24 March 2022

This year's Budget needs action not words as polling shows overwhelming support for expansion of newborn screening in Australia - whatever it costs

"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."

(Joh, mum of two)

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 with expanded national newborn screening.

Currently Australia only screens nationally for 25 diseases. California screens for 80, New York 66, and across Europe it's 50. Australia has fallen woefully behind.

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

"This year, a footnote in the federal Budget acknowledging these tragic death rates in our children is simply not enough – Australian babies need action with the introduction of national and expanded newborn screening, Better Access Australia Chair Felicity McNeill said.

"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 a 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.

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[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

Australia is in the tragic situation where we subsidise access to many treatments but do not test for those diseases through national newborn screening. By the time a baby is diagnosed irreparable cognitive or physical deterioration has already occurred, often leading to death.

As new medicines for rare diseases such as cystic fibrosis, spinal muscular atrophy (SMA), and Pompe are considered for funding by the Government, timely diagnosis to prevent irreversible damage is needed, but not currently available in Australia. Without diagnosis there is no treatment.

Worst still, with different tests provided in different states, the diagnosis and treatment of diseases in our newborns varies depending on where a baby is born.

"Not only does Australia screen for less than a third of diseases screened for in California, but it's a postcode lottery as to which diseases a baby will be screened for, Ms McNeill noted.

"This is why a baby born in Albury NSW with SMA or SCID will thankfully receive immediate treatment. But a baby born on the other side of the Murray River in Wodonga Victoria with the same disease will not be diagnosed until significant symptoms are present because of the damage being done due to lack of treatment. That damage is irreversible and can tragically have fatal consequences as Joh's family too sadly knows.

"How is this still possible in 2022? What will it take for federal leadership on this issue?

"Better Access Australia is not alone in our call for urgent reform, 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." Ms McNeill said

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."*

"It's time for Australian governments to do more to help save our babies and once again become a world leader in this most important area of unmet health need. Ms McNeill said.

"In the last four months we have had bi-partisan motions in the federal Parliament calling for urgent reform of Australia's newborn screening program, and a bi-partisan recommendation in a Parliamentary Inquiry also calling for federal action.

"No more words – it's time for action. Ms McNeill said.

On Budget Day 29 March, 820 babies will be born. Up to 5 of those babies will go undiagnosed and suffer unnecessary irreparable damage to their health. That damage may well be fatal.

"This year's budget needs to heed the community's call to action for a nationally expanded and funded newborn screening program to end the postcode lotteries and tragic lost of life in our kids."

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 are Better Access Australia is 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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