Media Release
18 October 2021

Gene therapy for pre-symptomatic SMA recommendation welcomed but without diagnosis there is no treatment:

Nationally updated newborn screening needed now.

Better Access Australia welcomes the announcement of the PBAC's recommendation of a new gene therapy for pre-symptomatic SMA children on Friday, coinciding with the day Australia first joined the international community in recognising pregnancy and infant loss and the impact that has on families and our community.

"But as the PBAC has previously acknowledged, without diagnosis there is no treatment," Better Access Australia Chair, Ms Felicity McNeill said.

"Australia's postcode lottery means most Australian babies will not benefit from this treatment.

"With newborn screening for SMA only offered in NSW, ACT and shortly in WA, only 2 in 5 babies born in Australia each year will have access to the basic screening test to access this treatment before irreparable damage occurs.

"That means when listed, this new treatment will potentially save the life of a baby in Albury, Woden or in Perth, but it won't protect the life of a baby born in Frankston, Wodonga, Plympton, Glenelg, Toowoomba, Alice Springs, or Burnie.

"And as the PBAC has acknowledged in making this recommendation, time to diagnosis matters.

"Right now, there are six petitions circulating calling for newborn screening of individual diseases in individual states. Parents of sick kids are doing all the heavy lifting and all levels of government are ignoring them. Enough is enough.

Our petition has over 11,800 signatories calling for an end to the buck passing by the federal and state governments by:

1. Undertaking a single once-off catch-up review of all existing technologies and evidence for the 50+ rare diseases we currently do not screen for,
2. A commitment to make this a truly national program so there is universal access in all states and territories funded by the Australian Government, and

3. A program for regular review of latest technologies that does not involve a 3 year multi-tiered process for review with no commitment to fund at the end of the process.

“At an investment of around $10 per baby or $3M a year, we could bring our newborn screening program into the 21st century and provide early diagnosis and access to treatment for up to 50 diseases and provide diagnosis for access to clinical trials,” Ms McNeill said.

“Minister Hunt will eventually announce the Government’s funding of this new treatment and we will welcome that announcement. Better Access is calling on the Government to also include in that announcement an end to the travesty that is Australia’s 1980’s newborn screening program and announce the one-off review and commitment to funding national newborn screening to protect and care for every child born in Australia.

“Because without diagnosis, there is no treatment.”

To join the 12,000 and counting people who have shown their support, please sign our petition here.

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