

XV Global Patients' Meeting of the INTERNATIONAL PATIENT ORGANISATION FOR PRIMARY IMMUNODEFICIENCIES

October 24-27, 2018
Lisbon, Portugal

Day 1 Wednesday, October 24, 2018				
Time	Duration	Subject	Speakers	Moderators
13.30-14.00	30'	Chair's Welcome	Jose Drabwell	
		Welcome to Lisbon, Portugal	TBC	
		Presentations New NMOs, IPOPI Board, staff, Board candidates	Jose Drabwell	
14.00-15.00	1'00	Interactive session • Ice breaker session	Christine Jeffery	
15:00-15:30		<i>Break</i>		
15.30-16:15	45'	Lecture • IPOPI: vision, achievement, future	Johan Prevot IPOPI Staff	
16:50		JOINT opening CEREMONY		

Day 2 Thursday, October 25, 2018				
Time		Subject	Speakers	Moderators
8.35-9.15	40'	Lecture • Parent support and children with PID 1. Advice to parents with small children – personal point of view 2. Advice to parents with teenagers – personal point of view 3. Overview and closing remarks	1. Hector Amaya 8:40-8:50 2. Anneli Larsson 8:50-9:00 3. Dragana Koruga 9:00-9:10	Dragana Koruga
9:15-10:05	50'	Joint session with INGID • Anti-infective medicines and Immunosuppressants	Dr Nizar Mahlaoui 9:25-9:50	Roberta Pena
10:05 – 10:35	30'	<i>Break</i>		
10:35 – 12:00	1h25	Interactive session • Strategic plan and fundraising	Christine Jeffery, Bruce Lim, Saara Kiema	
12:00-12:45	45'	Lecture • PID diagnostics and tests 1. From simple to more advanced methods 2. Access and technical aspects	1. Dr Melanie Wong 2. Prof Martin Van Hagen	Annie Pienaar
12:45 – 13:45	1h	<i>LUNCH</i>		
13:45-15:15	1h30	Sponsored workshop - Shire (closed session) • PID Principles of care 1. Lessons learnt from the Principles of Care survey 2. Emerging issues and threats 3. Future tools - towards a PID life index	1. Leire Solis 13:55-14:15 2. Thomas Kreil 14:15-14:40 3. Martine Pergent 14:40-15:05	Martine Pergent Violetta Kozhereva
15:15 – 16:00	45'	Lecture • Treating an adult patient: holistic approach Pulmonary, Gastrointestinal, Hepatology problems	Dr David Lowe 15:25-15:50	John Seymour
15:35 – 16:05	30'	<i>Break</i>		

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16:05-17:40	1:15	IPOPI/ESID/INGID joint session <ul style="list-style-type: none"> • Vulnerable patients 1. INGID: Pregnancy and uses of IGs 2. IPOPI: Aged patients and co-morbidities 3. ESID: Endocrinological disorders in children and adults Discussion	1. Carla Duff 16:15-16:35 2. Jose Drabwell 16:35-16:55 3. ESID TBC 16:55-17:15	Martine Pergent
17.40-19:30	1h50	<i>Time before dinner</i>		
19:30		PID Champions Awards Ceremony <ul style="list-style-type: none"> • The LeBien Award • The Luciano Vassalli Award • IPOPI anniversary celebration 		

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Day 3 Friday, October 26, 2018				
Time		Subject	Speakers	Moderators
08.35-9:30	00h55	IPOPI AGM <ul style="list-style-type: none"> Accounting report Auditors appointment IPOPI Executive board elections <i>Closed Session</i>	Christine Jeffery Jose Drabwell	Johan Prevot
9:30-10:15	45'	<i>Interactive session</i> <ul style="list-style-type: none"> Q&A with the plasma industry (global developments, quality management standards/per region, different players, plasma sourcing, tensions, shortages, price issues, safety issues) 	Setting the scene: Albert Farrugia 9:30-9:40 Jan Bult TBC 9:40-9:45 Paul Strengers TBC 9:45-9:50	Johan Prevot Panel: Jose Drabwell, Bruce Lim, John Seymour
10:15 – 10:45	30'	<i>Break</i>		
10:45-12h15	1:30	<i>Sponsored session - CSL Behring (closed session)</i> Immunoglobulins: everything you wanted to know and more! What are they, where do they come from, what are they for 1. Plasma collection 2. Manufacturing of IG products (key product characteristics) 3. Routes and settings (pros and cons) 4. Access to market 5. Q&A discussion 6. Conclusion	1. Stephan Walsemann, EPA 10:55-11:10 2. Liane Hoeffler, TBC Senior Director Plasma Products Development CSL Behring TBC 11:10-11:25 3. Geraldine Dunn, INGID 11:25-11:40 4. Leire Solis, IPOPI 11:40-11:55	Jose Drabwell
12:15 – 12:30	15'	Group Picture		
12:30 – 13:30	1h00	<i>LUNCH</i>		

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Day 3 Friday, October 26, 2018				
Time		Subject	Speakers	Moderators
13:30 -14:15	45'	Lecture • BMT, Gene Therapy and Gene editing for PIDs	Prof Bobby Gaspar TBC	Andrea Gressani
14:15-15:45	1h30	Interactive session • Public relations - basics for NMOs (3 workshops) - Crisis management (How to manage an event which you can't always foresee) - Fundamentals of PR workshop (3 different workshops, upon registration)	Blanca 14:25-14:35 Annie 14:35-14:45 TBC Otilia 14:45-14:55 TBC Workshop 14:55-15:45	Leire Solis Martine Pergent
15:45 – 16:15	30'	Break		
16:15-17:00	45'	Lecture • Ethics in PIDs: emerging issues - Genetic testing and pregnancy: how much should we know? - Blood and plasma donations: to remunerate or not?	NMO Panel: Morocco TBC Germany TBC Canada TBC	John Seymour, Saara Kiema
17:00-18:00	1h	Map report	MAP members	
18:00-18:15	15'	Chair's Farewell	Jose Drabwell	

Day 4 Saturday, October 27, 2018				
8:30 – 12:30	4h	Social event	On registration	
12:30		Closing session ESID-IPOPI-INGID		