

## PETITION

To: The Honorable Christine Elliott, Ontario Minister of Health

To: The Honorable Patti Hajdu, Federal Minister of Health

I am signing this petition on behalf of Marcel Muljarahardja of Brantford, Ontario.

Marcel is a new-born baby boy who at, the age of one week, was diagnosed with Spinal Muscular Atrophy (SMA).

This affliction is due to a defective gene which causes the baby's voluntary and involuntary muscles to stop working, including the ability to breathe. SMA is fatal --if not treated within six months, the infant will almost certainly die before the age of two.

There is one medicine available in Canada called Spinraza, but this medicine treats only the symptoms of the affliction, and cannot treat the disease itself. If this is Marcel's only treatment, he will be sentenced to an early and painful death.

There is also one medicine available in the United States called Zolgensma, a gene replacement therapy that actually does attack the disease, and which is medically recognized as a miracle cure. Unfortunately, this medicine just been approved in Canada on December 16, 2020 and it will still take several months for funding negotiations to take place between pan-Canadian Pharmaceutical Alliance and Novartis.

Although Marcel's parents have started a Go-Fund-Me, the reality is that it will not be able to raise this amount, certainly not within the six-month window of treatment.

I therefore ask that you, Ms Elliott and Ms Hajdu, take on Marcel's unfortunate situation as a case of compassion, and immediately fund Marcel either to take the treatment at Boston Children's Hospital, or to purchase one dose of Zolgensma to be brought to Toronto to be administered by Sick Kids' Hospital.

Although \$3 million is a huge amount of money, surely you will understand that it is microscopic compared to the 38 BILLION dollars that Ontario will spend this year alone in the fight against COVID, and 300 BILLION additional dollars that will be spent federally.

Yet, unlike COVID, and unlike the BILLIONS of dollars that are spent annually on health care for people who are often terminally ill with no hope of recovery, Zolgensma is a ONE-TIME treatment that has been proven to cure this affliction and which, if given to Marcel in time, will rescue him from almost certain death and allow him to live a normal and healthy life.

Ontario and Canada spend BILLIONS of dollars each year to treat such medical misfortunes as cancer, diabetes, heart attacks, Alzheimers, organ transplant, and numerous others, many of which are caused by an unhealthy lifestyle. Yet Marcel is a new-born baby boy who has done nothing wrong.

At this moment, Marcel is not showing any symptoms. If he can receive his dose of Zolgensma immediately, he will become the first baby in Canada EVER to be cured of SMA even before he begins to suffer from it.

When COVID hit our shores, all of our provincial governments, and our federal government, took instant action to protect us, provide emergency funding, and help us to heal. These combined expenditures at all levels will potentially total TRILLIONS of dollars.

Ms Elliott and Ms Hajdu, please find it in your hearts to spend \$3 million to save the life of one precious new-born infant. You have that power in your hands. Think of how proud you will be when you turn the darkness of certain death into the light of glorious life. Thank you and God bless you.

Signed,  
Daniel Muljarahardja