



WORLD PATIENT SAFETY DAY: NEWBORN SAFETY STARTS WITH NEWBORN SCREENING

September 17 is World Patient Safety Day and this year the World Health Organization (WHO) is drawing attention to maternal and newborn safety. Newborn safety starts with newborn screening.

The [Fourth Australian Atlas of Healthcare Variation](#) highlights the need for change in our health system where ‘variation in the use of health services is due to...differences in access to care’. It notes that such ‘differences in access to care... is unwarranted variation and represents an opportunity for the health system to improve’.

[Better Access Australia](#) (BAA) is calling on the federal government to heed the advice of its own advisers and fix newborn screening as part of a bi-partisan election commitment.

“Better Access Australia welcomes the WHO highlighting the importance of maternal and newborn safety. In line with September being global newborn screening awareness month, there has never been a better day to stop and demand governments make start of life as much of a priority as end-of-life treatment” BAA board member Helen Innes said.

“Newborn screening is the one of public health’s great success stories. It’s a tragedy that Australia’s newborn screening programs subjects our children to a postcode lottery and a 1980’s standard of care when 2021 treatments are available.

“A child in Perth is screened for one disease, another in Sydney and neither of them in Melbourne. No Australian baby should be discriminated against because of their postcode. Governments’ own reporting tells us this is not good enough.

“It’s not the way we would treat a cancer patient and it’s not the way we should treat our newborns.

“Then there’s the multiple other rare diseases none of Australia’s babies are screened and yet we have treatments available today. Why do other countries better protect their newborns than Australia? How is that a world-class health system?

“Parents should not be grieving for their child because they gave birth in an Australian hospital that does not screen for the same conditions offered in another or tragically, not screened for at all.

“How many patient groups right now are individually lobbying their state governments to help protect children against one disease? 50 diseases, across 8 states, individual by individual. Mostly all rejected. It’s not good enough. Ms Innes said.

“The inability for a baby with Spinal Muscular Atrophy, Pompe Disease or Sickle Cell Disease (or many other rare diseases) to access life-saving, critical care in a timely manner exemplifies the failure of the Australian healthcare system that must be addressed.

“Look at the lifechanging breakthroughs we have in the treatment of cystic fibrosis in Australia, because we screen for it at birth and in every state and territory. We want that opportunity for all treatable rare diseases and an end to the postcode lottery.

“821 babies will be born in Australia on World Patient Safety Day. If Australia wants newborn safety, we need universal and updated newborn screening. The best armour

against rare diseases comes with an iron-clad newborn screening program. The current postcode lottery and decades-old program leaves all Australian babies unprotected. Let's fix that before the next Healthcare Variation Atlas is issued." Ms Innes concluded

"We ask all in the community today to take five minutes to sign our [petition](#) to secure the safety of our newborns regardless of where they live and regardless of the disease they need to be screened for.

On **World Patient Safety Day** Better Access Australia, is calling on the Morrison Government and Opposition to make the following election commitment:

1. Conduct a six-month independent review of the clinical evidence of 50+ conditions already approved in the US and Europe to be added to Australia's newborn screening program, with the goal of bringing the program into the 21st century.
2. Include the funding of the recommended testing in the federal-state Hospital Pricing Agreements. The buck passing between state and federal governments must stop. We need a shared commitment to the future health of babies born in Australia.
3. Include a timetable for inclusion of genetic testing of newborns in these same agreements at a population and individual level, starting with the babies who receive a positive result from a newborn screening test. Newborn screening is the gateway to more complex and expansive genetic screening and Australia must not allow another 30-year gap in its health system to be accepted.

Media Contact: Timothy Davies –

P: 0466 640 539 E: tdavies@betteraccessaustralia.org.au