



Screen4Rare celebrates Rare Disease Day on 28 February 2023

The 300 million people worldwide who have a rare condition, as well as their families and caregivers, benefit from Rare Disease Day by increasing awareness and bringing about change.

This campaign is the worldwide coordinated movement on rare diseases, aiming to achieve fairness in social opportunities, healthcare, and access to diagnoses and treatments for those living with a rare condition. Increased equity for those who have a rare disease, and their families is one of the long-term objectives of Rare Disease Day during the coming ten years.

For this reason, Screen4Rare is committed to advocating to raise Newborn Screening (NBS) as a fundamental tool to access to care. NBS is critical to unlock the potential of new developments in genomics and personalized medicine.

In this sense, 2023 will be a key year considering the imminent publication of the new EU Pharmaceutical strategy for Europe - Revision of the EU's legislation on orphan medicinal products and Revision of the EU's legislation on medicinal products for pediatric use. In addition, the Czech and Swedish Presidency of the Council of the European Union have publicly declared their commitment to foster a consensus on a strongly expected EU Action Plan for Rare Diseases.

Screen4Rare is a multi-stakeholder platform which aims to exchange knowledge and best practices on NBS for rare diseases. It was launched by the International Patient Organization for Primary Immunodeficiencies (IPOP), the International Society for Neonatal Screening (ISNS), and the European Society for Immunodeficiencies (ESID).

Join us in celebrating Rare Disease Day today and the next [International Neonatal Screening Day \(INSD\)](#) on 28 June 2023 to support initiatives that call for greater collaboration and discussion on this crucial preventative action for the welfare of new parents, families, and caregivers.

