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## 2500 CHILDREN LOST EACH YEAR BUT GOVERNMENT DOESN'T CARE

Better Access Australia is calling on all political parties to take direct intervention to end the discrimination against our children and commit to modernising Australia's newborn screening program.

The federal government has announced a new and highly complex process for determining what conditions should be included in newborn screening.

Screening for inherited disease is becoming increasingly important with the emergence of targeted gene therapies that offer potentially curative outcomes.

"Unfortunately, Australia currently only screens for 25 conditions and we are well behind comparable countries," said BAA chair Felicity McNeill PSM.

California screens for 80 diseases. New York screens for 52 with a further 14 under a pilot program. All but four of these conditions have current treatments available.

The Morrison government's 2021-22 [Women's Budget Statement](#) acknowledged that the largest cause of death for girls aged 0-14 are perinatal and congenital conditions. It is the third biggest cause of death for boys aged 0-14.

"Australia currently loses 2,500 children each year to these conditions, many of which can be screened for and treated. But all levels of government are failing to act," continued Ms McNeill.

"The federal government recently abolished a failed newborn screening committee. However, rather than fixing the problem, it has now constructed a process that could take at least three years to consider and provide advice on screening for any single disease.

"At that rate we should catch up with California's standard of care by 2170 – if they are ever recommended," said Ms McNeill.

"This single disease-approach demands the carers of patients themselves pull together a highly complex Health Technology Assessment (HTA) submission. This is simply out of reach for many in terms of technical requirements and cost."

Ms McNeill said the federal government has spent the past five years reviewing 5,700 Medicare item numbers.

"It has reviewed an average of 22 items per week or over 1,000 items per year. Conversely, it has been happy to watch newborn screening languish."

Since 2016, the joint federal-state committee has considered seven conditions for the inclusion in the newborn screening program. Only one has been recommended. Yet it is not been actioned because of disagreement over who should fund the test.

"This committee has been abolished and replaced with just another long-term process that provides little hope for families wanting to make sure their kids are diagnosed and treated as quickly as possible.

"It's not too much to ask and it's time to stop asking patient groups to do the heavy lifting for these processes to protect all of Australia's children.

"Better Access Australia is asking all political parties to commit to an end to this discrimination against our children. We are calling for the adoption of a single six-month time-limited review of newborn screening with the goal of bringing the screening program we offer our children into the 21<sup>st</sup> century.

In the 1990s Australia was woefully behind the rest of the world in our childhood immunisation rates. It took direct intervention by Ministers to change that trajectory and today we are amongst the world leaders. We need that courage of conviction to intervene again.

"We will be writing to all of the patient groups relying on this expansion to encourage them to say – ENOUGH IS ENOUGH.

"We have a 1980s screening program for our children. It's time to act for all children born in Australia that are not given the protections afforded them in so many other countries.

"Newborn screening is the gateway to treatments, the gateway to genetic testing, the gateway to clinical trials, the gateway to parents doing everything they can to give their children the best start in life.

"Newborn screening is the gateway to ending the preventable loss of 2,500 of our children each year."

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For more information about newborn screening and to access videos on patient stories, please visit: [betteraccessaustralia.org.au](http://betteraccessaustralia.org.au)*

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