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FEDERAL BUDGET FAILS 300,000 BABIES

Tuesday's federal Budget has failed to deliver what Australian babies need most – a contemporary, universal newborn screening program.

"The Government's listing of a gene therapy for Spinal Muscular Atrophy Types 1 and 2 (SMA) should be cause for congratulations, but the sad reality is that two out of three babies that would benefit from this treatment will suffer irreparable damage due to delays in diagnosis because of Australia's postcode lottery for newborn screening. Better Access Australia Chair Felicity McNeill said

"With only NSW and ACT screening for SMA, the 200,000 babies born anywhere else in Australia will miss out on early diagnosis and treatment. When time to diagnosis matters both for ensuring the best response to treatment, and in some instances qualifying for access to treatment, the risk of no access to this 'life-saving and life-changing' treatment is unfortunately going to be the reality for most babies born in Australia with SMA.

"And unfortunately, this story is not unique to SMA with dozens of other lifesaving treatments available to treat many diseases available in Australia today but not included in newborn screening."

Australia only screens nationally for 25 diseases. This compares to California that screens for 80 diseases, of which 76 have treatments.

"Too often, by the time a baby is diagnosed in Australia, irreparable cognitive or physical deterioration has already occurred, often leading to death. Ms McNeill said

"As Joh, a mum of two has told us

> *'I lost my firstborn son because newborn screening in Australia does not currently include Severe Combined Immunodeficiency (SCID), despite the rest of our industrialized neighbours having it. An updated newborn screening would have meant my son would be alive today. Because we knew about it in my second child we were able to save his life and he is a thriving toddler now.' "*

Newborn screening tests that cost a few dollars per baby are saving tiny lives across America, Europe and Asia, but not in Australia.

Better Access Australia called for the program to be made universal, like Australia's National Immunisation Program, with an immediate review to include the 55 diseases screened for in California and not Australia, with bi-annual reviews thereafter to keep our health system contemporary for our newborns. It was not actioned by the Government.

#EnoughisEnough.

"2,500 Australian children are being lost every year to perinatal and congenital health conditions. As last year's Women's Budget Statement acknowledged, it is the largest cause of death for girls aged

0-14 and third largest for boys.[1] [2] *Many of these deaths could be prevented by bringing Australia's 1990s newborn screening program into the 21st century by expanding national newborn screening.* Ms McNeill said

"Better Access Australia is not alone in its call for national and expanded newborn screening.

"Recent national polling shows the Australian community know that the current state of newborn screening in Australia for rare diseases is simply not good enough and it's time to fix this – whatever it costs.

"In the recent Kore poll of 1258 Australians, 84% of respondents agreed that Australia should screen newborn babies for more diseases" Ms McNeill said.

"Assuming that early detection leads to better overall outcomes, why wouldn't you support this?"
(Respondent from Victoria)

"A whopping 95% of respondents said they would be willing to spend upwards of $50 per baby, with 68% saying "Whatever it costs" to match California's standard of 80 diseases." Ms McNeill added.

"$100 per child is peanuts in the context of what gets spent in the health system"
(Respondent from New South Wales)

"The good news is that it would only cost around $10-$20 per baby to improve our screening program. An incredibly small investment for such a huge saving of time to diagnosis, and maximum benefit of treatment for a healthier, longer life for kids with rare diseases. Ms McNeill added.

The national poll also showed that the community understands the detriments of the postcode lottery to the health of our kids with 85% of respondents supporting a national newborn screening program to ensure all babies are screened for the same diseases to end Australia's postcode lottery for diagnosis.

Kate, a rare disease nurse from the Centre for Community-Driven Research agrees, *"In rare disease we have enough challenges where solutions don't fit in a population health model, so when there is an affordable and effective solution that would ease the pressure on parents and the health system, I'm not sure why we don't take it."*

"In last night's budget Government invested new funds into improving screening rates for cervical, breast and bowel cancer – all wonderful and needed investments, but we need to start investing in start of life as much as end of life. We need a national and expanded newborn screening program now. Ms McNeill said

"*On Budget Day, 821 babies were born. Up to 5 of those babies will now go undiagnosed for one of 50 treatable diseases in Australia and suffer unnecessary irreparable damage to their health.*

"With that reality on all our consciences, it's time for all sides of the parliament to do more to save our babies and see Australia once again a world leader in this most important area of unmet health need – and fund expanded national newborn screening today" Ms McNeill said.

[1] Australian Government, Women's Budget Statement 2021-22, Canberra 2021 page 72
[2] Australian Institute of Health and Welfare, Deaths in Australia, Canberra 2020

What is Newborn Screening?

Newborn screening is a very low-cost heel prick test conducted within 48-72 hours of a child's birth to detect serious genetic conditions. A diagnosis of a rare disease through newborn screening means a baby's health can be managed within weeks of birth to reduce or stop the cognitive and physical harms an untreated rare disease can cause.

Polling Results at a glance

- Support for screening for more diseases was consistent in respondents identifying as male or female (83% and 85% respectively), with slightly higher percentage of male respondents supportive of screening for as many diseases as we can (54% and 52% respectively).
- Support for screening for more diseases was slightly higher in respondents under 45 years (85% versus 83%).
- Support for a national screening program was higher in respondents identifying as female (87%) versus male (83%).
- Support national screening was highest in persons 45 years and over 88% versus 82% for those under 45 years.
- Responses on how much Government should pay were strong in almost all states with the exception of WA which was the least likely to support higher levels of funding for meeting the costs of the screening process at 55% compared to the national average of 68%.
- QLD has the highest rates of respondents (7%) who did not support any increased funding for newborn screening.

The full survey data is available here.

What newborn screening reforms is Better Access Australia calling for?

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 by end of 2022.
2. Make newborn screening a nationally consistent and federally funded program replicating the successful model for Australia's National Immunisation Program.
3. Conduct bi-annual reviews of new bloodspot screening diagnostics as well as a plan for integration and adoption of genetic testing of newborns at a population and individual level, starting with the babies who receive a positive result from a newborn screening test.

For more information about Better Access Australia, please visit www.betteraccessaustralia.org.au

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