

Celebrating the second International Neonatal Screening Day (INSD) on June 28 2022

- The International Neonatal Screening Day (INSD) was launched in 2021 to raise awareness of neonatal screening and the potential benefits it can provide worldwide.
- Screen4Rare, composed of the International Society for Neonatal Screening (ISNS), the International Patient Organisation for Primary Immunodeficiencies (IPOPI) and the European Society for Immunodeficiencies (ESID), is behind the INSD initiative, and invites stakeholders across the globe to join the celebration and raise awareness for NBS.
- In 2022, as part of INSD's second celebration, Screen4Rare will organize an event with the European Union's informal MEP Alliance for Newborn Screening (NBS) to highlight the relevance of NBS within the EU and how to move forward to ensure the consistent quality of screening and good outcomes for those children identified as a result.

INSD 2022 is officially on 28 June, 2022. The date coincides with the birthdays of American microbiologist Dr Robert Guthrie and German medical doctor Horst Bickel and thus honors their landmark contributions to neonatal screening.

Screening can identify disorders early in life before the baby becomes ill, providing the chance for treatment which has the potential to have life-long benefits. Newborn screening can offer life changing benefits with one simple, quick procedure – a blood drop taken from the newborn's heel.

Currently, access to newborn screening and its delivery varies considerably in Europe and around the world. Establishing systems to share information about new research, pilot studies and best practices, as well as increasing awareness for patients, providers and policy-makers could have a profound impact on the health of newborns. **To ensure equitable access to high quality screening, we can learn from one another and promote good practices securing the best possible outcome for those children identified by screening.**

To raise awareness of NBS on the European Union (EU) level, as well as consider how the EU can support Member States in using best practices for NBS, Screen4Rare's 2022 INSD event aims to gather interested stakeholders for a discussion on "Improving quality - ensuring the best outcome" throughout the EU.

To celebrate INSD 2022, we invite stakeholders to engage in dialogue about the conduct of newborn screening to enhance quality and improve outcome. By sharing our experience of screening and learning from one another we can work alongside policy makers to deliver life changing benefits for children with rare disorders.

Messages from Screen4Rare's founding organisations:

“During 2021 almost 40,000 babies had their life changed by newborn screening – as we step forward in 2022 we know that new opportunities await with the advent of new technology and new treatments. It is a privilege to take this opportunity to join in a celebration of success and plan for the future – do join us on this journey!” *Prof J R Bonham, President, International Society of Neonatal Screening (ISNS)*

“The International Neonatal Screening Day is a celebration of all the opportunities that a good quality screening can bring to the lives of babies affected by a rare disease, such as severe combined immunodeficiency (SCID) where treatment exist. We invite all interested stakeholders to join us on INSD 2022 and raise awareness about the many benefits and the need for equitable access to newborn screening.” *Ms Martine Pergent, President, International Patient Organisation for Primary Immunodeficiencies (IPOPI)*

“The International Neonatal Screening Day is an opportunity to highlight the successes and challenges of newborn screening for rare diseases, in particular SCID. ESID is committed to work within Screen4Rare to raise further awareness and to build for the future in terms of new screening technologies and to prepare for new treatment modalities.” *Prof. Dr. I. Meyts, President, European Society for Immunodeficiencies (ESID)*

For more information and to [contact us](https://neonatalcreeningday.org), please visit the INSD website at [neonatalscreeningday.org](https://neonatalcreeningday.org).