

SMA New Zealand

New Zealand



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1. About

SMA New Zealand is made up of a team of one - Fiona Tolich. It is not an official charity and is run completely voluntarily. It was established in order to campaign for access to treatments in New Zealand.

SMA New Zealand has been pivotal in securing medicines access for those living with SMA and other conditions through Fiona's voice and profile as an advocate.

2. Mission

Driven by leaving no one behind, the whole existence of SMA New Zealand is around ensuring anyone living with SMA has fair and equitable access to the best possible health outcomes.

3. Focus.

Significantly, in a country that ranks at the bottom of the OECD for medicines access, we have managed to get two treatments across the line for SMA - Spinraza and Risdiplam. At this stage this is only accessible for those aged up to 18. It is a focus to ensure that everyone living with SMA in New Zealand has access and that people no longer need to leave their home/country to get access abroad (medical refugees - like Fiona Tolich who now lives in Australia).

There is a large focus on ensuring newborn screening is rolled out right across New Zealand, which is underway. Fiona is a part of the expert advisory group that will be focused on this.

The big next step is forming an action plan to safeguard SMA New Zealand's existence for future generations to come with the size and scale to provide more support to individuals living with SMA and their families.

