**Establishing Best Practices – how can newborn screening be supported in the European Union?**

**International Neonatal Screening Day 2022 Event**

**June 29th, 15.00 to 17.00 CEST, European Parliament, Brussels & virtual**

**International Neonatal Screening Day**

The International Neonatal Screening Day (INSD) was launched in 2021 to raise awareness of neonatal screening and the potential benefits it can provide worldwide. This year, as part of the celebration, Screen4Rare will organize an event with the MEP Alliance for Rare Disease Newborn Screening (NBS) to highlight the relevance of NBS within the EU and how to move forward for more equitable access.

You can register for the event, to attend either in person in Brussels or virtually, [here](https://forms.office.com/Pages/ResponsePage.aspx?id=5LJAWkDRpUKiid1kkOMNHbQ-NGfFFIJNpXoGxvPwhupUQ0tLQ0U2TUtERENMT0FVVE1LQjFFSUtSUS4u).

**Concept**

INSD 2022 is officially on 28 June, 2022. The date coincides with the birthdays of American microbiologist Dr Robert Guthrie and German medical doctor Horst Bickel and thus honors their landmark contributions to neonatal screening.

To raise awareness of NBS on the EU level, as well as consider how the EU can support Member States in using best practices for NBS, this event aims to gather interested stakeholders for a discussion on “Establishing Best Practices – how can newborn screening be supported in the European Union?”

Screening can identify treatable illnesses as early as possible to ensure rapid treatment, which has the potential to have life-long benefits. Screening for diseases with a known treatment can therefore improve the well-being and outcomes of a child’s life with only a simple, quick procedure – a blood drop taken from the newborn’s heel.

Currently, practices surrounding NBS are fragmented throughout the EU. This prevents the potentially life-saving tool from being equitably accessible throughout the Union. Establishing systems to better share information regarding new research, pilot studies and best practices, as well as increasing awareness for patients, providers and policy-makers could have a profound impact on the health of newborns. To reach equitable access, all stakeholders must come together to advocate for better practices that are transparent and originate from a robust evidence base.

**Agenda**

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| Introductions & welcome  *MEP Stelios Kympouropoulos & Johan Prevot, IPOPI, Screen4Rare* |
| What is the current state of newborn screening in Europe?  *Prof. Jim Bonham, ISNS, Screen4Rare* |
| Screen4Rare: An Overview of Activities  *Dr. Fabio Candotti, ESID, Screen4Rare* |
| What is the current EU standpoint on NBS?  *Prof. Milan Macek, NBS advisor to the Czech Council Presidency (tbc)* |
| How can the EU better support NBS: Roundtable discussion  *Dr. Jose Valverde, European Commission, DG SANTE Unit B3*  *Prof. Jim Bonham, ISNS, Screen4Rare ERN Expert Platform on NBS*  *Dr. Mirjam van der Burg, Leiden University Medical Center, Screen4Rare ERN Expert Platform on NBS*  *Prof. Maurizio Scarpa, MetabERN, Screen4Rare ERN Expert Platform on NBS* |
| Conclusions  *MEP Stelios Kympouropoulos* |

**Hybrid Event Details**

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We are happy to welcome attendees to the European Parliament in Brussels to attend in person, if this is available to them. Virtual attendees will be able to watch a livestream of the event as well as submit questions and comments.

Further details regarding in person attendance will be shared with those who identify in-person on the registration form**. Importantly, for Parliamentary events you must register in advance such that the proper accreditation information can be shared for security purposes**. As such, please register as soon as possible.