

A large group of people, including children and adults, are gathered outdoors for a protest. Many are holding signs with various messages and images. The scene is set in a public space with trees and a building in the background. The image is overlaid with a semi-transparent dark grey filter and several white diagonal lines on the right side.

# DEATH BY 1000 CUTS

A community torn apart

## SMA CLINICAL SUBTYPES

There are four primary types of SMA. Type is based on the age of onset symptoms and the highest physical milestone achieved. SMA Type I is most severe, and also the most common, representing over 60% of cases.

1

### Type 1 SMA

Onset: Before 6 months  
Milestones: no sitting



2

### Type 2 SMA

Onset: 6 - 18 months  
Milestones: Sitting,  
not walking



3

### Type 3 SMA

Onset: Childhood  
after 12 months  
Milestones: Walking



4

### Type 4 SMA

Onset: After 30 years old  
Milestones: Normal


















I WILL ALWAYS  
wonder  
WHO YOU WOULD  
have been



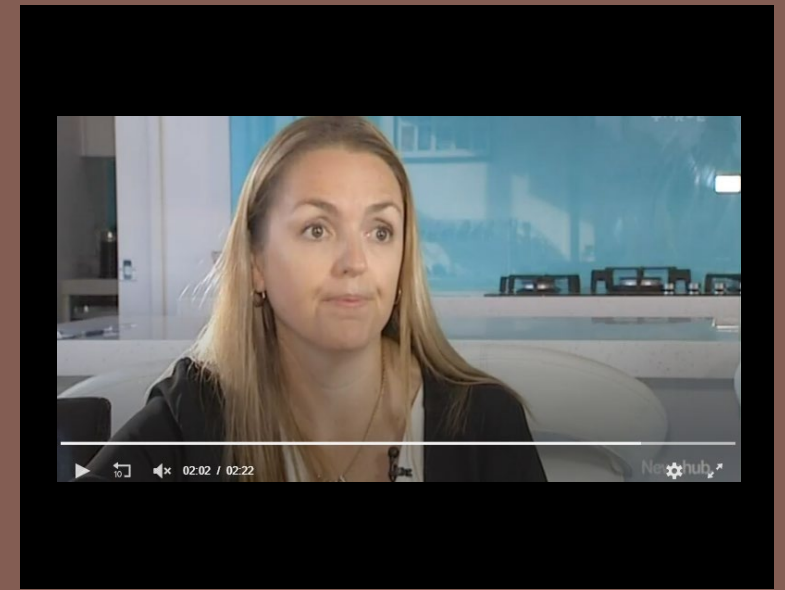














A sunset over a mountain range with a quote overlay. The sky is a mix of orange, yellow, and light blue. The mountains in the foreground are dark and silhouetted against the bright light of the setting sun. The quote is presented in two stacked dark rectangular boxes with white text.

The truth hurts, but  
silence kills.

Mark Twain

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"This complaint has highlighted that inconsistency and we committed to Fiona and to the Human Rights Commission that we would look at it because it wasn't consistent. It's something we've wanted to do but we haven't managed to do it in the last few years."

Both doctors are also highly critical of the way Pharmac has treated patient advocate Fiona Tolich, who [sparked Pharmac's review of child cancer drug funding by taking a discrimination case.](#)

Jackson, the medical director of the Cancer Society, believed Pharmac's response to Tolich amounted to intimidation.

"I think it's deeply troubling that Pharmac has appeared to link advocacy to a possible reduction in child cancer drug availability - that feels almost retaliatory."

"If you were advocating for any kind of change, to have the prospect that that could have a negative impact on kids affected by cancer hanging over you - that's extraordinary," he said.

"For a government organisation to put that out there as something that could happen as a consequence of that, I mean that would be extremely intimidating for any advocate, so I think that's quite troubling."





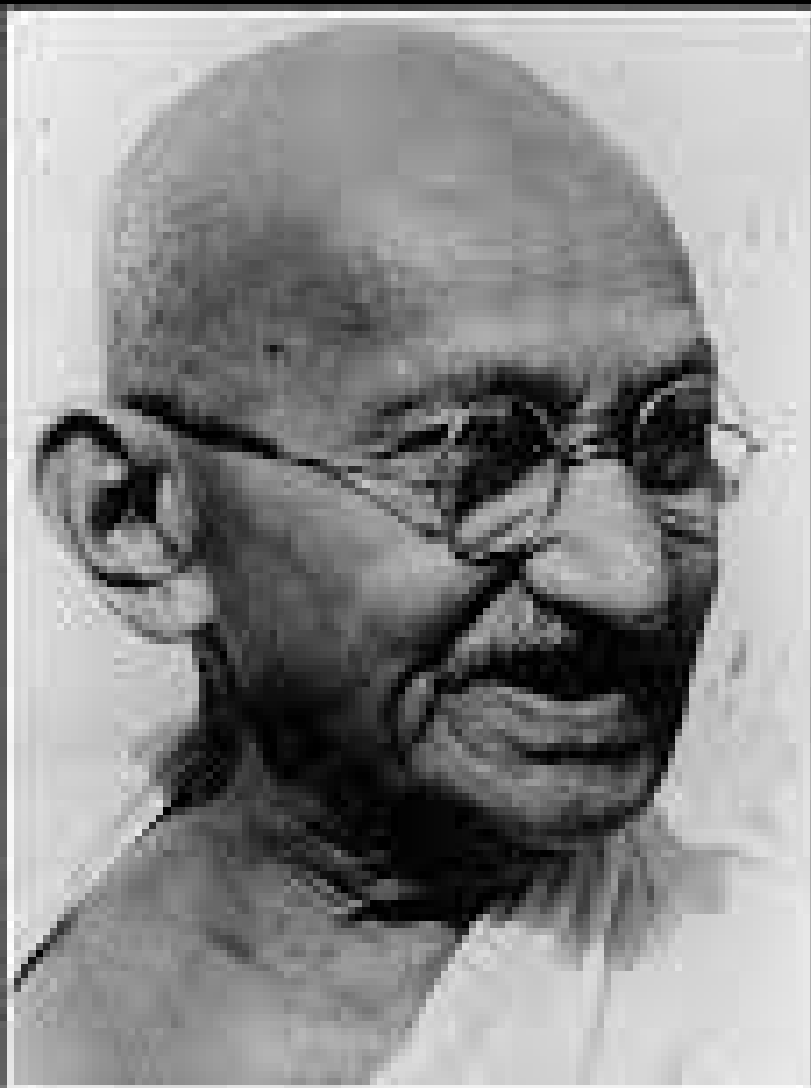
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**Grief**

**T R A U M A**





The true measure of any society can  
be found in how it treats its most  
vulnerable members

— Mahatma Gandhi —

AZ QUOTES



Extremist rhetoric refers to the expression of single-minded certainty by true believers in their extremist ideology.

“... you can hear some shit you really don't want to hear (sort of like a Smalley (*redacted*) interview!) That interview yesterday was utterly nauseating.”



First of all, I don't buy into extremist rhetoric.

Pharmac will be considering the drug for funding, this month, under its rare disorders fund. Spinraza's application will be considered alongside funding for 13 other new medicines, for diseases like Fabry disease, Pompe disease, cystic fibrosis and Gaucher disease.

Every reasonable New Zealander understands why they can't all be funded.

So which would you choose?

"I do know that Indira is a massive Fiona Tolich fan so likely already prejudiced," she writes in reference to SMA advocate Fiona Tolich.

# Who's driving the push to publicly fund \$1m drug for orphan disease spinal muscular atrophy?



25% OF KIDS / 4 ADULTS TO DATE





WHEREVER THE ART  
OF MEDICINE IS LOVED,  
THERE IS ALSO A  
LOVE OF HUMANITY.

(HIPPOCRATES)



# BECOMING A NEW AGE BIONIC WOMAN



## 2 MONTHS PRE-TREATMENT

UNABLE TO PERFORM HEEL, SHIN,  
SLIDE  
LAYING SCISSORS IMPOSSIBLE  
402M 6MWT

## 7 MONTHS IN

LAYING SCISSORS  
IMPROVED STRENGTH MEASURED  
BY OXFORD SCALE OF BILATERAL  
HIPS AND KNEES  
JUMP 2 FEET FURTHER  
420M 6MWT

## LATEST FIGURES

638M 6MWT – HEALTHY CONTROL  
RANGE  
10,000 + STEPS  
+VE FUTURE





# Val·ue

*/ˈvʌlyoʊ/*

*noun*

the regard that something is held to deserve; the importance, worth, or usefulness of something.

THANK YOU

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