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Money for just 12 hours of COVID testing would save tiny lives each year

An opportunity to save children's lives and prevent heartbreak rests in the hands of Federal politicians who are being urged to update Australia's newborn screening program to ensure babies with up to 75 rare, yet treatable diseases are diagnosed at birth.

Better Access Australia Chair Felicity McNeill PSM is calling on politicians ahead of the Federal Election to provide a cast-iron, bipartisan commitment to modernise Australia's national newborn screening program which was last updated almost 25 years ago.

"Australia's newborn screening program remains stuck in the 1980s, with no new conditions added to the national program for three decades, which means doctors are often unable to take advantage of medical breakthroughs to save tiny lives," she said.

"I urge Federal politicians to imagine they are a parent finding out that their baby has a rare disease months or years down the track, having missed out on diagnosis and life-saving treatment shortly after birth.

"Time to diagnosis matters. Every week that goes by without screening and diagnosis means vulnerable babies being ravaged by treatable conditions and lives lost. Australia urgently needs a 21st century newborn screening program," Ms McNeill said.

"Modernising the national screening program is an easy change for politicians to back that will dramatically improve countless lives and prevent heartbreak and suffering by enabling swift diagnosis and timely treatment.

"Testing all 300,000 newborns for an additional 50 conditions would cost just $3 million a year. This is small change for the Federal Government – the same amount we spend on COVID-19 testing every 12 hours.

"If Government can spend an eye-watering amount on COVID testing each day then they can afford the paltry sum required to diagnose tiny Australians so they can access life-saving treatments, including those that have just been added to the PBS," Ms McNeill said.

Last updated in the 1980s, Australia's national newborn screening program provides a quick and definitive diagnosis for 25 conditions – however, the program has failed to keep pace with medical advances or with overseas practice. In parts of the United States, babies are screened for 80 genetic conditions, 76 of which have treatments.

Perinatal and congenital conditions are the leading cause of death for girls aged under 14 years and the third highest for boys.[1]

Better Access Australia is calling on politicians to ensure the national newborn screening program is robust and ends the cruel lottery of differences in newborn testing across Australia.

"It's a travesty that a baby born in Tweed Heads can be screened at birth for spinal muscular atrophy, but a baby born on the Gold Coast with this same condition will miss out on early

diagnosis. No one should miss out on critical screening and treatment because of the state that they are born in," Ms McNeill said.

With new treatments for Pompe disease on the November Pharmaceutical Benefits Advisory Committee agenda, and multiple new genetic therapies already on our doorstep, the time for Australia's newborn screening program to catch up with the treatments it is the gateway of access to is now.

"Australians are being failed by an antiquated screening program which serves to delay diagnosis, causing irreparable damage, and worse still, is entirely avoidable. Enough is enough.

"Babies with rare diseases don't have the luxury of time. We need a 21st century national newborn screening program now, because without diagnosis there is no treatment," Ms McNeill concluded.

Ahead of the next Federal Election, Better Access Australia is calling on the Morrison Government and Opposition to back the following:

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.

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.

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Reference:

1. Australian Institute of Health and Welfare (AIHW). Life expectancy
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(girls) https://www.aihw.gov.au/reports/men-women/female-health/contents/how-healthy/life-expectancy-and-mortality
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