Speech By

Hon. Leanne Linard

MEMBER FOR NUDGEE

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ADJOURNMENT

Sanfilippo Syndrome

Hon. LM LINARD (Nudgee—ALP) (Minister for Children and Youth Justice and Minister for Multicultural Affairs) (6.09 pm): I rise this evening to talk about Sanfilippo syndrome, a rare genetic syndrome that causes fatal brain damage. It is a type of childhood dementia and, tragically, most children diagnosed with it will never reach adulthood. In Australia approximately one in 70,000 children are diagnosed with Sanfilippo syndrome.

At the end of 2019 my long-term electorate officer and friend Jill and her husband, Brendan, received the devastating news that their son Rory has Sanfilippo syndrome. Jill had become concerned that Rory was not quite meeting his learning milestones in kindy and then prep so she visited a paediatrician to identify if he was experiencing a learning difficulty. She and her husband visited a paediatrician with a child with suspected developmental delays and left with a terminal diagnosis. Jill and Brendan described receiving this news as absolute devastation, like the world stopped turning and nothing would ever be the same. They were advised to also have their daughter, Anna, then two, similarly tested. Their devastation at Rory's diagnosis was soon to be confirmed a second time in Anna's case.

Sanfilippo is a metabolic disorder which means there is a problem with one of the chemical reactions that naturally occur in the body. It is caused by the lack of an enzyme that normally breaks down and recycles a large complex sugar molecule called heparan sulfate. Sanfilippo mostly affects the brain and is one of a group of conditions called childhood dementia. Over time brain cells fill up with waste that the body is unable to process. As the brain gets progressively damaged, children experience severe hyperactivity, disordered sleep, loss of speech, cognitive decline, cardiac issues, seizures, loss of mobility and finally death, usually before adulthood. There is currently no treatment or cure available to children diagnosed with this devastating disease, but there is hope. Researchers around the world are working hard to develop effective treatments.

In June Brendan will be participating in Hike for Hope 2021, walking the Larapinta Trail with other supporters of the Sanfilippo Children's Foundation. Their aim is to raise money and awareness of this very rare condition. This adjournment speech is my small contribution to supporting their efforts to raise awareness of this rare and cruel condition—this speech and a contribution to Brendan's Hike for Hope fundraiser page at Sanfilippo.org.au. In November last year Jill and Brendan welcomed baby Juliette to the family who is thankfully unaffected by the condition. They are now fighting to give Rory and Anna a long future with their younger sibling, whom they adore.