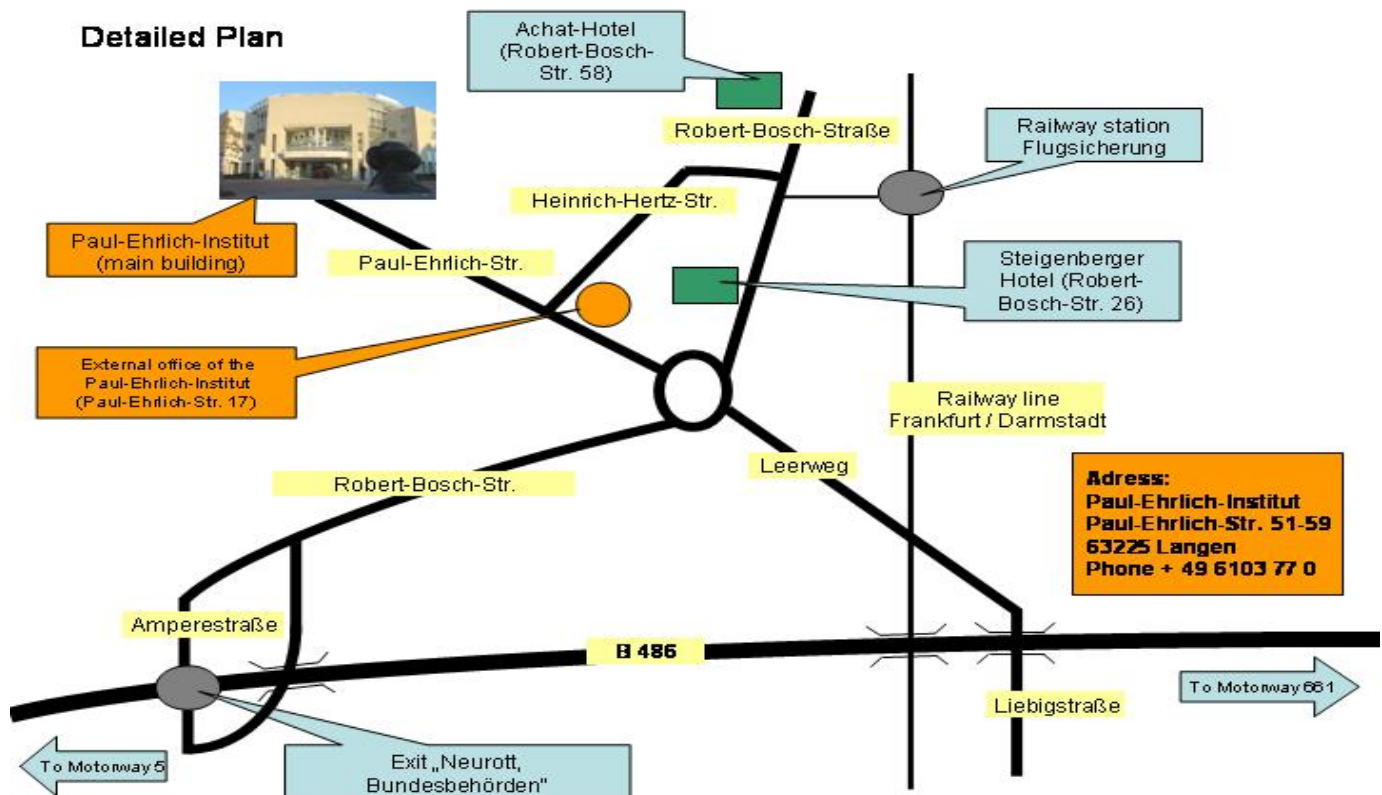
Aims of the conference

The strategic objective of this conference is to use the meeting as the basis for wider recognition of PID as a public health issue in the EU. An EU Consensus Conference is necessary because there is a minimal awareness of PIDs among EU and Member State policy makers or public health officials, and little understanding of the negative public health and cost impact these diseases have if they continue to remain largely un- or mis- diagnosed.

Date and Location

The PID Consensus Conference will take place on 19-20 June 2006 at the Paul-Ehrlich-Institut in Langen (Germany).

Detailed Plan



Day 1: 19 June 2006

SESSION I PIDs – AN EU PUBLIC HEALTH ISSUE

- 09.15** Welcome and Introduction
09.35 Overview of PIDs in the EU, Goals and Objectives of the Meeting
09.55 The Benefits on an EU approach to Rare Diseases
10.15 Addressing inequalities of access to healthcare in an expanded Europe
10.35 PID – a Public Health Issue?

10.55 – 11.10: Refreshment Break

SESSION II WHAT ARE PRIMARY IMMUNODEFICIENCIES

- 11.10** Overview of Primary Immunodeficiency in adults and children
11.30 Prevalence in the EU
11.50 Treatment Options: immunoglobulin therapy – the major therapy choice in PID
Treatment Options: Bone Marrow transplants/ gene therapy
12.10 Disparity of diagnosis, care and treatment for PIDs between Member States of the EU

12.30 – 13.00: Questions and Answers

SESSION III CONSEQUENCES OF MISSED OR DELAYED DIAGNOSIS

- 14.00** Consequences of Delayed Diagnosis: Mortality/Morbidity
14.20 Consequences of Delayed Diagnosis: Quality of Life
14.40 Consequences of Delayed Diagnosis: A patient story
15.00 Consequences of Delayed Diagnosis: Health-care costs

15.20 - 15.40: Refreshment Break

SESSION IV PUBLIC HEALTH INTERVENTIONS TO ADDRESS PID

- 15.40** Evaluating Strategies for Early Identification of People with Primary Immunodeficiencies
16.00 Uses of Genetic Testing for Primary Immunodeficiency, i.e. Newborn Screening for Severe Combined Immunodeficiency (SCID)
16.20 The role of nurses in recognising PIDs
16.40 Successful European Patient Registry for a Disease Other than Primary Immunodeficiency, i.e. Cystic Fibrosis
17.00 Educational Outreach Efforts by:
 - **Physicians:** J-Project
 - **Patients:** Europe, US
 - **Nurses:** UK**17.20** What can we learn from the US – what are the positive effects from the US Consensus Conference?

17.40 – 18.00: Questions and Answers

Day 2: 20 June 2006

SESSION V DEVELOPMENT OF RECOMMENDATIONS & CONSENSUS FOR PUBLIC HEALTH ACTION TO ADDRESS PIDS IN THE EU

TIME: 09.30 – 13.00

Breakout Groups

Group A Screening and Diagnosis

Group B Awareness and Education

Group C Treatment and Care

Prepare Group Reports

***Group Reports and
Recommendations***

12.30 – 13.00 **MEETING CLOSURE**
THANKS TO SPEAKERS, ATTENDEES & SPONSORS

13.00 – End of Conference