



December 2017

Spinal Muscular Atrophy is the childhood version of motor neurone disease and is the number one genetic killer of infants under the age of 2 years.

Dear Member of Parliament,

I am contacting you today as a concerned constituent of your electorate, and to make you aware of the challenges faced by our family who are touched by a rare genetic disease called Spinal Muscular Atrophy. SMA is a progressive muscle wasting disease and a revolutionary new drug called Spinraza, has been developed and successfully trialled and commercialised in the USA for patients with Spinal Muscular Atrophy. This drug is the first potential treatment option for Spinal Muscular Atrophy all over the world, and patients here in Australia need access to it as soon as possible. Currently there are untreated babies that are dying from the disease.

When approved it will transform the quality of life of patients and families living with Spinal Muscular Atrophy (SMA) around Australia.

Did you know?

- 600 people plus are living with Spinal Muscular Atrophy in Australia.
- 1 in 6,000 live births are affected by Spinal Muscular Atrophy
- 1 in 35 people carry the gene for SMA in Australia
- A SMA baby is born when BOTH parents are carriers of this gene, neither parent is to blame. There is a 1 in 4 chance of having a baby with SMA.

The Spinal Muscular Atrophy community needs your support to ensure that sufferers of the disease have access to the drug that can improve and transform their quality of life. In some cases simple everyday tasks such as scratching, using a pen, or cutting food to eat, is extremely limited or someone else has to do this task for them.

As my local member I ask you to share this information with your colleagues and please speak out in Parliament to make sure that the future decisions made by the TGA and PBAC are guided by the unique knowledge and experience of people living with SMA.

It is vital that the voice of the SMA community is heard loud and clear – everyone deserves access to life changing drugs and treatments and Spinraza is a resounding example of this for our community. If you would like further information please contact Julie Cini, CEO of Spinal Muscular Atrophy Australia Inc. on smaaa@smaaustralia.org.au

Kind Regards

Member of the Spinal Muscular Atrophy Community