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PRESS RELEASE

Rare Disease Day: Neonatal screening for rare diseases could save more than 100,000 newborns each year

Brussels, 29th February - Today, on the occasion of Rare Disease Day, Screen4Rare highlights the importance of neonatal screening for those living with a treatable rare disease. Neonatal screening is one of the most successful public health programmes that allows for the early detection and treatment of rare diseases by testing newborns for a range of inherited conditions.

Research has shown that early asymptomatic detection through neonatal screening, when connected to proper therapy, can be life-changing and even lifesaving for many children born with rare disorders. In 2021, 38,000 babies were identified with a rare disease as a result of newborn screening and received timely access to their treatment. This accounts for 1 baby every 15 minutes.

102,000 newborns could be saved globally from death or life-altering illnesses each year if proper screening tests and treatment were in place. Despite its undeniable importance, only one in three 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 ensure equitable and quality access to neonatal screening globally and help making best practice become common practice.

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

"Rare Disease Day presents an opportune moment for us to underscore the importance of the INSD initiative. It's a prime occasion to spread the word about how crucial neonatal screening is for hastening diagnosis and treatment for those living with a treatable, rare disease. As part of the initiative, we hope to help decision makers understand the benefits of neonatal screening to future generations by providing equity of access to all newborns."

Join us in observing Rare Disease day today, and marking your calendars for the forthcoming International Neonatal Screening Day (INSD) on June 28. Together, let's raise awareness and advocate for equitable access to early detection and treatment for all infants worldwide.

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/ @Screen4Rare

#InternationalNeonatalScreeningDay