

IPOPI 13th PID Forum

Newborn screening for rare diseases. A PID perspective

Wednesday 4th December 2019 – 15:00-17:00

Room A5G305, European Parliament, Brussels

15:00 **Opening remarks**

- **Manuel Pizarro MEP** (S&D, Portugal)
- **Tilly Metz** (Greens/EFA, Luxembourg)
- **Sirpa Pietikäinen** (EPP, Finland)
- **Irena Joveva** (RE, Slovenia)

15:10 **Setting the scene**

Martine Pergent, *International Patient Organisation for Primary Immunodeficiencies (IPOPI)*

15:20 **The Aspects of Newborn Screening**

- **Dr Peter Schielen**, *International Society for Neonatal Screening (ISNS)*
- **Dr Nizar Mahlaoui**, *Medical expert*

15:40 **The Impacts of Newborn screening**

- **Stela Andreea Pirvu**, *Romanian Association for Patients with Primary Immunodeficiencies (ARPID)*
- **Alberto Casaca**, *Associação Portuguesa de Doentes com Imunodeficiências Primárias (APDIP)*

16:00 **Discussion with EU Member States on Newborn Screening**

16:20 **Open floor for discussion**

16:45 **Wrap-up from IPOPI & ISNS & ESID**

16:50 **Concluding remarks**

Manuel Pizarro MEP (S&D, Portugal)