

IPOPI –750 participants at IPIC2019 and a Call to action on NBS for rare diseases launched at the European Parliament

IPIC2019

IPOPI, the International Patient Organisation for Primary Immunodeficiencies welcomed 750 participants interested in learning more about diagnosis and clinical care of primary immunodeficiencies (PIDs) at IPIC2019, the fourth International Primary Immunodeficiencies Congress, held in Madrid, Spain, at the Hotel Marriot Auditorium, on 6-8 November 2019. **Dr Enrique Terol**, the European Commission representative for European Reference Networks (ERNs), was invited to give the Welcome Address. He provided an overview of the idea behind the creation of the ERNs and shared the challenges that lay ahead, especially the integration in national health care systems and the effective support at hospital level.

IPIC2019's programme featured world-renowned experts in the field of PID as well as other key stakeholders who shared their invaluable experience and unique perspectives on major clinical developments and advances in the field.

The programme engaged international delegates through interactive sessions and pertinent topics, such as, Management of respiratory issues in PID, Novel PID diagnostics, Management of complex PID cases, Regional clinical priorities, Gene therapy developments, Managing PID in adulthood and old age, Ethical issues around PID care and diagnosis, Perspectives on future care and diagnosis developments. **96% of the congress participants stated that IPIC2019 was useful to extremely useful to their professional activity.**

The congress was designed to advance PID clinical care by putting the patients' interest at the centre of all discussions.

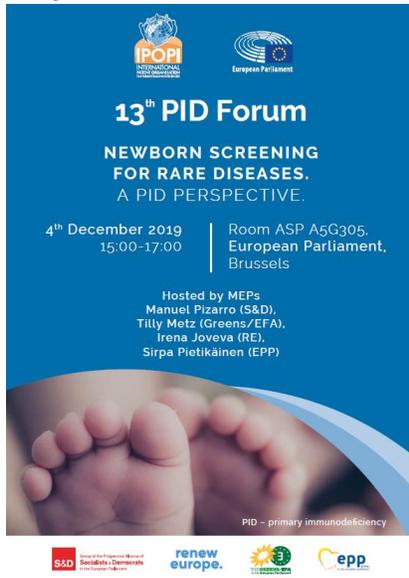
The congress was **endorsed by 37 medical and professional societies** and was granted **12 Continuing Medical Education (CME)** credits by the European Union of Medical Experts. **213 abstract for posters presentation** were approved for the congress, many from young physicians with an interest in PID. The authors of the three best posters were awarded with a monetary prize and given the opportunity to present their work in a dedicated congress session. A series of 8 Guided Poster Walks also featured on the programme, giving numerous additional poster presenters the opportunity to provide flash presentations of their research and engage with delegates.

Martine Pergent, IPOPI President, stated that IPOPI was 'excited to be back in Europe for the 2019 edition of IPIC indicating that IPIC2019 *'aimed to deliver a diverse and stimulating scientific programme focusing on the state of the art in PIDs diagnosis and clinical care.'*

Please watch the IPIC2019 short video [here](#).

IPOPI 13th EU PID Forum launched an NBS for rare diseases Call to action

IPOPI's 13th EU PID Forum was dedicated to "Newborn screening for rare diseases. A PID perspective" and took place on December 4, 2019 at the European Parliament (Brussels, Belgium).



4 Members of the European Parliament (MEPs) co-chaired the event, namely, Dr Manuel Pizarro (Social-Democrats, Portugal), Ms Tilly Metz (Greens, Luxembourg), Ms Irena Joveva (Renew Europe, Slovenia) and Ms Sirpa Pietikainen (European People's Party, Finland). Dr Tudor Ciuhodaru MEP (Social-Democrats, Romania) also actively participated in the meeting. The meeting set up the scene for a strong political debate on the need for newborn screening for rare diseases including crucially severe combined immunodeficiencies as well as other severe forms of PIDs (such as complete Di George syndrome).





A **Call to action**, highly supported by the MEPs present and by the Forum participants was launched. The need for the development and implementation of overarching guidelines in the field of newborn screening for rare diseases and the creation of a European newborn screening standing committee was highlighted. This, to facilitate the exchange of best practices and recommendations on newborn screening and allow national decision-makers to better access information and solid evidence from other Member States.

Mrs Martine Pergent, IPOPI's President, moderated the Forum and gave the floor to the speakers. Dr Pieter Schielen, on behalf of the International Society for Neonatal Screening, and Dr Nizar Mahlaoui, from Necker Hospital and IPOPI's Chair of the Medical Advisory Panel, presented the challenges of newborn screening as well as the medical aspects involved in the screening of newborns and their diagnostic's path. In his closing remarks, Mr Johan Prevot, IPOPI Executive Director stated that "there is an urgent need to improve the mechanisms by which NBS is assessed and adopted by different EU Member States, for all newborn EU citizens including babies born with SCID to have the same access to life-saving preventative programmes" Newborn screening for rare diseases, using SCID as an example, has been the topic of an EU-wide campaign IPOPI is currently working on in close collaboration with the International Society for Neonatal Screening (ISNS) and the European Society for Primary Immunodeficiencies (ESID).

IPOPI is grateful to ISNS representative, Dr Peter Schielen, and to ESID President, Prof Isabelle Meyts, for their presence and contributions to the Forum. A full report of the Forum will shortly be published on [IPOPI's website](#). Stay tuned!