Muscular Dystrophy New Zealand

Huge win for SMA

An agreement has finally been reached between Pharmac and Biogen for the funding of Spinraza

On Wednesday 28th September, Pharmac released a proposal to fund Spinraza (Nusinersen) for people aged 18 and under with SMA from 1st January 2023. Until now, there has been no funded treatment in New Zealand for SMA, yet three treatments available across the Tasman.

There are four main types of SMA, the most severe being type 1. Tragically SMA type 1 is also the most common type, with approximately 50% of cases having this diagnosis. Without treatment, babies with SMA type 1 will never be able to sit up, will lose the ability to swallow, and ultimately pass away in New Zealand on average at 13 months old. There are about 35 children in Aotearoa living with SMA.

Fiona Tolich, the lead patient advocate for SMA in Aotearoa, was also celebrating the news, having battled to get Spinraza funded since 2018, when the manufacturer applied to drug-buying agency Pharmac.

"I literally cried. And I'm not a big crier. Years of emotions all came out at once. It's been a tough road to get here and we've lost some kids along the way.

"The future for Kiwi children has changed so significantly and they now have hope. And they won't need to know what so many others before them have had to experience. They have a different trajectory. They have a future."

Tolich, who has SMA herself, said the advocacy was not finished, with plans to advocate for access to Spinraza to widen to adults, as well as getting other options to allow our community the best chance at life.

Pharmac's director of operations Lisa Williams said the challenge had always been finding the money, as the medicine had been on its funding wishlist since 2018, the same year Australia funded it.

"What that means is it's always been a medicine we wanted to fund, if we had funding available to progress it. And it's really exciting to be in a position now that we can progress it to funding," Williams said in an interview.

Health Minister Andrew Little said in a statement that the decision was in line with the recommendations of the Government-ordered review of Pharmac, which said more work should be done on funding medicines for people with rare disorders. "It could make a substantial difference to the lives of the young people who receive it," he said.