

e-Update

February 2005.



There are three very major reasons for sending this edition of e-update!
The IPOPI meeting, alongside ESID and INGID, 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

BUDAPEST 2006

This meeting promises to be one of the best ever Congresses. We have conducted a site visit and can assure everyone that the venue is quite spectacular in every way with lots of space and a very helpful local congress organization. The programme for the entire conference and some very attractive photographs of Budapest are included with this newsletter. This is an important time for clinical immunology and for national patient organizations, so do try to make a point of being there!

OCTOBER 4 – 7 2006

For fuller details 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 EUROPEAN CONSENSUS CONFERENCE

As we reported in the December issue, this 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 from this landmark meeting.

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. It is essential that all NMOs, clinical immunologists and nurses groups join us in mounting a campaign to secure a place on this list for Ig. It is so important that we can use the argument that Ig is on the List, rather than have Health Ministers in developing countries telling us that they will not spend money on Ig because it is not on the WHO List!! So, make sure your NMO is feeding information to IPOPI about how it can help. We will be e-mailing draft supporting letters to help you with the campaign.

**And a quick reminder....IPPC
meets in Prague – March 7/8!**

www.ippc2006.com

XIIth Meeting of the European Society For Immunodeficiencies
IXth Meeting of the International Patients Organisation For Primary Immunodeficiencies
VIIth Meeting of the International Nursing Group For Immunodeficiencies
4 - 7 October 2006
BUDAPEST CONGRESS CENTER
BUDAPEST



IPOPI PRELIMINARY PROGRAM

Wednesday, October 4, 2006

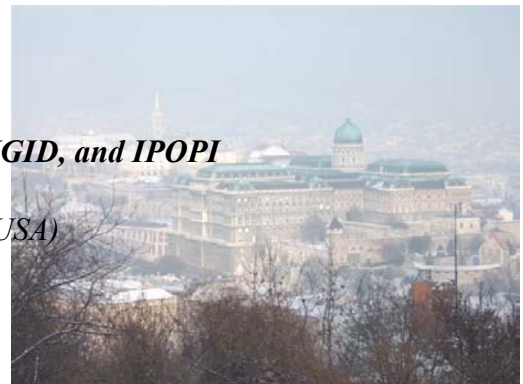
13:00 IPOPI Board meeting

17:30 OPENING SESSION

Presidents of the ESID-2006 Meeting, ESID, INGID, and IPOPI

18:00 Keynote lecture by *R.A. Gatti (Los Angeles, USA)*

19:00 COCKTAIL RECEPTION



Thursday, October 5, 2006

08:30 – 09:00 **Opening of IPOPI Meeting** - Introductions and general get together

09:00 – 09:30 **IPOPI Strategic Plan Presentation**
Anneli Larsoon, Martine Pergent (common with YA)

09:30 – 10:00 **EU PIDs Awareness campaign**
Conference and Consensus Statement - Joint Project with ESID-IPOPI-INGID-EFIS
David Watters (common with INGID)

10:00 – 10:30 Coffee Break



10:30 – 11:30 **IPOPI SP Workshops**

The aim will be to secure support and further input from existing and potential NMOs

11:30 – 12:30 **IPOPI Specialist session: Quality of Life**

Jennifer Puck (common with YA)

12:30 – 14:00 LUNCH

14:00 – 15:00 **Presentation of outcomes from SP Workshops**

Joint ESID-IPOPI-INGID workshop

15:00 – 16:30 **WORKSHOP 1** (Room: Bartók)

“Gene therapy”

M. Cavazzana – Calvo (Paris, France), *M. Grez* (Frankfurt, Germany)

15:00 – 16:30 **WORKSHOP 2** (Room: Patria)

“Infections in PID patient”

A. Cant (New Castle, UK), *F. Schumacher* (Brescia, Italy)

16:30 – 18:00 **WORKSHOP 3** (Room: Patria)

“Immunoglobulin replacement therapy”

B. Grimbacher (Freiburg, Germany), *H. Chapel* (Oxford, UK)

16:30 – 18:00 **WORKSHOP 4** (Room: Bartók)

“Long-term outcome of stem cell transplantation”

M. Abinun (New Castle, UK), *W. Friedrich* (Ulm, Germany)

IPOPI Board (only) Round Table with PPTA

19:30 CONCERT



Friday, October 6, 2006

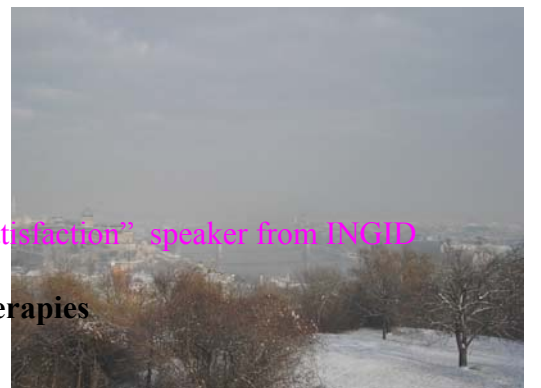
09:00 – 10:00 **IPOPI AGM and elections**

10:00 – 10:30 Coffee Break

10:30 - 11:30 **Joint session with INGID on the topic “Patient Satisfaction” speaker from INGID**

11:30 – 12:30 **IPOPI Specialist session: Breaking News in therapies**

Helen Chapel (common with INGID)



12:30 – 14:00 LUNCH

14:00 – 15:00 **Running an Awareness Campaign –**
Vicki and Fred Modell (Joint with ESID-INGID)

15:00 – 16:00 **Raising the Funds and Doing the Job**
Reports from selected NMOs incl. Eastern European speakers

16:00 – 16:30 Coffee Break/Posters viewing

16:30 – 17:30 **IPOPI Specialist session: Genetics – the future of medicine**
Anna Villa (common with YA and INGID)



20:00 BANQUETTE DINNER

Saturday, October 7, 2006

09:00 – 10:00 **MAP Session :**
Teresa Espanol, MAP Chair (common with YA)

10:00 – 10:15 **YA Report**

10:15 – 10:30 **Evaluation and closing remarks**

10:30-11:00 Coffee Break

Closing ceremonies – as ESID program

11:00 – 11:30 **Final keynote lecture**
J-L. Casanova (Paris, France)

11:30 CLOSING

12:00 – 13:00 **Joint Meeting IPOPI/ESID/INGID Boards**

13:00 **New Board meets (until 15:30)**

Note: This color type indicates “to be agreed”



See you in Budapest!!