



Speech by


**Michael Hart**

**MEMBER FOR BURLEIGH**

Hansard Thursday, 13 September 2012

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## **KABUKI SYNDROME**

 **Mr HART** (Burleigh—LNP) (1.24 am): Kabuki syndrome is a rare genetic disease that affects approximately only one in 32,000 people. The syndrome can take on a range of characteristics, including intellectual disability, distinctive facial features and skeletal abnormalities. The gene that causes this developmental delay is still not known.

Adrian Herron was born with this very rare disease and has spent the past 28 years of his life dealing with this disease day in and day out. It was not until Adrian was 12 years old that he was diagnosed with Kabuki syndrome. Adrian was born with key characteristics of the Kabuki syndrome, including a cleft palate and turned-in feet. Adrian's dedicated parents assisted him as much as they could, taking him to get his feet corrected and so on. After seeing countless doctors, the only diagnosis that Valerie Herron was given was that he had attention deficit disorder. After years of misdiagnosis, Valerie was directed to the Royal Children's Hospital Brisbane, where within minutes of arriving she was informed that her son had the rare condition of Kabuki syndrome.

After being given the chance to finally understand his condition, Adrian now lives as close to a normal life as he can. Adrian, who is turning 29 in October, has for the past five years been working for Coles supermarkets, where he is given the responsibility of working 16 hours a week independently. Adrian is able to achieve this through the constant support of his passionate and caring mother, Valerie.

Valerie came to my office to see me with the hope of raising awareness of this almost unknown disease that affects her and her family daily. The disease is so difficult to spot as each child presents slightly different characteristics. Kabuki syndrome is not always obvious at birth, as the characteristics of Kabuki develop over time. As with many rare diseases, doctors may not be overly familiar with the conditions that accompany Kabuki syndrome, so many cases remain undiagnosed.

Currently, there is no specific awareness day for Kabuki syndrome. It is only covered as part of World Rare Disease Day, which was celebrated on 29 February this year. The Australian Kabuki Syndrome Association hold an annual family day to attempt to raise awareness specifically of Kabuki syndrome and the effects it has on the lives of patients and carers. A family day and education seminar is being held in my electorate today and for the next couple of days at the Burleigh Tallebudgera Recreation Centre. These vulnerable individuals deserve our support and recognition. I encourage and fully back acknowledgment of a state-wide awareness day for this cause.