




Speech By
Laura Gerber

MEMBER FOR CURRUMBIN

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PRIVATE MEMBER'S STATEMENT

Spinal Muscular Atrophy

 **Mrs GERBER** (Currumbin—LNP) (2.17 pm): Today I call on this House to move for Oakley, just like the 14,000 people who have signed this petition calling on the government to support newborn screening for SMA. I table the petition.

Tabled paper: Nonconforming petition titled 'Move for Oakley Petition' regarding testing for spinal muscular atrophy [554](#).

Imagine this: two beautiful baby girls born within a month of each other, both born with the name 'Oakley', but one born in Queensland and one in New South Wales and, tragically, both born with spinal muscular atrophy, a motor neurone disease known as SMA. The difference? New South Wales's baby Oakley was tested for SMA in the newborn screening process. Her SMA was picked up at birth and, thanks to early treatment, New South Wales baby Oakey is set to live a normal life almost unaffected by SMA. For baby Oakley in Queensland the outlook is not as bright, because Queensland's newborn screening process does not include testing for SMA. Baby Oakley in Queensland did not get the opportunity to receive early treatment. Her SMA was not detected until she started showing symptoms. By then it is too late; the damage is done and can never be undone. Baby Oakley in Queensland will never sit up or walk. She needs a feeding tube and a machine to breathe. She may not live to see her second birthday. While Oakley in New South Wales is reaching all of her milestones and has the opportunity to live a good life, Oakley in Queensland is likely to become another SMA statistic.

To put this into perspective, SMA in children is not rare. It is the most common genetic cause of death in infants under the age of two. One in 35 people carry the gene. That means that two people in this chamber here today carry the gene and will pass that on to their children. It could have been any one of us that was forced to watch as our child lost the ability to move, to swallow, to breathe and eventually to pass away.

Ten weeks ago I wrote to the Minister for Health imploring her to support screening for SMA in Queensland. I am yet to receive a response, and two months is too long to wait for a child born with SMA. The minister needs to Move for Oakley. This is above politics. This is a matter pertaining to the life and death of children in Queensland and it deserves bipartisan support. We are not trailblazing with this in Queensland. This has happened in New South Wales and the test only costs \$10. It saves lives and, in the long run, it saves our health system money. We must Move for Oakley and include testing for SMA in the newborn screening process.