19th PID Forum Agenda

14:00 – 14:10 Welcome & Opening remarks

MEPs Carlos Zorrinho (S&D, Portugal) and Marina Kaljurand (S&D, Estonia)

14:10 – 14:20 Setting the scene: PIDs and digitalisation of healthcare

Martine Pergent (IPOPI Executive Committee Chair)

14:20 – 14:40 The potential of digitalisation:

Epidemiology and research

Prof Mikko Seppänen (Adjunct professor, Specialist in Internal Medicine and Infectious Diseases FCIS, Head Physician, HUS Helsinki University Hospital, FINLAND)

Global cooperation and data-sharing

Prof Nicholas Rider (Associate Professor of Pediatrics, Associate Medical Information Officer- Data Operations, Director, Jeffrey Modell Foundation Center for Primary Immunodeficiency at TCH, Baylor College of Medicine, Texas Children's Hospital)

The use of semantic web and FAIRification in rare disease registries

Prof Mark Little (Professor of Nephrology and Consultant Nephrologist Trinity College Dublin / Tallaght and Beaumont Hospitals)

14:40 – 15:20 Panel discussion on digitalisation and PID medical care

Moderated by Johan Prevot (IPOPI Executive Director)

Commission representative (invited)

Dr Nizar Mahlaoui (Unité d'Immuno-Hématologie & Rhumatologie pédiatrique, Hôpital Universitaire Necker-Enfants Malades, Assistance Publique-Hôpitaux de Paris (AP-HP))

Friedolin Strauss (Patient representative)

Prof Isabelle Meyts (Professor in Faculty of Medicine KU Leuven, Head of Inborn Errors of Immunity Unit)

15:20 – 15:30 Closing Statements

MEP co-hosts