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102,000 NEWBORNS COULD BE SAVED EVERY YEAR IF PROPER SCREENING WERE IN PLACE – CELEBRATING INTERNATIONAL NEONATAL SCREENING DAY

Brussels, 28 June - Every year, more than 38,000 newborns benefit from a life-changing diagnosis enabled by neonatal screening, but over 100,000 newborns with rare diseases do not have access to any form of screening at birth. Today, Screen4Rare commemorates International Neonatal Screening Day (INSD) to highlight the immense impact of neonatal screening, a life-changing tool that allows for the early detection of rare diseases and timely access to treatment and care.

On the occasion of INSD, Screen4Rare honours those who provide life-changing, and sometimes life-saving, improvements to newborn babies with treatable rare diseases by calling on decision-makers across the world to prioritise and promote equity of access for all newborns.

Taking place on the birthday of Dr Robert Guthrie, a microbiologist who revolutionised the field of neonatal screening, this year's celebrations mark 60 years of progress in neonatal screening.

Neonatal screening is a healthcare programme of the highest importance that allows for the early detection and treatment of rare diseases by testing newborns for a range of inherited conditions. In 2021, it helped identify rare diseases in 1 out of every 10,000 babies that were screened. This amounts to a diagnosis every 15 minutes and approximately 38,000 infants receiving timely access to essential treatment as a consequence of the test.

However, only 1 in 3 newborns worldwide undergo any form of screening while many infants are only screened for a limited number of conditions. There is an urgent need to enhance access to neonatal screening globally and eliminate inconsistencies between screening programmes.

Commenting on the awareness day, Professor Jim Bonham, President of the International Society for Neonatal Screening (ISNS) and one of Screen4Rare's founding members, said:

"International Neonatal Screening Day provides a great opportunity to celebrate the life-changing benefits offered by neonatal screening. In Europe, we hope to help decision makers recognise that the EU is perfectly positioned to drive cross-border collaboration on rare diseases and extend the benefits of neonatal screening to future generations by providing equity of access to all European newborns."

With the European elections just around the corner, Screen4Rare calls on the EU to support improvements in the field of neonatal screening programmes and help alleviate the global burden of rare diseases.

By allocating resources, supporting collaborative European networks, developing comprehensive screening programmes and ensuring access to them, governments across the world can take advantage of this significant public health achievement and continue saving the lives of babies.

For more information, please contact:

Johan Prevot

Executive Director, IPOPI
johan@ipopi.org

Jim Bonham

President, ISNS
j.bonham@nhs.net

Fabio Candotti

President, ESID
fabio.candotti@chuv.ch

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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