## AN OPEN LETTER TO THE PRIME MINISTER OF NEW ZEALAND, JACINDA ARDERN

Wednesday, 1st April 2020

## **Dear Prime Minister,**

We, 35 leaders of health-related non-government organisations, applaud the efforts you have made to stem the spread of Covid-19. We wholeheartedly support your call for a nationwide lockdown in an attempt to protect the elderly and the most vulnerable in our society. In the face of this crisis, your government has passed legislation, enabling the expenditure of \$52 billion and thus far those who have received assistance includes businesses, employees, and mortgage holders.

Yet there is one group who we represent and who you have spoken about the need to protect during this crisis who desperately require funding immediately in order to live; patients with pre-existing health conditions across a range of rare disorders, chronic illnesses, and cancers. Now, more than ever, the most vulnerable in our society need your help in the fight against this virus. As we know from the sad experiences of other countries, those with pre-existing health conditions are particularly susceptible to dying from Covid-19, and certain countries and states are informing such patients that they will not be treated at all if they contract the virus.

Prior to this global pandemic, New Zealand had a medicine funding crisis. New Zealand is woefully out of touch with the rest of the world when it comes to the funding of modern medicines. We ask that your government immediately provide a significant funding boost to our drug buying agency, Pharmac, and instruct the agency to purchase far more modern medicines that treat those with rare disorders, chronic illnesses and cancers.

Those with compromised-immune systems are extremely defenceless against Covid-19 and our country leads the world in funding the least amount of immunotherapy drugs. Also, the burden on the healthcare system would be alleviated if we funded more medications. Some patients who require intravenous medication could take a pill that does the same job from the comfort of their own home and lessen the risk of contracting Covid-19 by not needing to visit hospitals.

Many families who were considering leaving New Zealand to access medications not available in New Zealand, no longer have that option as various countries including ours, close their borders. It also prevents those who were importing their privately funded medications from doing so. Many more patients were also dependent upon their Givealittle pages to fund medications that they desperately needed, and with the sudden downturn in the economy, the value and frequency of the donations are decreasing rapidly.

Prime Minister, we want to leave you with the words of Lisa who lives just out of Taupo. Her three-year old son, Tama, has a rare disorder called Spinal Muscular Atrophy and desperately needs the drug, Spinraza, funded. She states "If my son contracts Covid-19, he dies. If I stay in New Zealand, he dies. If I rely on Givealittle, he dies. I have nowhere to turn to save the life of my son".

As you have said on numerous occasions, this



Tama

time is about protecting our most vulnerable, about prioritising the health needs of our country over our economic challenges, and about the importance of being kind to one another.

Right now, Prime Minister, we need you to be kind to those most at-risk of dying from Covid-19. We welcome the opportunity to meet with you, virtually, to discuss these life and death matters.

Thank you.

Patient Voice Aotearoa

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