

# 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 min	<b>Chair's Welcome</b>	Jose Drabwell	
		<b>Welcome to Lisbon, Portugal</b>	Ricardo Perreira Dr Susana Lopes da Silva	
		<b>Presentations</b> New NMOs, IPOPI Board, staff, Board candidates	Jose Drabwell	
14.00-15.00	1h00	<b>Interactive session</b> • <b>Ice breaker session</b>	Christine Jeffery	
15:00-15:30		<i>Break</i>		
15.30-16:15	45 min	<b>Lecture</b> • <b>IPOPI: vision, achievement, future</b>	Johan Prevot IPOPI Staff	
16:50		<b>JOINT opening CEREMONY</b>		

Day 2 Thursday, October 25, 2018				
Time		Subject	Speakers	Moderators
8.35-9.15	40 min	Lecture • <b>Parent support and children with PID</b> 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 min	Joint session with INGID • <b>Anti-infective medicines and Immunosuppressants</b>	Dr Nizar Mahlaoui 9:25-9:50	Roberta Pena
10:05 – 10:35	30 min	Break and poster presentations (e-poster room)	Martine Pergent Whitney Goulstone Antonino Trizzino	Leire Solis
10:35 – 12:00	1h25	Interactive session • <b>Strategic plan and fundraising</b>	Christine Jeffery, Bruce Lim, Saara Kiema	
12:00-12:45	45 min	Lecture • <b>PID diagnostics and tests</b> 1. From simple to more advanced methods 2. PID diagnosis and hormones	1. Dr Melanie Wong 2. Prof Martin Van Hagen	Annie Pienaar
12:45 – 13:45	1h00	LUNCH		
13:45-15:15	1h30	Sponsored workshop - Shire (closed session) • <b>PID Principles of care</b> 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. Dr Thomas Kreil 14:15-14:40 3. Martine Pergent 14:40-15:05	Martine Pergent Violetta Kozhereva
15:15 – 16:00	45 min	Lecture • <b>Treating an adult patient: holistic approach</b> Pulmonary, Gastrointestinal, Hepatology problems	Dr David Lowe 15:25-15:50	John Seymour
15:35 – 16:05	30 min	Break		



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16:05-17:40	1h15	<b>IPOPI/ESID/INGID joint session</b> <b>• Vulnerable patients</b> 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. Olle Kämpe 16:55-17:15	Martine Pergent Geraldine Dunne Peter Jandus
17.40-19:30	1h50	<i>Time before dinner</i>		
19:30		<b>PID Champions Awards Ceremony</b> <b>• IPOPI anniversary celebration</b> <b>• The LeBien Award</b> <b>• The Luciano Vassalli Award</b>		

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Day 3 Friday, October 26, 2018				
Time		Subject	Speakers	Moderators
08.35-9:30	55 min	<b>IPOPI AGM</b> ( <i>Closed session – for IPOPI NMOs only</i> ) <ul style="list-style-type: none"> <li>Accounting report</li> <li>Auditors appointment</li> <li>IPOPI Executive board elections</li> </ul>	Christine Jeffery Jose Drabwell	Johan Prevot
9:30-10:15	45 min	<b>Interactive session</b> <ul style="list-style-type: none"> <li><b>Q&amp;A with the plasma industry</b> (global developments, quality management standards/per region, different players, plasma sourcing, tensions, shortages, price issues, safety issues)</li> </ul>	Setting the scene: Albert Farrugia 9:30-9:40  Industry Panel: Jan Bult, PPTA Dr Jackie Kerr, Paul Ehrich Institute TBC	Chair: Johan Prevot  Moderators: Jose Drabwell, Bruce Lim, John Seymour
10:15 – 10:45	30 min	<i>Break</i>		
10:45-12h15	1h30	<i>Session sponsored by CSL Behring using donations collected at ESID 2017)</i> ( <i>Closed session - for IPOPI NMOs only</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. Martin Imboden, Director Plasma Product Development CSL Behring - 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 min	<b>Group Picture</b> (location TBC)		
12:30 – 13:30	1h00	<i>LUNCH</i>		
13:30 -14:15	45 min	<b>Lecture</b> <ul style="list-style-type: none"> <li><b>BMT, Gene Therapy and Gene editing for PIDs</b></li> </ul>	Prof Bobby Gaspar	Andrea Gressani
14:15-15:45	1h30	<b>Interactive session</b> <ul style="list-style-type: none"> <li><b>Public relations - basics for NMOs</b></li> <li><b>- Crisis management</b></li> </ul>	Blanca, Puerto Rico 14:25-14:35 Annie, South Africa	

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		(How to manage an event which you can't always foresee)  - <b>Fundamentals of PR workshop</b> (3 different workshops, upon registration)	14:35-14:45 Otilia, Romania 14:45-14:55  Workshop 14:55-15:45	Leire Solis Martine Pergent
15:45 – 16:15	30 min	Break		
16:15-17:00	45 min	Lecture • <b>Ethics in PIDs: emerging issues</b> (ethical cases sent by NMOs discussed)	NMO Panel: Maria Anebane, Hajar Whitney Goulstone, CIPO Yvonne Okx, SAS	John Seymour, Saara Kiema
17:00-18:00	1h00	Map report	MAP members	
18:00-18:15	15 min	Chair's Farewell	Jose Drabwell	

Day 4 Saturday, October 27, 2018				
8:30 – 12:30	4h00	Social event	On registration	
12:30		Closing session ESID-IPOPI-INGID		