Screen4Rare celebrates Rare Disease Day on 28 February 2022

Rare Disease Day raises awareness and generates change for the 300 million people worldwide living with a rare disease, their families and carers.

This campaign is the globally coordinated movement on rare diseases - working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease. One of the long-term goals of Rare Disease Day over the next decade is increased equity for people living with a rare disease and their families.

In light of this, Screen4Rare advocates the importance of newborn screening (NBS) as a key element to access to care. 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 Severe combined immunodeficiency (SCID).

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.

Screen4Rare warmly encourages all interested stakeholders to support Rare Disease Day initiatives, and join in calling for increased collaboration and discussions on this key preventative measure for the wellbeing of newborns, families and carers.

Furthermore, stay tuned for other similar awareness campaigns such as the upcoming International Neonatal Screening Day (INSD) held on the 28 June 2022.