Date

[Title] [Name]

Member of Parliament

[Address]

Dear [Title] [Name]

Re; New life-saving treatment for spinal muscular atrophy (SMA) needs Pharmac funding

I have / my [family member e.g daughter / friend / colleague], [name] has/ spinal muscular atrophy also known as SMA. You probably haven’t heard of SMA before - it’s a rare disease that affects around 100 New Zealanders and can be life threatening.

SMA is a recessively inherited condition. Most people don’t know they carry the gene, but about 1 in 50 people do. They probably won’t know it until they have a child with the condition. SMA can be severe or mild but always causes physical weakness and loss of movement due to atrophy of the nerves supplying the muscles. Intellect is not affected at all.

The severe form of spinal muscular atrophy, SMA type 1, is the leading genetic killer of babies. People with SMA type 2 or 3 experience symptoms that take away the everyday freedoms many people take for granted like walking or lifting a cup to take a drink. For others with SMA type 4 symptoms can be mild and experienced later in life. So you can see this is a diverse community, where symptoms can be life-threatening, moderate or mild, and everything in between.

I / my [family member e.g daughter / friend / colleague] was diagnosed with SMA type [x] when they were [xx] years of age. When I/they was/were diagnosed there was no treatment available but I am writing to you today because I want you to know that there is now an established treatment for SMA called Spinraza.

Other countries have fast tracked the approvals process for Spinraza, and it was approved by the USA Food and Drug Administration in December 2016 for treating all types of SMA, in Europe in 2017 and in Australia this year.

Here in New Zealand, registration of the drug with MedSafe is imminent but, as you’re aware, access to Spinraza depends on approval for funding by Pharmac. The pharmaceutical company marketing Spinraza, (Biogen), will be making its application to Pharmac shortly and we are hoping for a positive outcome.

SMA is a serious progressive condition, and it is crucial that Spinraza is made available and funded for Kiwis [like me/my family member] with urgency, because Spinaraza achieves better outcomes when it is administered as early as possible, before symptoms progress. This is the ***only*** treatment option [my child/family member/ friend] has to delay the onset of symptoms that can cause severe disability, illness, and even premature death.

Medicines access for rare disorders is a very topical issue and it is important that we can count on your support to have access to life-saving treatment for all New Zealanders affected by SMA.

*Optional sentence below if you want a meeting:*

I appreciate your interest and would love to talk to you about this issue in more detail. Please contact me at [number/email] to set up a meeting.

Yours sincerely,

[Name]

[Address]