23 April 2023

PRIME MINISTER BREAKS ELECTION COMMITMENT TO AUSTRALIAN BABIES

The Government has confirmed the Prime Minister's commitment to nationalise and expand newborn screening will no longer be met either by the start date of 1 July 2023 nor at the world best practice level of 80 diseases. With up to five babies every week missing an important diagnosis *Better Access Australia* is calling on the Prime Minister to honour his commitment to catch up with the rest of the world as promised in 2023 – not in 2050.

"On 6 April 2022 the Prime Minister announced Labor's election commitment to expand newborn screening to 80 diseases. He specifically mentioned Pompe disease as a disease to be screened for and treated as part of his election commitment. Yet the Government has since confirmed that Pompe and 40 plus other diseases are nowhere on their workplan for 2023. Felicity McNeill Chair of Better Access Australia (BAA) said.

"On 6 April 2022, Mark Butler tweeted his commitment to Nate's mum Jenna, that no other family would ever go through their pain of losing their beloved baby boy to Pompe disease, because Labor was going to expand and nationalise newborn screening to 80 diseases. And yet Pompe and 40 plus other diseases are still nowhere on the public workplan for the Albanese government.

"Each year 2,500 children are lost to perinatal and congenital conditions in Australia. It is the biggest cause of death for girls under 14 and third for boys. Many of these deaths are preventable with early diagnosis and treatment.

"Labor promised to fix this in 2023, but 12 months after the Prime Minister gave hope to thousands of families who had lost their children to diagnosable and treatable diseases, no child in Australia is any closer to a diagnosis and treatment at birth.

"Labor promised pompe families, gaucher families, fabry families, SCID families and dozens of other families and support groups in rare diseases they deliver a national and expanded newborn screening for 80 diseases by 1 July 2023. But they have overpromised and underdelivered, handing money over to the states without fixing the program for the babies that need it." Ms McNeill said

Over 15,000 people signed a petition asking for this reform, and 84% of people polled in the lead up to the 2022 election supported the immediate national expansion of the program by 1 July 2023.

"Every day that the expansion of the newborn screening program to 80 diseases is delayed is an inevitable and preventable loss of little lives or irreversible damage to a baby's health.

"When a Prime Minister stands up and commits to screen babies at a world class level of 80 diseases, we should be able to believe him.

"When a Prime Minister stands up and says that screening will include Pompe disease, we should be able to believe him.

"The Prime Minister needs to stop the bureaucracy entrenching its existing disease by disease state by state philosophy by stealth and demand they honour his commitment to Australian parents and grandparents, aunts and uncles to screen all our newborns for at least 80 diseases in 2023 to give them the best start in life.

"Without the Prime Minister's intervention, we will be waiting until 2050 to deliver this election commitment of 80 diseases. Without his intervention, too many little lives will be lost."

QUICK FACTS

- Newborn bloodspot screening is a low-cost test conducted within 48-72 hours of birth to detect serious genetic conditions. Diagnosing a rare disease through screening means a baby can immediately access life-saving treatments to reduce or stop the cognitive and physical harms otherwise caused. Without it, death or permanent disability are inevitable outcome.
- On 6 April the Prime Minister announced he would end the postcode lottery of newborn screening by making it national and expanding to the world class level of 80 diseases.
- The fully costed election commitment by the Parliamentary Budget Office which confirms rollout by 1 July 2023. It included a one-off review of the 80 diseases and thereafter bi-annual reviews of new diseases and the existing screening program to add and update as necessary.
- The Minister for Health and Aged Care and his department have since confirmed that:
    - funding has been provided to the states and territories to standardise the existing screening program with the intent of ensuring all states are screening for the existing 28 diseases by end of 2023 (include already recommended SMA, SCID and Galastemia).
    - the existing process of putting a single disease test through the Medical Services Advisory Committee (MSAC), (an average of 12-18months will remain. This process led to the relative inertia of inaction as evidenced on the department's website.
    - Diseases recommended will still be subject to states allocating funding for the test.
- MSAC is not the place for assessing population level newborn screening, which is why BAA from the outset of its election commitment campaign had proposed a one-off MBS taskforce type model. This would focus on the clinical need not just the cost-effectiveness of the screening because just like national vaccinations population level screening is by its nature not cost effective as MSAC has found on multiple occasions in newborn screening and lung screening.
- How do we know this? MSAC reviews of individual diseases continue highlighting the lack of cost effectiveness of diagnosis and treatment (cheaper for children not to be born [pre-screening] rather than bloodspot screening for early identification and treatment). The impact of this is very real as the following two examples highlight:
    - In July 2020 an MSAC public summary document stated that it supports public funding of reproductive carrier testing for fragile X syndrome, spinal muscular atrophy (SMA) and cystic fibrosis through the MBS, as termination of pregnancies will result in *"…reduced costs to the health system as a result."*[1][2]
    - This advice built on MSAC"s 2019 advice on screening for SMA that noted: *"A shift from disease-based screening to population-based newborn screening would increase the overall numbers of false-positive results and thus overtreatment to some extent. On the other hand, wider uptake of pre-pregnancy carrier screening, or first trimester screening, may reduce the number of individuals born with SMA".* [3]

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[1] MSAC Application 1573 Final Public Summary Document July 2020 (msac.gov.au), p.3
[2] BiopharmaDispatch, Outdated mindset that favours avoidance of birth over cost of treatment, (MSAC.gov.au) 28/6/2021
[3] MSAC, Screening for SMA co-dependent technology 2019 Public Summary Document, page 4, para 1 20