Media Release
25 November 2021

INQUIRY REPORT DELIVERS BI-PARTISAN SUPPORT TO END NEWBORN SCREENING POSTCODE LOTTERY TODAY

The House of Representatives Standing Committee for Health Aged Care and Sport has tabled its Report on *Approval processes for new drugs and novel medical technologies in Australia* and in doing so recommended a national solution to fix newborn screening in Australia in 2022.

In June this year the Department of Health announced another convoluted solution to newborn screening in Australia after the current process was set aside by the abolition of the various joint committees associated with the Council of Australian Governments Government framework in 2020.

This solution established a multi-year, multi-committee process, perpetuating the disease-by-disease state-by-state evaluation and funding process leaving Australia woefully behind the rest of the world and babies at unacceptable risk of delayed diagnosis and the associated risks of preventable disability and death.

Better Access Australia has challenged this process and demanded a nationally funded program delivered via a one-off catch-up review of existing bloodspot screening testing technology for Australia, and an ongoing commitment to regular reviews of the technology for inclusion in the program.

Today, the Committee chaired by the Member for North Sydney Mr Trent Zimmerman MP has delivered bi-partisan recognition of the inadequacy of that process and recommended an immediate fix to deliver national newborn screening for all babies born in Australia and an end to the postcode lottery:

> *The federal, state and territory health authorities complete the standardisation of newborn screening across Australia*
>
> *As part of that process, the Australian Government work with states and territories to expand the newborn screening program based on new understandings of genomic testing for conditions and international best practice*
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> *That the Australian Government in collaboration with states and territories, conduct reviews every two years to determine whether the screening program should be further expanded based on new Australian and international scientific and medical knowledge.*[1]

"Better Access Australia welcomes bi-partisan support for the recommendation to fix newborn screening in Australia with a universal and updated system to end the postcode lottery and bring the program into the 21st century," said Better Access Australia Chair, Ms Felicity McNeill

"We want to thank the Committee led by Mr Zimmerman for this recommendation that will save lives and prevent families' heartbreak.

"Newborn screening is a very low-cost 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

[1] Parliament of the Commonwealth of Australia, The New Frontier - Delivering better health for all Australians Recommendation 21 p. xxxix

health can be managed within weeks of birth to reduce or stop the cognitive and physical harms an untreated rare disease can cause."

In California a newborn is screened for 80 conditions. In Australia, they are only screened for 25.

Newborn screening in Australia occurs via five different state-based programs that has resulted in drastically different outcomes for babies with the same condition between states and territories.

"Our proposed fix and now this recommendation is small change for governments – around $3 million a year to properly screen and protect every baby in Australia. In the lead-up to an election this needs to be a commitment from the major parties for the health of our babies," Ms McNeill said.

"Whilst newborn screening has been scapegoated through the shifting of responsibilities at federal and state levels this recommendation calls for a union between federal, state and territory governments to fix this problem. After decades of inaction and obfuscation now is the time for change.

"We have real-world evidence available from international programs for over 50 conditions that is available for consideration today.

"Tests that cost a few dollars per baby are saving tiny lives across America, Europe and Asia. It's time for Australian governments to do more to help save our babies and become world leaders again in this most important area of unmet health need.

"Screening for only 25 conditions means that some families will be told their baby has a rare disease from a newborn screening test. They will be shocked but they will have the capacity to access treatments or modify their baby's diet to keep them happy and healthy and possibly access clinical trials.

"Other families, however, will take their child home from hospital and not realise the test they needed was not one of the 25 their baby was screened for. Their baby's diagnosis will likely come at a point that treatments funded through the PBS and Life Saving Drugs Program cannot reverse the cognitive or physical deterioration that has occurred. It will come too late to access a clinical trial.

"We along with many families, patients, a growing chorus of the community, politicians and now this Committee are saying #EnoughIsEnough. Three decades of inaction on newborn screening has been too long.

"Newborn screening is the key to our children's future. Australian governments have a duty to heed the advice of the Committee and fix this problem for the next generation."

"Better Access Australia wants to particularly thank the Deputy Chair of the Committee Dr Freelander who alongside his commitment to the first #1000Days of a child's life has led the charge on the need for a national newborn screening program this year. He has led the charge of a growing number of parliamentarians from all sides of politics to listen to the #VoicesThatCannotBeHeard and give them a voice in our Parliament. Thank you."

For more information about newborn screening and our #MindTheGap campaign, please visit:

www.betteraccessaustralia.org.au

Please join the 13,000+ who have already signed our petition calling for Australian governments to fix newborn screening.

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