To whom this may concern,

I am writing this statement on behalf of my 8yr old son Jayden Greenhalgh.

Jayden was diagnosed with Duchenne muscular dystrophy (DMD) on October 13th 2015. And on that day 'D' day (diagnosis day), our hearts sank with grief as all our hopes, dreams and aspirations for our first born son frizzled away in a blink of an eye.

DMD is a rare genetic disorder, it is a progressive muscle wasting illness which causes eventual paralysis from the neck down and premature death. The life expectancy is 20-30years. The statistics for Duchenne are 1: 3500, so really not so rare, but rare enough that we had never heard of it before, and now we live and breathe it.

As heart breaking as it is, a ray of hope was given to us around diagnosis, as we soon discovered that our son had the nonsense gene mutation and was compatible for a new drug- the first ever drug for DMD, Translarna.

The medication Translarna is not a cure but slows down the disease process. Which could mean years of extra life for our son. Years! Something money cannot buy. However our ray of hope soon diminished as we were informed that the drug was not yet approved here in Australia but most probably would in two years. Two years passed, my son turned five and no news on accessing Translarna came.

This was not only painful but frustrating as at the time Translarna was available in more than 20 countries through expanded access programs or commercial sales including UK, Scotland, Italy, Germany, Brazil and Israel. And at the same time, in our own country, Australia, there were around 20 families accessing the drug through expanded access programs. The reason being that a clinical trail was held here is Australia. It was based in Victoria and NSW. Children were recruited from SA, VIC, NSW, QLD and NZ. When the trial ended, those families had been allowed to continue with the drug, perhaps as a reward for participating in the trial. However there were some children left behind

who were either too young to go on the trial or not diagnosed before the trail began. This included my son Jayden.

It was unfair that my son was left to suffer, it was unfair that his life should be made shorter as he could not access a drug that other families in his same county and same state could.

Jayden had no voice at 5years old, he is now 8 and still has no voice and no cure for DMD. Not only did he not get translarna, he has not been selected for another clinical trial, treatment or ray of hope.

Help Jayden and other children like him to get access to these vital drugs for rare genetic disorders.

My son is a beautiful boy, he is charming, funny and eccentric. He is a son to me and my husband, a brother, a nephew, a grandson and most of all a child, a child who misses out on so much as it is. Please dont let him miss out on life as well as time waits for no one and certainly wont wait for the bureaucracy of the current situation of access to new medication.

Kind regards

Donna Greenhalgh

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