



Newborn Screening saves lives: How could the EU support Member States in the next institutional mandate?

Meeting Report – Recommendation Paper

On 6 November 2024, [Screen4Rare](#) (S4R) founder organisations – International Patient Organisation for Primary Immunodeficiencies (IPOPI), International Society of Neonatal Screening (ISNS), and European Society for Immunodeficiencies (ESID), held an event in Room 5G1 of the European Parliament to discuss the group's recommendations to prioritise newborn screening (NBS) for treatable rare diseases with greater institutional support in the next EU political mandate 2024–2029, and the benefits of the collaboration between S4R and the European Reference Networks (ERNs).

The event, hosted by S4R champion MEP Billy Kelleher (Renew, Ireland) and supported by the participation of MEP András Kulja (EPP, Hungary) representing the S4R MEPs Alliance, fostered dialogue between EU institutions and S4R leaders Johan Prevot (IPOPI), Prof. James Bonham and Peter Schielen (ISNS). Progress of the ERNs' work was also underscored thanks to valuable insights provided by Dr. Andrea Bordugo and Prof. Maurizio Scarpa (ERN MetabERN), and Dr. Alessandra Magnani (ERN RITA).

Important steps towards integrating NBS into national healthcare systems across Europe have been made in recent years. Initiatives like the JARDIN Joint Action and the inclusion of NBS in the 2023 Spanish Presidency Conference on ERNs, underscore growing recognition of this issue.

However, challenges persist in ensuring equitable and sustainable NBS across Member States, one example being that funding gaps hinder the full integration of ERNs into national systems. While more screening does not necessarily mean better screening, there are significant and unwarranted differences in the number of conditions screened across Member States. New advances in genomic sequencing present a crucial opportunity, but sustained EU political support and coordination over the next five years will be essential to realise these possibilities and to avoid further inequity.

Support for these efforts was reaffirmed during recent high-level meetings. Former Health Commissioner Stella Kyriakides expressed her endorsement of S4R's objectives in September 2023. Further, the EU Commission invited S4R to present its goals at the ERN Board of Member States meeting of 22 October 2024, marking an important step in fostering direct dialogue with national policy-makers.

To build on this momentum, S4R, ERNs, and European institutions agree on the following actions:

- **Strengthen S4R dialogue with EU institutions for the inclusion of NBS in the 2024-2029 policy priorities.**
- **Enhance ERN support in NBS through better funding and ERN-led initiatives that align with national needs.**
- **Consider the creation of an EU advice and best practices contact point within the ERN structure to support Member States in strengthening their NBS systems, share best practices, and improve consistency across NBS programs in the EU, while respecting national healthcare autonomy.**

S4R looks forward to building on this work in the next EU institutional mandate 2024-2029. Highlighting the opportunity to promote equitable NBS for treatable diseases through coordinated action and continued support in the EU and beyond will be crucial for our families and babies.