neonatalscreeningday.org

JOIN THE CELEBRATION!

INTERNATIONAL NEONATAL SCREENING DAY

JUNE 28

2022

WHAT IS INSD?

On 28th June we are celebrating International Neonatal Screening Day! Neonatal screening is a life changing tool that allows for early detection of rare diseases and timely access to treatment and care.

For more information and to participate in the campaign visit:

http://neonatalscreeningday.org/

https://twitter.com/Screen4Rare

WHY AN INSD?

Raise awareness about the critical role of neonatal screening in accessing timely treatment and saving lives

Consider scientific advances in screening programmes

Support information exchange mechanism, data and expertise on neonatal screening

Assess the benefits for patients and the healthcare system at large

Early detection of rare diseases via neonatal screening, before symptoms appear and when linked to appropriate treatment - can be life changing and even lifesaving!

Committed to

GIVING NEWBORNS A BETTER CHANCE AT LIFE FROM BIRTH

140 million babies
are born worldwide annually

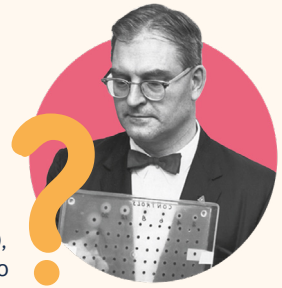
Unfortunately, only about **1 of 3 newborns receive screening** of any type and many babies are only screened for one or two conditions

~102,000
more newborns
could be saved globally from death or life-altering aliments each year if proper screening tests and treatment were in place.

NEONATAL SCREENING FACTS

- 745M babies have been screened for Phenylketonuria (PKU) since screening began in the US in the 1960s.
- 62,000 babies with PKU have been identified since and have had access to a life changing treatment.
- 38M babies were screened at birth in 2021, that is approximately 27% of the babies born in the world.
- 38,000 babies were identified with a rare disease as a result of the screening in 2021 and received timely access to their treatment. This accounts for 1 baby every 15 minutes.

WHY JUNE 28?



June 28th celebrates Dr Robert Guthrie's birthday (June 28, 1916 – June 24, 1995), a microbiologist who introduced the paper blood spot card and a new assay to screen newborns for PKU in the United States in the 1960s.

His work and activities revolutionised the detection of children with inborn conditions, enabling the improvement of children's health. Dr Guthrie dedicated his life to raise awareness of the need for neonatal screening for treatable conditions.

NEWBORN SCREENING IS A PROCESS

All of these steps ideally occur within 1 week to facilitate early diagnosis and treatment

EDUCATING FAMILY AND COLLECTING THE SPECIMEN

TESTING THE SPECIMEN

GIVING RESULTS TO THE FAMILY AND HEALTHCARE PROVIDERS

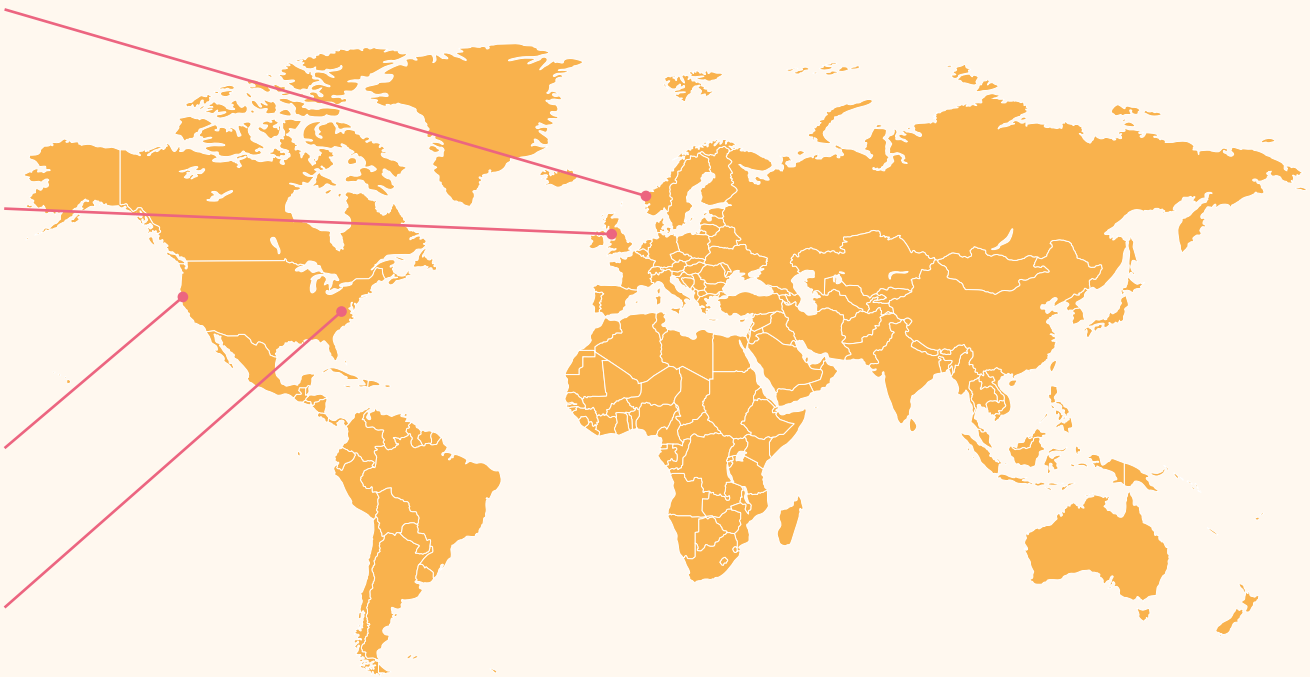
PKU, NEONATAL SCREENING, AND THE ROLE OF ADVOCACY

1934: Norwegian mother, Borgny Egeland and her children, were the principal characters in the "story" involving her physician, Dr Asbjörn Fölling, to understand the cause of her children's intellectual disability - **led to discovery of PKU**

1951: The pioneers in discovering the first treatment for PKU were a two-year-old called Sheila Jones, her mother Mary, and three dedicated professionals at Birmingham Chirldren's Hospital: Evelyn Hickmans, John Gerrard and Horst Bickel - **led to creation of phe-free formula**

1957: Physician and father of child with intellectual disability, Dr. Willard Centerwall, discovers "diaper test" for PKU

1958-61: Dr. Robert Guthrie develops and refines bacterial inhibition assay for detection of PKU at birth



INSD EVENTS

Raise awareness throughout the world about the importance of neonatal screening with your own event. We invite you to share your activities through the INSD website as well as explore other 2022 happenings which are taking place.

We honour the many positive past achievements in what is just the beginning of global celebrations for INSD!

JOIN THE screen4rare INITIATIVE

The INSD is an initiative led by the International Society for Neonatal Screening (ISNS), the International Patient Organisation for Primary Immunodeficiencies (IPOPI) and the European Society for Immunodeficiencies (ESID), which have been working in partnership under the multi-stakeholder Screen4Rare initiative to promote the importance of neonatal screening.

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