

IPOPI 12th PID Forum

Rare disease priorities in the European Parliament 2019-2024: the voice of PID patients

Tuesday 27 November 2018 – 16:00-18:00

Room A5E-3, European Parliament Brussels

Moderated by Martine Pergent, IPOPI

16:00	Welcome by José Inácio Faria MEP (EPP, Portugal) – video intervention
16:05	Introductory remarks Sirpa Pietikainen MEP (EPP, Finland) Dr. Anna Zaborska MEP (EPP, Slovakia)
16:15	Rare diseases: what can be improved in the next 5 Years, Johan Prévot, International Patient Organisation for Primary Immunodeficiencies (IPOPI)
16:25	Newborn screening for severe forms of PIDs and other rare diseases, Gerard Loeber, International Society for Neonatal Screening (ISNS)
16:35	Improving diagnosis for rare diseases, Mirjam Van der Burg Leiden University Medical Hospital
16:45	Availability of life-saving therapies: patient's perspectives on areas of improvement <ul style="list-style-type: none"> • France, Martine Pergent, IPOPI • United Kingdom, Susan Walsh, PID UK • Cyprus, Savvas Savva, Cyprus Primary Association and Friends
17:15	Upcoming activities from the Commission Steering group on promotion and prevention, John Ryan, European Commission
17:30	Discussion
17:50	Concluding remarks Roberta Metsola MEP (EPP, Malta)