Screen4Rare & MEP Alliance for Newborn Screening for Rare Diseases

Establishing Best Practices – how can newborn screening be supported in the European Union?
29 June 2022, European Parliament (Brussels)
Key facts about the event

• First event by Screen4Rare and the MEP Alliance for Newborn Screening for Rare Diseases

• Organised at the European Parliament in Brussels under the chairmanship of MEP Stelios Kympouropoulos

• Significant interest from KoLs around the world: overall more than 200 registrants

• Participation of around 100 participants in person & online
Key facts about the event

- The event had a **doublefold objective**:
  - Highlight the **relevance** of newborn screening within the EU and how to **move forward for more equitable access**;
  - Introduce the **work** developed by Screen4Rare and the ERNs through the **3 workstreams** and contextualise in a **political context**.

- There will be a **second event** of Screen4Rare and the MEP Alliance for Newborn Screening towards the **end of 2022**.
Key facts about the event

- Speakers & participants were representatives of:
  - European Parliament
  - European Commission
  - Upcoming Czech Presidency of the Council of the EU
  - ERNs
  - Newborn screening experts
  - Medical professionals
  - S4R partnering organisations
  - Patient organisations
Screen4Rare and the EU MEP Alliance for Newborn Screening have our #INSDD22 event today, hosted by MEP @Kyproupolous. Join us to learn about the variations in Neonatal Screening as well as what the EU has on the agenda in the coming months!

Social engagement
Retweets of S4R posts:
- ESID (including colleague accounts)
- IPOPI (including colleague accounts)
- ISNS
- Novartis Ireland
- SMA Europe
- SMA Ireland
- ERN RITA
- AECOM
- MetabERN
- Medical & scientific professionals (personal accounts)
IPOPI activities & projects

- Improve access to early diagnosis & patient-centred care
- Build capacity and support IPOPI’s national member organisations
- Educate, promote knowledge and data sharing
- Strengthen multi-stakeholder collaboration

August 2021