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PRESS RELEASE

Screen4Rare launches campaign celebrating 60 years of newborn screening

Brussels, 28 March 2023 - Three months to go! Screen4Rare prepares to mark 60 years of progress on International Neonatal Screening Day on 28 June 2023. Neonatal screening is a game-changer for children with severe and occasionally life-threatening disorders in terms of timely diagnosis and appropriate treatment.

Empirical data currently available from global neonatal screening programs and trials shows unequivocally that early asymptomatic detection made possible by neonatal screening, when connected to proper therapy, can be life-changing or even lifesaving. Most national programs include screening for some conditions such as phenylketonuria (PKU) or congenital hypothyroidism (CH), but, despite growing attention over the past decade, the implementation of screening for other conditions such as severe combined immunodeficiencies (SCID) or spinal muscular atrophy (SMA) is more limited.

For this reason, Screen4Rare is committed to leading the International Neonatal Screening Day (INSD) initiative. This is crucial to raise awareness about the critical role of neonatal screening in accessing timely treatment and saving lives, to consider scientific advances in screening programmes, to support information exchange mechanism, data, and expertise on neonatal screening, and to assess the benefits for patients and the healthcare system at large.

INSD is a fantastic chance to spread the word about how crucial neonatal screening is for hastening diagnosis and treatment around the globe. For this reason, on June 28, we will honor the foresight of those who made neonatal screening possible.

This will inspire a new generation of stakeholders to expand neonatal screening's advantages to more children who are suffering from a wider range of disorders.

INSD is an initiative led by the International Society for Neonatal Screening (ISNS), the International Patient Organization for Primary Immunodeficiencies (IPOPI) and the European Society for Immunodeficiencies (ESID), which have been working in partnership under the multi-stakeholder Screen4Rare initiative to promote the importance of neonatal (newborn) screening

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

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About Screen4Rare:

Screen4Rare is a multi-stakeholder platform launched by the International Patient Organisation for Primary Immunodeficiencies (IPOPI), the International Society for Neonatal Screening (ISNS), and the European Society for Immunodeficiencies (ESID) aiming to exchange knowledge and best practices on NBS for rare diseases. The group's ultimate objective is, through policy engagement, to work towards ensuring that all babies can have equitable access to newborn screening; a life-saving tool for conditions such as SCID.

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<https://neonatalscreeningday.org/>



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