

My name is Nicole Pasterczyk and I am a Lehigh University student and a UN Youth Representative for the Australian NGO CLAN and the @MATES4Kids movement. I am also the sister of a sibling living with a rare non-communicable disease, phenylketonuria (PKU), diagnosed by newborn screening (NBS).

A non-communicable disease, or NCD, is a long term health condition that does not spread from person-to-person. Examples include Type 1 diabetes, cancer, asthma, congenital hypothyroidism, PKU, cystic fibrosis and congenital adrenal hyperplasia.

It is estimated that 1 in 4 children live with an NCD. The CDC notes NCDs account for 41 million deaths each year with about 85% in low/middle-income countries. These inequities can be attributed to delayed diagnosis and limited access to medicines, healthcare and social services.

Access to NBS plays an important role in diagnosing many childhood NCDs so that treatment can be started before adverse effects develop. NBS Programs are universally available in high-income countries, including heel-prick blood tests, hearing tests and pulse oximetry checks.

NBS can overcome economic/social inequities as it does not discriminate against babies on the basis of gender, ethnicity or economic status when universally available. NBS meets WHO criteria: it is cost-effective, acceptable, available, and safe.

Rapid scaling of NBS is possible. For instance, the Indonesian Minister of Health has committed to scaling NBS to 90% coverage by the end of 2024 - efforts are so far on track, with this upper-middle income country already scaling newborn screening coverage from just 2.3% of newborns in 2022 to 65% by the end of 2023. These are remarkable achievements, given Indonesia is a vast archipelago, with the 5th highest birth rate in the world (4.8 million babies annually).

Cost benefit analyses show that administrations that cover NBS costs reap benefits in reduced developmental delay/disability. For equitable scaling of NBS, Universal Health Coverage is essential. Families living in vulnerable situations are less likely to be forced into making life-and-death decisions about how to spend limited resources when screening and treatment are affordably available.

Globally, 40 million babies are born annually, yet only $\frac{1}{3}$ receive screening. It is unacceptable that NBS is not uniformly available.

My question is: how to we prepare for the Summit of the Future 2024, the UN HLM on Noncommunicable Diseases in 2025, and lead up to the SDGs in 2030, to scale universal coverage of NBS so that we #LeaveNoChildBehind?