




Speech By
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MEMBER FOR CURRUMBIN

Record of Proceedings, 12 May 2022

PRIVATE MEMBERS' STATEMENT

Spinal Muscular Atrophy, Testing

 **Mrs GERBER** (Currumbin—LNP) (2.06 pm): It was just over a year ago that I first called on this House to imagine two beautiful baby girls born within a month of each other, both named Oakley, and both born with the motor neuron disease SMA. The difference between them is that the Oakley born in New South Wales was tested for SMA at birth, able to access early treatment, and now lives a relatively normal life. The Oakley born in Queensland did not get this testing. Her SMA was not detected until she started showing symptoms. Baby Oakley in Queensland may never walk, needs help breathing and her life expectancy is unknown.

SMA is the leading genetic cause of death in infants under the age of two. Every year babies are diagnosed with SMA. One in 35 people carry the gene—two people in this chamber. It has to be picked up at birth otherwise the damage can never be undone. At the moment it is a postcode lottery. Babies born in New South Wales, ACT and WA are tested for SMA at birth; Victoria has just announced they will. Since 2019 the AMA has advocated for Queensland to test for SMA at birth. The test itself would cost the system \$10. That's it!

It has been 15 months since I first wrote to the health minister urging her to include testing for SMA in our newborn screening tests. Each moment this state government delays implementation means that more children are being diagnosed too late. Baby Mia, from Brisbane, was born in May last year with type 1 SMA. I tragically received the heartbreaking news that she passed away in November last year. This Queensland family was forced to watch their beautiful baby deteriorate from SMA and tragically pass away because SMA is not screened for at birth in Queensland. Baby Louis from Toowoomba was born in March this year with type 1 SMA and again was diagnosed too late. He is receiving treatment but, like baby Oakley, he too will suffer the impacts of SMA on his tiny little body. These are just two recent cases. There are many other Queensland families who are heartbroken and too traumatised to talk.

This cannot keep happening to Queensland families and children when all it would take is for this health minister to commit to testing at birth like other states. This state government is telling us they want us to wait for yet another committee to consider whether it should be implemented before taking action. That is why the SMA community and I have organised to march on this parliament on 22 June this year to bring to the government's attention the urgent need for action. I am imploring this health minister to take action. This is a matter pertaining to the lives of Queensland children and the impact of that on their families. This deserves bipartisan support.