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PRESS RELEASE

One year after the WHO Resolution on Rare Diseases: Accelerating access to neonatal screening worldwide

Brussels, 28 June 2026 – On this International Neonatal Screening Day (INSD), **Screen4Rare** calls on governments, health authorities, and international organisations to accelerate the implementation and expansion of universal neonatal screening programmes, one year after the adoption of the World Health Organization's (WHO) [Resolution on Rare Diseases: a Global Health Priority for Equity and Inclusion](#).

The landmark WHO resolution recognised the importance of early diagnosis and timely intervention for people living with rare diseases and highlighted the need for equitable access to healthcare services worldwide. One year later, Screen4Rare welcomes the growing momentum around neonatal screening but stresses that much more remains to be done to ensure that every newborn benefits from early detection of treatable rare conditions.

"Neonatal screening is one of the most effective public health measures available today. It enables early diagnosis, timely treatment, and better health outcomes for children with serious but treatable conditions," said **Johan Prevot**, Executive Director of the International Patient Organisation for Primary Immunodeficiencies (IPOPI). "The WHO resolution provided a clear mandate for action. We now need governments to translate that commitment into concrete national policies and sustainable screening programmes."

Neonatal screening has transformed the lives of countless children and families by identifying conditions before symptoms appear. Early diagnosis can prevent severe disability, avoid irreversible complications, and, in many cases, save lives. Despite these benefits, significant disparities in access remain across and within countries.

"Every newborn should have the same opportunity to benefit from early detection, regardless of where they are born," said **Jim Bonham**, President of the International Neonatal Screening Society (ISNS). "While important progress has been made over the past year, millions of babies are still not screened for conditions that are detectable and treatable at birth. Improving access to appropriate and well organised neonatal screening remains an urgent global health priority."

Building on recent progress

Over the past year, several countries have continued to strengthen and expand their neonatal screening programmes. The inclusion of Severe Combined Immunodeficiency (SCID) in national screening programmes in countries such as Portugal and France marks an important milestone in ensuring that children with this life-threatening condition can receive timely treatment. Similar efforts are underway in multiple regions around the world, demonstrating growing recognition of the value of neonatal screening as a cornerstone of preventive healthcare.

At the same time, advances in screening technologies and treatment options are creating new opportunities to identify a wider range of rare diseases early and improve long-term outcomes for affected children and their families.

Fabio Candotti, President of the European Society for Immunodeficiencies (ESID), highlighted the impact of early detection: "For conditions such as SCID, every day counts. Early diagnosis through neonatal screening allows healthcare professionals to intervene before serious infections occur, dramatically improving survival and quality of life. The progress we are witnessing is encouraging, but we must ensure that these advances reach all newborns everywhere."

From commitment to action

As the international community reflects on the first year since the adoption of the WHO resolution, Screen4Rare calls for renewed commitment to:

- Expand access to equitable and evidence-based neonatal screening programmes;
- Strengthen national policies and sustainable funding mechanisms;
- Promote international collaboration and the sharing of best practices;
- Support the integration of new screening technologies and validated conditions;
- Ensure timely access to diagnosis, treatment, and follow-up care for all identified newborns.

On this International Neonatal Screening Day, Screen4Rare reaffirms its commitment to working with policymakers, healthcare professionals, patient organisations, and international partners to make neonatal screening accessible to every child.

Together, we can turn the promise of early diagnosis into a reality for all newborns—ensuring that every child, regardless of where they are born, has the opportunity for a healthier future.

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About: 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 neonatal screening; a life-saving tool for conditions such as SCID.

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