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LABOR'S COMMITMENT TO A NATIONAL AND EXPANDED NEWBORN SCREENING PROGRAM WILL SAVE TINY LIVES

At the Midlands hospital in Perth today, Opposition Leader Anthony Albanese announced that a Labor Government would make newborn screening a national program and would expand its coverage to 80 diseases making Australia once again a leader in newborn health – a feat not seen since the 1980s.

Better Access Australia welcomes this announcement as a giant step forward in protecting Australia's newborns.

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

"821 babies will be born today. Better Access Australia Chair Felicity McNeill said.

"Five of those babies' families will go home thinking the heel prick test their baby received protected them, only to be told months or years later that their child is suffering from a degenerative and lifethreatening condition that could have been treated at birth but wasn't because Australia screens for less than a third of the rare diseases we provide subsidised treatment for today.

"That's 5 babies today, 35 this week, 140 in April, 1700 babies born in 2022 that will not have been diagnosed and treated from birth as their families had rightfully expected.

"Today, Labor has announced a program that will end these statistics for our newborns.

In introducing a national and expanded newborn screening program for Australia Labor will triple the number of diseases we screen our babies for at birth, making Australia a world leader in newborn health once again.

"In last week's budget the Government announced funding of potentially curative treatments for Spinal Muscular Atrophy (SMA), but tragically only 1 in 3 babies in Australia will be screened for access to this treatment because only NSW and ACT screen for SMA.

"And without diagnosis, there simply is no treatment. Ms McNeill stated.

"Labor's commitment to a national and expanded newborn screening program will end the postcode lottery for our babies and end the complete lack of access to screening anywhere in Australia for over 50 diseases we can treat from birth" Ms McNeill added.

Recent national polling showed that 84% of respondents agreed that Australia should screen newborn babies for more diseases and 85% agreeing it should be a national program.

"It's not just Better Access Australia that has called for action on newborn screening. The community has too, Ms McNeill said



"They have heard Nate's story and Olympia's story. They have heard Renee's story and Joh and Adriana's stories. Stories of unnecessarily delayed diagnosis with tragic consequences. All which could have been prevented with national and expanded newborn screening.

"Treatments for Pompe have been available since 2011 and yet not one state or territory screens for the disease. This announcement from Labor would end that inequity in access for babies not only with Pompe but SMA, Severe Combined Immuno Deficiency (SCID), sickle-cell disease, Fabry, Gaucher and San Filippo diseases to name but a handful of the 50 diseases we don't screen for today.

"With perinatal and congenital conditions the leading cause of death for girls under 14 and third largest for boys, it is simply unacceptable to keep listing new treatments and not screening for their access." Ms McNeill said

The need for national and expanded newborn screening has been recognised by both sides of politics both in the Final Frontier Parliamentary report and in bi-partisan motions for reform on the Parliamentary floor.

"Better Access Australia thanks Labor and in particular Dr Freelander and the Hon Mark Butler for turning words into action with this announcement today, Ms McNeill said

"We welcome Labor's commitment and assume the Coalition will support any move that ensures funded treatments get to babies that need it through national expanded and uniform newborn screening" Ms McNeill said.

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.

The full survey data is available <u>here</u>.

For more information about Better Access Australia, please visit <u>www.betteraccessaustralia.org.au</u>

Media contact: Timothy Davies | M: 0466 640 539 | E: tdavies@betteraccessaustralia.org.au

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