

IPOPI Global Patient Meeting Marseille, France 16-19 October 2024

Agenda

Day 1: Wednesday 16th October, 13:30 – 19:10			
Durati on	Time	Presentation	Speaker
Session 1: Welcome Session Moderator: Martine Pergent			
1h15	13:30-13:40	Chair's Welcome	Martine Pergent
	13:40-14:40	IPOPI team welcome - Ice breaker	Whitney Goulstone, Otilia Stanga, Miriam Ferreira
	14:40- 14:45	IRIS Welcome to Marseille	Pierre Aubisse, IRIS representative
45'	14:45-15:30	CGD at 70: Where Have We Been and Where are We Going?	Prof Steven Holland, USA
Session 2: Interactive workshop How to bring my patient organisation to the next level? <i>Sponsored Session by X4 Pharma</i> Moderators: Martine Pergent + Dr John Seymour			
1h30	15:30– 17:00	How to bring your patient organisation to the next level? (Skill building workshop)	Martine Pergent and Dr John Seymour
	17:00-17:15	Break before JOINT OPENING CEREMONY (ESID 17:05-17:15)	
Follow ESID Programme			
	17:15-17:35	ESID-IPOPI-INGID JOINT OPENING CEREMONY – Plenary Hall	
	17:35-18:00	ESID Honorary Lifetime Achievement Award	
	18:10-19:10	ESID Opening Keynote Lecture	
	19:10	Welcome Reception – Exhibition Area	

Day 2: Thursday 17th October, 08:30 – 17:00			
	Time	Presentation	Speaker
Session 3 Newborn screening and diagnosis in the context of the genomic revolution <i>Sponsored Session by Chiesi</i> Moderator: Roberta Anido de Pena + Dr Nizar Mahlaoui			

1h30	8:30 – 10:00	<ul style="list-style-type: none"> • The newborn screening international landscape & how to get screening off the ground (10') • SCID newborn screening: learning from countries who have implemented it (15') • New horizons for SCID newborn screening? – the case of Malaysia – (10') • Diagnosis in the context of genomics (15') • Panel discussion: The future of newborn screening and the role of genomics (20') • Identification of key points and priorities (10') 	<ul style="list-style-type: none"> • Johan Prévot, IPOPI Executive Director • Prof Dr Fabian Hauck, Germany • Bruce Lim, IPOPI Vice-President • Dr Cybel Mehawej, Lebanon (recorded) • All speakers from the session
30'	10:00-10:30	BREAK (ESID 10:00-10:30)	
Session 4 Fundraising: get inspired! Moderator: Cynthia Olotch + Alicia Bartos			
1h30	10:30 – 12:00	Discover NMO initiatives in fundraising (speed dating format)	Presenters: Pierre Aubisse, France (IRIS); Emi Homareda, Japan (PID-Tsubasa-no-Kai); Bruce Lim, Malaysia (MyPOPI); Tracy Shaw, USA (IDF); Maria Anebane, Morocco (HAJAR); Sian van den Bogaerd-Rance (SAS); Somayeh Khojaste, Iran (IPIA); Silvia Casati and Sergio Vicentini, Italy (AIP); David Josey (Immunity Canada)
Session 5 Unmet needs in rare diseases, differing perspectives <i>IPOPI-ESID-INGID joint session</i> Moderator: Jose Drabwell			
45'	12:00 – 12:45 (IPOPI room)	Unmet medical needs versus unmet patient needs 3 perspectives: physicians, nurses, patients	<ul style="list-style-type: none"> • Martine Pergent, IPOPI President • Prof Fabio Candotti, ESID President • Mary Louise Daly, INGID
1h45	12:45-14:00	LUNCH (ESID 12:45-14:45)	
Session 6 Primary and secondary immunodeficiencies: Defining and establishing communalities <i>Sponsored Session by Takeda</i> Moderator: Whitney Goulstone + Prof Silvia Sanchez-Ramon			
1h30	14:00-15:30	Immunodeficiencies, a growing and complex family <ul style="list-style-type: none"> • Let's consider the wording (15') • Defining PIDs (15') 	<ul style="list-style-type: none"> • Prof Markus Seidel, Austria • Dr Jacques Rivière, Spain • Dr Virgil Dalm, Netherlands

		<ul style="list-style-type: none"> • Defining SIDs (15') • PIDs/SIDs what are the communalities? (15') • Panel discussion (20') • Key priorities (10') 	<ul style="list-style-type: none"> • Prof Felipe Suarez, France • All speakers from the session
Session 7 Access: Availability, Affordability, Coverage <i>Sponsored Session by Biotest</i> Moderator: Bruce Lim + Leire Solis			
45'	15:30 – 16:15	What strategies are used to access universal coverage? <ul style="list-style-type: none"> • Set the scene: How does this work from availability to coverage (10') • Industry perspective (10') • What do NMOs need to know in medical economics (10') Panel discussion (15')	<ul style="list-style-type: none"> • Leire Solis, IPOPI Health Policy and Advocacy Senior Manager • Henrik Oehme, Biotest • Prof Dr Cornelis Boersma, Netherlands
30'	16:15-16:45	BREAK (ESID 16:00-16:30)	
Session 8 DIY: introduction to IPOPI toolkit Moderator: Otilia Stanga + Rafael Graca + Miriam Ferreira			
45'	16:45-17:30	<ul style="list-style-type: none"> • Launch the IPOPI Toolkit (10') Introduction to specific tools (speed dating format) (35') Topics include: Advocacy, Awareness, Fundraising, Communication and Media, and others.	<ul style="list-style-type: none"> • Miriam Ferreira, IPOPI NMO Programmes Officer Presenters: Iqbal Hossain, Bangladesh (PIDPSB); Carolyn Dews, Australia (IDFA); Blanca Imbert, Puerto Rico (APIP); Jorey Berry, USA (IDF); Jose Verstegen, Netherlands (SAS); Leire Solis, IPOPI Health Policy and Advocacy Senior Manager; Bruce Lim, Malaysia (MyPOPI); Johan Prévot, IPOPI Executive Director
	17:30	End of day	
19: 30	PID Champions Awards Ceremony <i>Entry by Pre-registration with IPOPI</i>		

Day 3: Friday 18th October, 09:00 – 17:45			
	Time	Presentation	Speaker

Session 9: IPOPI Annual General Assembly (CLOSED SESSION-IPOPI Members only) Moderator: Martine Pergent and Johan Prévot			
1h30	08:30 – 10:00	AGM	<ul style="list-style-type: none"> • Martine Pergent • Johan Prévot
	10:00-10:30	Break (ESID 10:00-10:30)	
Session 10 Mental health and PIDs Joint session IPOPI – INGID Moderator: Dr John Seymour + Ms Liz Davis			
1h	10:30 – 11:30	Mental Health and PIDs: sharing our perspectives <ul style="list-style-type: none"> • What does Mental Health embrace from the patient's perspective (10') • What do we know about Mental Health? (10') • How to address Mental Health? (10') Discussion and Q&A (30')	<ul style="list-style-type: none"> • Cédric Anchisi, France • Dr Julia Hews-Girard, Canada • Toya Al, Belgium
Session 11 Outlook on new and innovative therapies Moderator: Jose Drabwell + Dr Lúcia Mamede			
1h	11:30-12:30	New and innovative therapies <ul style="list-style-type: none"> • Paediatric perspective (20') • Adult perspective (20') Panel discussion (20')	<ul style="list-style-type: none"> • Prof Bénédicte Neven, France • Prof Silvia Sanchez-Ramon, Spain • Both speakers
30'	12:30 – 13:00	Group picture	
1h	13:00 - 14:00	LUNCH (ESID 12:00-14:00)	
Session 12 Artificial intelligence, how can it help the PID community? <i>Sponsored Session by CSL Behring</i> Moderator: Martine Pergent + Johan Prévot			
1h30	14:00 -15:30	AI, how can it help the PID community? <ul style="list-style-type: none"> • What do we speak of (10') • State of art: AI impact on Treatment, Diagnosis, registries, Medicines, Research, documentation (10') • Diagnosis: the example of Dr Wharehouse (10') Q&A 30' <ul style="list-style-type: none"> • Team productivity thanks to AI (examples) (15') Q&R 15'	<ul style="list-style-type: none"> • Dr Nizar Mahlaoui, IPOPI Medical Advisory Panel Chair. • Dr Jacques Rivière, Spain • Dr Nicolas Garcelon, France • Martine Pergent, IPOPI President • Rafael Graca, IPOPI Comms Manager
30'	15:30-16:00	Break (ESID 15:30-16:00)	

Session 13 Meet the IPOPI MAP and NEX - ESID highlights Moderator: Dr Nizar Mahlaoui / Prof Martin van Hagen/ Roberta Anido de Pena & Cynthia Olotch (patient panel)			
20'	16:00-16:20	State of art with Immunoglobulins	Prof Albert Farrugia, Italy (recorded)
1h10	16:20-17:30	Panel discussion	Moderators with IPOPI MAP members: Prof Tadej Avcin, Dr Virgil Dalm, Dr Cecilia Poli, and Prof Antonio Condino-Neto.
Chair's Farewell			
15'	17:30 – 17:45	Closing Speech	Martine Pergent

Day 4: Saturday, 19th October			
IPOPI Social Event Entry by Pre-registration with IPOPI			
		Social programme	
	13:14:10	ESID Closing Lecture	
	14:10-14:30	ESID Closing ceremony	