Media Release

The Hon Mary-Anne Thomas MP
Leader of the House
Minister for Health
Minister for Ambulance Services

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PROTECTING VICTORIAN BABIES BY EXPANDING NEWBORN SCREENING

Victorian newborns will be the first in Australia to be screened for an additional rare but serious health condition, helping to identify babies at risk and making sure they get the lifesaving treatment they need sooner.

Minister for Health Mary-Anne Thomas will today visit the Murdoch Children's Research Institute (MCRI) to announce that Victoria will be the first jurisdiction to test for the rare and serious genetic disorder biotinidase deficiency, as part of the Newborn Bloodspot Screening Program.

Commonly referred to as the heel prick test, the screening program will now test for 34 conditions – helping parents get their children early treatment and support for rare health conditions, so they can live long, healthy lives.

Biotinidase deficiency is an inherited metabolic disorder where the body cannot recycle biotin, leading to a deficiency that if left untreated, can cause neurological issues like seizures, developmental delays, and other issues such as hair loss, hearing and vision problems.

The condition can be treated, so early diagnosis through the newborn bloodspot screening program will help prevent serious health consequences.

Importantly, its addition will also enable MCRI to obtain population-based estimates of this rare condition at a local level. Internationally, it is reported that approximately one in 60,000 babies will be diagnosed with the deficiency in countries that screen for the condition.

The Allan Labor Government has invested more than $1 million to roll out the addition of more conditions to the program, including conditions such as spinal muscular atrophy, severe combined immunodeficiency and congenital adrenal hyperplasia.

The screening is offered to parents of all newborns within their first 72 hours of life, at no cost. In 2024, more than 75,000 newborns were screened – nearly all babies born in Victoria.

The Newborn Bloodspot Screening Program began in Victoria in 1966 and has screened more than 3.6 million babies to date – with one in 1,000 are found to have a rare but serious condition such as congenital hypothyroidism and cystic fibrosis.

More information on the program is available at vcgs.org.au/newborn-bloodspot-screening.

Quotes attributable to Minister for Health Mary-Anne Thomas

"Every Victorian baby deserves the best start in life – and expanding our newborn screening program means babies born with serious health conditions get the very best care from the moment they are born."

"Newborn babies will now be tested for 34 rare and serious conditions at no cost – giving Victorian parents peace of mind and ensuring babies get the care and treatment they need sooner."

Media contact: Max Resic 0435 256 250 | max.resic@minstaff.vic.gov.au