



Screen4Rare & MEP Alliance for Newborn Screening for Rare Diseases



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

29 June 2022, European Parliament (Brussels)

Screen4Rare founding organisations:



Key facts about the event

- First event by **Screen4Rare** and the **MEP Alliance for Newborn Screening for Rare Diseases**
- Organised at the European Parliament in Brussels under the chairmanship of **MEP Stelios Kympouropoulos**
- Significant interest from KoLs around the world: overall more than **200 registrants**
- Participation of around **100 participants** in person & on-line



Key facts about the event

- The event had a **doublefold objective**:
 - Highlight the **relevance** of newborn screening within the EU and how to **move forward for more equitable access**;
 - Introduce the **work** developed by Screen4Rare and the ERNs through the **3 workstreams** and contextualise **in a political context**.
- There will be a **second event** of Screen4Rare and the MEP Alliance for Newborn Screening towards the **end of 2022**.



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](#).

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.

Key facts about the event



- Speakers & participants were representatives of:
 - European Parliament
 - European Commission
 - Upcoming Czech Presidency of the Council of the EU
 - ERNs
 - Newborn screening experts
 - Medical professionals
 - S4R partnering organisations
 - Patient organisations

Agenda

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, Chairman National Coordination Centre for Rare Diseases – UH Motol, Prague, Czechia

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

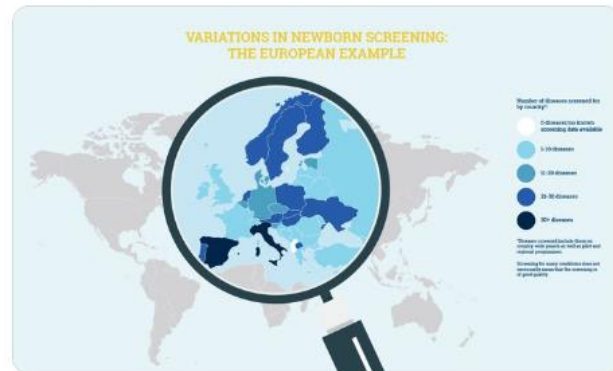
MEP Stelios Kympouropoulos

Social engagement



Screen4Rare and the EU MEP Alliance for Newborn Screening have our [#INS2022](#) event today, hosted by MEP [@Kypouropoulos](#). Join us to learn about the variations in [#neonatalscreening](#) as well as what the EU has on the agenda in the coming months!

Traducir Tweet



Screen4Rare lo retweeted



ERN-RITA @ERNRITA · 28 jun.

ERN-RITA is celebrating this 2nd [#INS2022](#) and is strongly committed in 3 task forces that address the topic with the objective of tackling the discrepancies throughout the European Union and broader!



International Society for Neonatal Screening... @ISNSNeona... · 30 jun. ...
Our week of celebrating [#InternationalNeonatalScreeningDay](#) has come to a close. Thanks to [@Screen4Rare](#), [@ESIDmeeting](#), [@ISNSNeonatal](#), [@ipopipid](#), and all who joined us in raising awareness about the life-saving benefits of [#neonatalscreening](#). See you next year on June 28th!



Screen4Rare v 2 más

International Neonatal Screening Day Event 29th of June 2022

Home / About ESID / International Neonatal Screening Day Event 29th of June 2022

International Neonatal Screening Day Event 29th of June 2022

Dear Colleagues,

On behalf of Screen4Rare, we have the pleasure of inviting you to the International Neonatal Screening Day (INS2022) Event, "Establishing Best Practices – how can newborn screening be supported in the European Union?," hosted in collaboration with the [MEP Alliance for Rare Disease Newborn Screening \(NBS\)](#).

The event will be taking place in hybrid format, both in the European Parliament as well as online, on Wednesday, 29th June, 15.00 to 17.00 CEST.

Should you be interested in participating, either in person or virtually, please do not hesitate to register by clicking [here](#). You can find the agenda and additional information [here](#).



Become an E today!



Screen4Rare lo retweeted

Health First Europe @HealthFirstEU · 30 jun.

A warm thanks to our member [@ipopi_info](#) and [@Screen4Rare](#) for inviting Health First Europe to a successful meeting at [@Europarl_EN](#) to discuss the importance of [#newbornscreening](#) and [#equitableaccess](#) across the EU!



IPOPI @ipoppi_info · 29 jun.

A sincere thank you to MEP host [@Kypouropoulos](#), [@Screen4Rare](#), EU MEP Alliance for Newborn Screening, and other valued participants for a great [#INS2022](#) meeting! We are looking forward to the resulting outcomes following key discussions on [#neonatalscreening](#) in the EU.

Screen4Rare @Screen4Rare · 29 jun.

Our [#InternationalNeonatalScreeningDay](#) event – and week of celebrations – have come to an end, with MEPs and [#INS2022](#) partners underlining the importance of including [#neonatalscreening](#) in upcoming policy.

Mostrar este hilo



S. Kypouropoulos @Kypouropoulos · Jun 27

On 29th June, I will be hosting the MEP Alliance for Newborn Screening & [@Screen4Rare](#)'s [#InternationalNeonatalScreeningDay](#) event.

Join me to raise awareness for this life-saving tool & discuss how to establish best practices in the EU!

Register here: [bit.ly/3xUAPoq](#)

Screen4Rare lo retweeted



SMA-Europe @SMAEurope · 29 jun.

Today, from [@SMAEurope](#) we attend the event organised by [@Screen4Rare](#) and the EU MEP Alliance for Newborn Screening, hosted by MEP [@Kypouropoulos](#) Join us! [#INS2022](#) [#SpinalMuscularAtrophy](#) [#RareDisease](#)

1

4

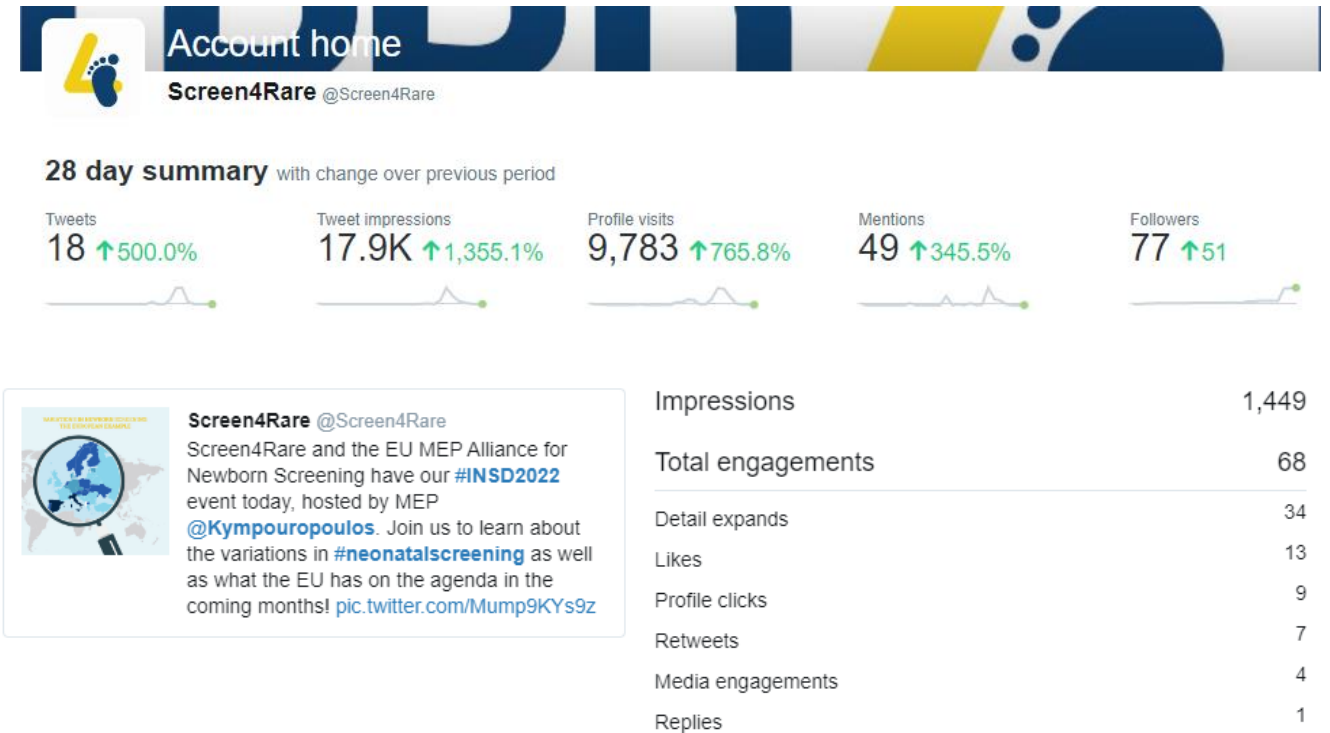
11



S4R Twitter snapshot

- **Retweets of S4R posts:**

- ESID (including colleague accounts)
- IPOPI (including colleague accounts)
- ISNS
- Novartis Ireland
- SMA Europe
- SMA Ireland
- ERN RITA
- AECOM
- MetabERN
- Medical & scientific professionals (personal accounts)





Improve access to early diagnosis & patient-centred care



Build capacity and support IPOPI's national member organisations



Educate, promote knowledge and data sharing



Strengthen multi-stakeholder collaboration