

## **IPOPI WHIM WORKSHOP**

## 25 October, 14h-17h UK time

Session 1: The global WHIM environment Moderator: Martine Pergent	
14:00 10 min	<ul> <li>Welcoming words and introduction</li> <li>IPOPI welcome, Martine Pergent, IPOPI President</li> <li>Supporting corporate partner's welcome, Michele Rhee, VP of Patient Affairs and Advocacy, X4 Pharmaceuticals</li> </ul>
14:10 20 min	<ul> <li>Setting the scene – IPOPI patient and doctor perspective</li> <li>Johan Prevot, IPOPI Executive Director</li> <li>Dr Nizar Mahlaoui, Chair IPOPI Medical Advisory Panel, Past Chair of ESID-registry, CEREDIH, France</li> </ul>
14:30 40 min	<ul> <li>Current WHIM data collection around the world</li> <li>Prof Raffaele Badolato, University of Brescia, Italy</li> <li>Dr Pamela Lee, The University of Hong Kong</li> <li>Prof Anna Shcherbina, Rogachev Federal Scientific and Clinical Centre of Pediatric Hematology Oncology and Immunology, Moscow, Russia</li> <li>Prof David Dale, Division of General Internal Medicine, University of Washington, USA</li> </ul>
15:10 20 min	<ul> <li>Patient experience and expectations</li> <li>John Seymour, Chair Immune Deficiency Foundation, IPOPI Board member, USA</li> <li>Sharon Vacher, WHIM patient representative expert, Australia</li> </ul>
15:30 15 min 15:45	Identification of data collection needs  • Discussion (ALL)  Comfort break (10 min)
Session 2: Towards a global WHIM data sharing platform Moderators: Johan Prevot, Nizar Mahlaoui	
15:55 20 min	Technical presentation: global WHIM data sharing platform + Q&A  • Dr Femida Gwadry-Sridhar, CEO & Founder Pulse Infoframe
16:15 30 min	All participants
16:45 10 min	Identification of steering committee and roles     All participants
16:55 5 min	Martine Pergent



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