



CURE SMA CANADA
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August 4, 2020

Dear Members of the PMPRB,

The Canadian Spinal Muscular Atrophy community is highly concerned about the proposed price restrictions and the effects they will have on the lives of patients affected by rare diseases.

Spinal muscular atrophy affects approximately 1 in 11,000 births - it is the number one genetic cause of death for infants. It is a disease that robs people of physical strength by affecting the motor nerve cells in the spinal cord, taking away the ability to walk, eat, or breathe. Individuals with SMA have difficulty performing the basic functions of life, like breathing and swallowing. However, SMA does not affect a person's ability to think, learn, and build relationships with others.

An SMA diagnosis can bring a lot of uncertainty. Many factors can impact what living with SMA will mean for a patient and their family. In the past, families never had hope for the future, time with their children was going to be limited, the hope they possessed was only how long that time would be. Promising new treatments changed the SMA landscape, patients have seen dramatic changes in quality of life as well as longevity. We are proof of the benefits of accessing lifesaving therapies and the tremendous impact that they have on lives. We have experienced how before treatment, a patient spent many days in hospital, saw many specialists, medical equipment, missed school and work days and ultimately the untimely loss of life. The patients in the SMA community finally accessed treatment, we saw far less days in hospital, more school days, more work days, endurance and most importantly, more time was gifted with our loved ones.

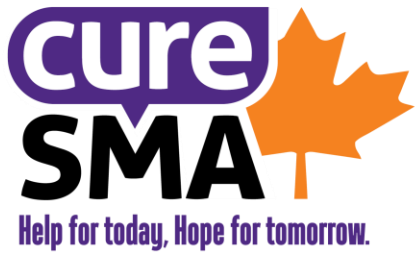
Imagine our deep concern with the proposed limitations with the price restrictions that will eliminate the SMA community from accessing future lifesaving treatments. We know these restrictions will stop pharmaceutical companies to file in Canada, we know that clinical trials in Canada has already seen a dramatic drop, we know that Canadians with rare diseases will lose out on quality and quantity of life. With a disease like SMA, every day matters, these restrictions will delay access to treatments, less drugs will be launched in Canada, medical costs and hospitalizations will increase and the patients will pay the highest price, the loss of time.

What is the PMPRB stating? That our lives don't matter?

Please put an immediate full stop to this proposed price restriction, the SMA community has a great deal to offer Canada. More information and discussion is needed, we are very willing to provide input to assist this decision.

HELP FOR TODAY. HOPE FOR TOMORROW.

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Ultimately, our lives are in your hands.

Make the right decision!

Sincerely,

Susi Vander Wyk
Executive Director of Cure SMA Canada
On behalf of the Spinal Muscular Atrophy Community of Canada

Best regards,

Susi Vander Wyk
Executive Director

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