

# 10<sup>TH</sup> PID FORUM

## TACKLING THE DIAGNOSTIC ODYSSEY IN RARE DISEASES THROUGH ERNs: THE CASE OF PIDS

22 NOVEMBER 2017 | 14.00-16.00

ROOM A5E-3 | EUROPEAN PARLIAMENT | BRUSSELS

- 14.00-14.05 | Welcome by José Inácio Faria MEP**
- 14.05-14.10 | EU added value in rare disease diagnosis**  
Rory Palmer MEP
- 14.10-14.20 | PID Diagnostic disparities across EU**  
Peter Jandus, ESID WP Development
- 14.20-14.30 | Presenting ERN-RITA: goals & way forward**  
Johan Prévot, ERN-RITA Board Patient Representative
- 14.30-15.10 | Improving PID diagnosis, through raising awareness on:**
- The diagnostic odyssey from a patient perspective  
Ricardo Pereira, APDIP President
- Newborn Screening in the EU as a way to improve  
PID diagnosis and patient outcome  
Dr Nizar Mahlaoui, Necker Hospital
- When to consider a PID diagnosis and how to use ERNs  
Prof Siobhan Burns, Royal Free Hospital London
- Molecular testing inequalities and how ERNs can address them  
Prof Marielle van Gijn, University Medical Centre Utrecht
- 15.10-15.20 | Future of ERNs**  
Enrique Terol, European Commission, DG SANTE
- 15.20-15.30 | Key recommendations on making ERNs a powerful tool  
to improve rare disease diagnosis**  
Jose Drabwell, IPOPI Chair
- 15.30-15.55 | Discussion**
- 15.55-16.00 | Closing remarks**  
Johan Prévot, IPOPI Executive Director