

WELCOME TO

the IXth

IPOPI MEETING

Ipopi Meeting Budapest 2006



The global organisation working to improve the quality of life for people with primary immunodeficiencies



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IPOPI

INTERNATIONAL
PATIENT ORGANISATION
FOR PRIMARY IMMUNODEFICIENCIES

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The global organisation working to improve the quality of life for people with primary immunodeficiencies

Thursday, October 5, 2006

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

09:00 – 09:30 **IPOPI 2006-2009 Strategic Plan Presentation - (Chair J. Drabwell)**

Anneli Larsoon, Martine Pergent (common with Young Adult group)

09:30 – 10:00 **EU PIDs Awareness campaign: EU PID Consensus Conference and Consensus Statement - Joint Project with ESID-IPOPI-INGID-EFIS (Chair A. Larsoon)**

David Watters

10:00 – 10:30 Coffee Break

10:30 – 11:30 **IPOPI Specialist session: Genetics – the future of medicine (Chair S. Baxter)**

Anna Villa (common with INGID)

11:30 – 12:30 **IPOPI Specialist session: Quality of Life (Chair B. Pizzera)**

Joie Davis (common with Young Adult group)

12:30 – 14:00 LUNCH

14:00 – 15:00 **Presentation of IPOPI Rules of Procedures and Assessment** (**Chair K. Antilla**)

David Watters, Bianca Pizzera

Joint ESID-IPOPI-INGID

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)

17:00 – 18:00 **Round Table with Industry** : Balance of 2006 and projects for the future

-for Board Members only- (**Chair B. Pizzera**)

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19:30 CONCERT

(or, at the choice of participants)

20:00 BAXTER GET TOGETHER DINNER

(17.30 – welcome drinks on the terrace)

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Friday, October 6, 2006

09:00 – 10.00 IPOPI AGM and elections (Chair D. Watters)

10:00 – 10:30 Coffee Break

10.30 - 11.30 **The WHO essential list of medicines: Immunoglobulins - State of the Art**

Johan Prevot, Dr. Durgjit Singh (Chair Vicki Modell)

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

H. Longhurst, C. Kinnon (common with INGID) (Chair Eva Brox)

12:30 – 14:00 LUNCH

14:00 – 15:00 **Running an Awareness Campaign – (Chair M.Pergent)**

Vicki and Fred Modell (common with ESID-INGID)

15:00 – 16:00 **Raising the Funds and Doing the Job: Experience from IDF, US**

Marcia Boyle, Kathy Antilla (Chair Joy Rosario)

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

16:30 – 17:30 **EDUCATIONAL SYMPOSIUM: How to build an effective patient organisation to**

secure access to care (Chair Sven Fandrup)

Brian O'Mahony, Sven Fandrup

20:00 BANQUETTE DINNER

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Saturday, October 7, 2006

09:00 – 10:00 MAP Session : (Chair T. Espanol)

Teresa Espanol, MAP Chair (common with YA)

10:00 – 10:15 YA Report (Chair S. Fandrup)

10:15 – 10:30 Evaluation (Chair M. Pergeant, A. Larsoon)

Closing Remarks

10:30-11:00 Coffee Break

CLOSING CEREMONIES – Joint session ESID-IPOPI-INGID (Room Patria)

11:00 – 11:30 Final keynote lecture

J-L. Casanova (Paris, France)

11:30 CLOSING

12.00 – 14.00 Joint Lunch Meeting ESID/ IPOPI/INGID Boards

14:00 – 16.00 New Board meets

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