



XIIIth Meeting of the
**INTERNATIONAL PATIENT ORGANISATION
 FOR PRIMARY IMMUNODEFICIENCIES**

29 October – 1st November 2014,
 Prague, Czech Republic



Prague Congress Center - Room Terasa 1

Wednesday – 29 October 2014

Time	Subject	Speakers	Moderators
09.00 – 12.30	Board meeting		
12.30 – 13.30	Lunch		
13.30 – 14.00	Chair's Welcome Welcome to The Czech Republic Remembrance Ceremony Logistical remarks	Jose Drabwell Sarka Charbuska Christine Jeffery Johan Prevot	Johan Prevot
14.00 – 15.00	WORKSHOP Poster session – who is who? (Name, country, NMO, function in NMO) NMOs can make miracles happen	Dragana Koruga Christine Jeffery	Martine Pergent Christine Jeffery
15.00 – 15.30	Coffee Break		
15.30 – 16.00	Achievements and Challenges: What have been your major achievements and Challenges since Florence? Experiences from NMOs	Jose Drabwell	Martine Pergent Christine Jeffery
16.00 – 17.00	Joint opening session		
18.00 – 19.00	Opening keynote		
19.00	Welcome reception		

Thursday – 30 October 2014

Time	Subject	Speakers	Moderators
09.00 – 10.30	CLOSED SESSION - Panel discussion: Strategies and possibilities for fundraising	Panel: Marcia Boyle, Bogdan Gajewski TBC	Martine Pergent and Joy Rosario
10.30 – 11.00	Break		
11.00 – 11.45	Innovative treatments for PIDs - Fears and hopes	Dr. Despina Moshous	Jose Drabwell
11.45 – 12.30	Living with a chronic disease How can your NMO help and support the families	Dr. Mari Campbell	Christine Jeffery
12.30 – 13.45	Lunch		
13.45 – 14.30	WORKSHOP – <i>IPOPI/INGID Joint Session</i> “Can I really ask that question?”	TBC Kate Sullivan	Marcia Boyle
14.30 -15.15	WORKSHOP How to maximize collaboration between	Panel: Dragana Koruga; Joy	Sven Fandrup



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	IPOPI NMOs and national organizations for Rare Diseases/other patient organisations?	Rosario; Kees Waas	
15.15 – 16.00	IPOPI report IPIC and other reports - PLUS activities and achievements - Updates on current and upcoming projects - Tools - Survey results	Johan Prevot	Martine Pergent
16.00 – 16.30	Break		
16.30 – 17.15	How the immune system functions	Dr. Martin Van Hagen	Sven Fandrup
19.00	IPOPI Biennial Dinner <ul style="list-style-type: none"> • Bob Le Bien • Luciano Vassali Award 	Jose Drabwell Martine Pergent	

Friday – 31 October 2014

Time	Subject	Speakers	Moderators
09.00 – 10.30	IPOPI ANNUAL GENERAL MEETING CLOSED SESSION	Jose Drabwell	Johan Prevot
10.30 – 11.00	Break		
11.00 – 11.45	WORKSHOP The importance of Data collection	Panel: Marcia Boyle, Dr Benjamin Gathmann, Martine Pergent	Martine Pergent
11.45 – 12.30	PID and autoimmunity: Managing autoimmunity and autoinflammation complications	Prof. Luigi Notarangelo	Maria Michelfelder
12.30 – 14.00	Lunch		
14.00 – 15.15	WORKSHOP World PI Week: Awareness ideas and strategies	Panel: Jose Drabwell, Marcia Boyle, Leire Solis	Joy Rosario
15.15 – 16.00	Gene Therapy and Stem Cell Transplantation (SCT) and Bone Marrow Transplantation (BMT) – How it works	Dr. Nizar Mahlaoui	Sven Fandrup
16.00 – 16.30	Break		
16.30 – 17.00	Newborn Screening	Prof. Jennifer Puck	Jose Drabwell
17.00 - 18.00	Highlights from ESID	MAP members Dr Denning	Dr N Mahlaoui



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Saturday – 1 November 2014

Time	Subject	Speakers	Moderators
09.45 – 10.45	The importance of evaluation What have you learnt and will take back to your NMO?	Johan Prevot Leire Solis Magda Lourenço	Johan Prevot
10.45 – 11.00	Chair's farewell	Jose Drabwell	
11.00 – 12.00	Social/ networking time		
12.00 – 13.00	Presidential lecture: PIDs where do we go?	ESID Chair	
13.00 – 14.30	Board meeting		