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— AUSTRALIA —

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**MEDIA RELEASE**

## **LITTLE LIVES NEEDS A LITTLE SUPPORT TOO MINISTER HUNT**

With 30 September marking the end of newborn screening awareness month, the Morrison Government has once again shown that when it comes to the first 1,000 days of life, they are just not interested.

Better Access Australia, as part of its #30ReasonsWhy campaign across social media channels, is calling for the urgent reform of Australia's newborn screening program to drag the 1980's testing program into the 21<sup>st</sup> century. Screening for only 25 rare diseases when we have treatments for over 70, Australia's health system is continuing to fail our newborns.

"Newborn screening is not just about diagnosing a curable or treatable disease, it is the gateway to clinical trials and research as Australian children and their families living with childhood dementia know too well." Better Access Australia Board Member Helen Innes said.

"In Dementia Action Week where the theme is 'a little support makes a big difference' Better Access Australia is asking when will Governments understand that dementia is not just a disease of the ageing, it is a disease that takes the lives of our children at an annual rate comparable to to childhood cancer.<sup>1</sup>

"With the announcement of \$38.5 million for dementia support for senior Australians<sup>2</sup>, the Minister has forgotten that dementia is destroying the lives of our children too.

"Childhood dementia is under diagnosed, under supported, and grossly underrepresented in the research and funding support from the federal government," Ms Innes continued.

"Time to diagnosis matters in all rare diseases, and that's equally the case for diseases without current treatments.

"Some lysosomal storage disorders can be a precursor to childhood dementia. We could screen for many of those today. We screen for none," Ms Innes said.

Screening leading to diagnosis is the gateway to the health system, the gateway to clinical trials, the gateway to the NDIS, the gateway to understanding and support, the gateway to prevention, and the gateway to research and possible treatments and cures.

"When will the Morrison Government open the gate and let our kids into the health system?"

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<sup>1</sup> Report: [Childhood Dementia: The case for urgent action](#) (p.6)

<sup>2</sup> Press release: [\\$38.5 million to support senior Australians in Dementia Action Week](#)

In Dementia Action Week Better Access Australia is calling on the Morrison Government to take some action and show a 'little bit of support' for childhood dementia.

"We are calling on the Morrison Government to deliver the same quantum of funding and investment in childhood dementia support services and research that the community has welcomed this week for older Australians.

"It's time to #mindthegap in childhood dementia diagnosis, support, treatment and care. We can do better and we must," Ms Innes said.

"Remember, in the 1980s we were screening for cystic fibrosis, with limited treatment options, but recognising the importance of a diagnosis, and the importance of research and investment for our children's future.

"The benefits of that screening, and that investment in support and research is the foundation of dramatically changed health outcomes for babies born with cystic fibrosis today.

"We want that same transformation for all children with rare diseases, especially children with childhood dementia.

"We need a new attitude to newborn screening and the rare diseases we do and don't know how to treat today. Diseases like childhood dementia.

"It's Dementia Action week – it's time to act."

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*For more information about newborn screening, please visit: [betteraccessaustralia.org.au](http://betteraccessaustralia.org.au)*

*To sign our petition to fix newborn screening please visit:  
<https://www.change.org/p/australian-parliaments-fix-newborn-screening>*

**Better Health, Disability and Social Services by 2030**  
***Better Access Australia***