**For Immediate Release**
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# Edmonton Family Asking for AHS Compassion Funding to Save Toddler's Life with Multi-Million Dollar Drug

**Edmonton** - Imagine your special needs child had a fighting chance at life but the drug you needed was out of reach, worth 2.8 million dollars?

Edmonton toddler, Kaysen Martin, was diagnosed with Spinal Muscular Atrophy Type 1 (SMA 1), a motor neuron disease affecting the voluntary muscles that are used for lung support, swallowing, crawling, walking and head control.

Approximately 1 in 6000 babies are born with SMA. Most children with SMA 1 do not live to see their 2nd birthdays.

The drug Zolgensma is the first gene therapy that could provide a one-time forever treatment for Spinal Muscular Atrophy. Zolgensma is coming to Canada; however the drug must be administered before the age of 2. The price tag of the drug is 2.8 million dollars and Kaysen turns 2 in just 17 days, on July 17th. Time is running out.

Kaysen's parents, Lana Bernardin and Mark Martin, have spent the last 2 years fighting for Kaysen to receive the only other available drug currently available in Canada, called Spinraza. The first two years of treatment with Spinraza cost around 50% of one Zolgensma infusion, but Spinraza treatments must continue for life at a cost of $375,000 each year. The four initial loading doses of Spinraza in the first year of treatment total $750,000. A one-time dose of Zolgensma would save Alberta Health Services thousands of dollars and a life time of support for Kaysen if approved now.

"We are exhausted and scared," says Lana Bernardin, Kaysen's mother. "But we have to keep fighting. We've started a petition, we are working tirelessly with the Canadian Organization for Rare Disorders to lobby Alberta Health Services to help us. We have yet to hear if they'll provide this therapy for Kaysen and we only have 17 days till he will no longer qualify for this treatment."

“Every Canadian baby should have the very best chance for life, says Durhane Wong-Rieger, with the Canadian Organization for Rare Disorders. Time is running out for Kaysen and yet the cost effectiveness of Zolgensma is clear. In terms of quality of life, one infusion of Zolgensma would save Kaysen sedation and multiple spinal infusions of Spinraza each year. We are calling on the Alberta Minister of Health, Tyler Shandro, to provide this gift to Kaysen and to Health Canada to approve this drug for Kaysen and his family.”

The drug company and makers of Zolgensma, Norvartis, have applied to Health Canada for approval of the drug. However, Health Canada has already approved a Special Access Program, so Kaysen can get the drug prior to approval if funding becomes available through Alberta Health Services. Zolgensma was given FDA approval in the United States in May of 2019 and is currently the most expensive drug in the world. In patient testing, babies with the most severe form of the disease who got the treatment within 6 months of birth had limited muscle issues. It is best administered early in life.

To sign the Martin’s Change.org petition click here.

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