

The Senate Community Affairs Committee
Parliament house
Canberra ACT 2600



Dear Senators,

My name is Brandon. I am 14 years old and I have Duchene Muscular Dystrophy.

No doubt you are well aware of the effects of DMD. But I thought I should tell you about some of the difficulties I encounter.

I love sport and enjoy watching cricket and football on TV. A few years ago I played soccer but unfortunately I cannot run any more. At least I am able to watch my class mates play.

The School went on a camp to Tuross it was great I was able to go with my friends this was possible because the teachers were very good and helped me. The Kayaking was great fun and teacher made sure I didn't fall in the water. However I was not able to go in the surf and take part in the snorkelling.

My mum takes me to school and I catch a bus home. ACTION have promised to provide a tilt bus but this does not always happen. When an ordinary bus comes I am unable to climb up the steps and as the bus driver cannot help me I am left at the bus stop. Luckily I have a mobile phone and I can ring one of my parents to pick me up. My Grandad meets me at the bus stop near my home to help me off the bus.

I am so lucky to have wonderful parents who look after me so well. Every six months mum or dad take me to Melbourne to the Royal Children's hospital to see Dr Kornberg. At one stage I was part of a clinical trial the medicine I had to take helped. Unfortunately the trial was suspended. I hope they will be able to start again but I do not know when this will be.

My parents are now getting for the day when I have to use a wheelchair. This means that they will have to make a lot of changes to the house and get a van which can be converted to take the wheelchair. All of this is going to cost a lot of money. Also my grandparents are having changes to their house as I cannot climb the steps any more.

Although I do not fully understand what the National Disability Insurance Scheme will mean to me and my family. I hope it will help make our lives a lot better by easing many of the problems facing us in the future. Please help us.

Brandon Stroud

Brandon Stroud
11 January 2013