

28.06.2024

# PRESS RELEASE

## International Neonatal Screening Day

Calling for Global Implementation of Neonatal Screening Programmes

Brussels, 28 June 2024 - Today, on International Neonatal Screening Day (INSD), Screen4Rare calls on governments worldwide to develop universal neonatal screening programmes aligning with the World Health Organization's (WHO) [resolution](#) on reducing maternal, newborn and child mortality.

The WHO's provision on neonatal screening could be transformative for children around the world with treatable rare diseases. For current and future generations neonatal screening is not merely a test; it can be a life-changing public health intervention that has the power to diagnose and treat disorders at their earliest stages.

Despite public health [becoming](#) a priority concern for many citizens, global access to this cost-effective intervention remains out of reach for many. Currently, only one in three babies undergo any form of screening at birth.

A simple heel-prick test, if universally implemented and accompanied by proper treatment, could help over 100,000 newborns annually and significantly improve their long-term outcome.

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

*"Addressing the challenges posed by rare disease requires collaboration and cohesion that transcends national borders. With citizens worldwide participating in elections this year, we remain hopeful that the importance of protecting the health and well-being of our children will remain a priority. Recent advances in diagnosis and treatment provide new opportunities to improve lives and the WHO's reference to newborn screening serves as a timely reminder to take advantage of this potential."*

We urge governments to carefully consider the role of newborn screening in public health policy and extend the benefits of this life changing intervention to many more children in 2024.

***For more information, please contact:***

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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.

**FIND OUT MORE**



[www.neonatalscreeningday.org](http://www.neonatalscreeningday.org)



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