

**IPOPI Global Patient Meeting  
Gothenburg, Sweden  
12th – 15th October 2022**



**Day 1: 12th October, 13:30 – 19:00**

<b>Time</b>	<b>Presentation</b>	<b>Speaker</b>
<b>Session 1: Welcome Session 13:30-15:30 Moderator: Martine Pergent</b>		
13:30	Chair's Welcome	Martine Pergent
13:50	PIO Welcome to Gothenburg	Maria Monfors
14:00	Time to make new friends	Christine Jeffery and Natalie Helena
<b>Session 2 : Looking ahead to targeted therapies and emerging threats 15:30 – 16:30 Moderator: Jose Drabwell</b>		
15:30	Upcoming targeted therapies for PIDs	Dr Nizar Mahlaoui
15:50	Awareness on possible emerging threats	Prof Steve Holland
16:10-16:30	Q&A	ALL
17:05-17:15	<b>Break before JOINT OPENING CEREMONY (Plenary Hall)</b>	
<b>Follow ESID Programme</b>		
17:15-17:35	JOINT OPENING CEREMONY – Plenary Hall	
17:35-18:00	ESID Honorary Lifetime Achievement Award	
18:00-19:00	ESID Opening Keynote Lecture	
19:00	Welcome Reception – Exhibition Area	

**Day 2: 13th October, 08:30 – 18:35**

<b>Time</b>	<b>Presentation</b>	<b>Speaker</b>
<b>Session 3: Telling our story with data</b> 08:30 – 09:15 <b>Moderator: John Seymour and Christine Jeffery</b>		
08:30	ESID Registry: How does it work and its value for PIDS?	Mikko Seppänen
08:40	Q&A	
08:45	Data: from basics to brilliance part 1: Telling your story	Christine Jeffery and John Seymour
08:55	Data: from basic to brilliance part 2: Telling IPOPI's story	
09:05	Data and the IPOPI NMO Toolkit	
<b>Joint Session with INGID-IPOPI: The importance of nurses in caring for PID patients of all ages</b> 09:15 – 10:00 <b>Moderator: Cynthia Olotch and Jose Drabwell</b>		
09:15	How nurses can improve quality of life of patients with PID	Moderators: <b>Gaby Strotmann and Prof Ann Gardulf</b> Sarita Workman
09:35	Testimony of personal experience	Kersti Urbala
09:40	Q&A	ALL
10:00-10:30	<b>BREAK</b>	
<b>Session 5: COVID-19: Global Perspectives and Lessons Learnt</b> Sponsored by Takeda 10:30 – 12:00 <b>Moderator: Bruce Lim and Roberta Anido de Pena</b>		
10:30	Research Aspect	Prof Martin van Hagen
10:45	Management Aspect	Prof Isabelle Meyts
11:00	European Medicines Agency perspective	Dr Manuela Mura
11:15	Coronavirus neutralizing antibody titers in IG preparations	Prof Thomas R. Kreil
11:30	Regional patient panel questions and answer	Jessie Qu, Jorey Berry , Dragana Koruga
11:45	Discussion	ALL
<b>Session 6: Rare among rare: Less common PIDs</b> 12:00 – 12:45 <b>Moderator: Andrea Gressani</b>		
12:00	Rare PIDs in children	Dr Olaf Neth
12:15	Rare PIDs in adults	Prof Raffaele Badolato
12:30	Q&A	ALL

12:45-13:45	<b>LUNCH</b>	
<b>Session 7: Clinical research, clinical trials: How do organisations partner?</b> <b>13:45 – 15:15</b> <b>Moderator: Christine Jeffery</b>		
13:45	Researchers' Perspective: The example of eGLILD	Prof Klaus Warnatz
13:55	RECOMB: How collaboration is done	Prof Arjan Lankester
14:05	Opportunities and challenges in LMIC	Prof Gesmar Segundo
14:15	NMO Perspective	Jose Verstegen
14:25	Pharmaceutical company perspective	Lori Neri X4 Pharmaceuticals
14:35	Session summary presentation	Christine Jeffery
15:00	Q&A	ALL
<b>Session 8: Addressing a public health issue: Newborn Screening International Day (neonatal screening) on 28<sup>th</sup> June</b> <b>15:15 – 16:00</b> <b>Moderator: Bruce Lim</b>		
15:15	Newborn screening: Why, how and the conditions	Leire Solis
15:25	SCID Newborn screening outside of Europe: Asian pilot	Bruce Lim
15:35	Advocacy programme explanation: A case study of achievement in Spain	David Jimenez
15:45	Q&A	ALL
16:00-16:30	<b>IPOPI Programme Break</b>	
<b>Bonus Session: Let's work together</b> <b>National Member Organisation Interactive session</b> <b>16:30–17:30</b> <b>Moderator: Miriam Ferreira and Leire Solis</b>		
<b>IPOPI ESID INGID Joint Session: PID/IEI and SID uniting immunodeficiencies?</b> <b>17:35 – 18:35</b> <b>Moderator: Roberta Anido de Pena</b>		
17:35	ESID: Clarification of the 3 terms, what borders?	Prof Isabelle Meyts
17:55	IPOPI: How does this affects the awareness and advocacy campaigns	Johan Prevot
18:05	INGID: Does this make any difference from the nursing perspective?	Emily Carne
18:10	Discussion	ALL
<b>PID Champions Awards Ceremony</b> <b>19:00-00:00</b> <b>Entry by Pre-registration with IPOPI</b>		

Day 3: 14th October, 08:30 – 18:35		
Time	Presentation	Speaker
<b>Session 9: IPOPI Annual General Assembly (CLOSED SESSION-IPOPI Members only)</b> 08:30 – 09:30 Moderator: Johan Prevot and Martine Pergent		
<b>Session 10: How to involve physicians</b> 09:30 – 10:15 Moderator: John Seymour and Otilia Stanga		
09:30	How to involve physicians, at personal level, at patient organisation level. Panel discussions	Dr Mihaela Bataneant, Prof Silvia Sánchez-Ramón, Anneli Larsson, Dimas Adhi Sugiharto
10:15-10:45	<b>BREAK</b>	
<b>Session 11: PID talks: Share, learn and get inspired</b> 10:45 – 12:15 Moderator: Christine Jeffery and Julia Nordin		
10:45	Discover 18 NMO initiatives across diverse topics	18 NMO representatives
12:30-13:30	<b>LUNCH</b>	
13:15 – 13:30	<b>Group Picture</b>	
<b>Session 12: Where are we with curative treatments?</b> 13:30 – 14:15 Moderator: Jose Drabwell		
13:30	Introduction to curative treatments	Prof Bénédicte Neven
13:45	Thymus regenerative therapy	Dr Graham Davies
13:55	Gene therapy – gene editing	Dr. Maria Pia Cicalese
14:05	Q&A	ALL
<b>Session 13: Back to the future, looking towards 2030</b> 14:15 – 15:45 Moderator: Martine Pergent and John Seymour		
14:20	What will change in the way we consider and describe PIDs by 2030?	Prof Martin van Hagen
14:30	Access to diagnosis and treatment	Prof. Silvia Sánchez-Ramón
14:40	Q&A	
14:50	Immunoglobulin replacement therapy	Prof Stephen Jolles
15:00	Challenges and Successes: What are the perspectives of the industry?	Maarten van Baelen (PPTA) Leni von Bonsdorff (IPFA)
15:10	Q&A	
15:15	Panel Discussion	ALL
15:45-16:15	<b>IPOPI Programme Break</b>	
<b>Session 14: Alternative medicines: Benefit and no harm</b> 16:15 – 17:00 Moderator: Otilia Stanga		

16:15	ABC of Nutrition for PID patients	Dr. Iren Alexoi
16:30	Improving health: which gives benefits and will do no harm	Prof Nahla Erwa
16:45	Q&A	ALL
<b>Update Session: ESID highlights</b> <b>17:00 – 18:00</b> <b>Moderator Dr Nizar Mahlaoui</b>		
17:00	Highlights by IPOPI Medical Advisory Panel	Prof Nahla Erwa, Dr Cecilia Poli, Prof Charlotte Cunningham-Rundles, Dr Olaf Neth, Prof Klaus Warnatz, Prof Aziz Bousfiha, Dr Tadej Avcin, Dr Virgil Dalm.
<b>Session 16: Chair's Farewell</b>		
18:00	Closing Speech	Martine Pergent

<b>Day 4: 15th October, 10:00 – 13:30</b>
<b>IPOPI Social Event</b> <b>Entry by Pre-registration with IPOPI</b>