Dear (insert MP or MPP or Ministry of Health or Miniter of Health NAME),

I am writing to you today regarding the situation of young infants and toddlers in Ontario diagnosed with Spinal Muscular Atrophy (SMA). **There are at least four children under the age of two and a half who have an urgent need to receive the newly approved life altering gene therapy, Zolgensma**. Their names are **Jaxon, Marcellinus, Stephanie and Tiffany** (twins).

SMA is caused by a loss of specialized nerve cells called motor neurons that control muscle movement. It is a devastating progressive disease that robs babies of their ability to move, talk, swallow and eventually breathe through the death of motor neurons (the communication link between the brain, spinal cord and the body’s muscles). SMA is the number one genetic killer of children under the age of 2. While there is an existing treatment available ([Spinraza](https://smanewstoday.com/forums/forums/topic/key-differences-between-spinraza-and-zolgensma/)), it only slows the progression of the disease, it does not stop it. **Zolgensma stops it.**

Health Canada approved Zolgensma on December 16th, 2020 but the standard review and funding process through CADTH and the pan-Canadian Pharmaceutical Alliance (pCPA) is ongoing and will likely take many months to complete. While I would like to ask you to expedite that process, I recognize that it does exist for a reason. With that said, **the children with current diagnoses of SMA do not have time to wait to receive treatment. With every day that passes, more irreversible damage is done to their bodies.** They need to be treated as quickly as possible to halt the destruction this disease causes.

**I would like to draw your attention to the number of Ontarians who consider prompt access to Zolgensma an important issue.** Pre-Health Canada approval, a federal e-petition was posted online for one month in Fall 2020 ([petition e-2868](https://petitions.ourcommons.ca/en/Petition/Details?Petition=e-2868)) asking the Federal government to work with provinces to support early access to Zolgensma for these children who are being left behind by the standard pharmaceutical approval and funding process. **1,412 Ontario residents signed this petition.** **3,710 Canadians signed this petition.** Access to Zolgensma for these children who so desperately need it is something that Ontarians want to see happen **now**.

I understand that while no public announcement has been made, the government of Ontario has communicated to some physicians and families that they may be able to access Zolgensma on a case-by-case basis under the [Exceptional Access Program](http://health.gov.on.ca/en/pro/programs/drugs/eap_mn.aspx). **I am writing to ask that you make this information public and encourage all physicians to support and advocate for access for their patients. I am further asking you to approve the requests submitted as quickly as possible to provide these children with access to this pivotal treatment.**

**None of these children should be left behind and miss out on a life-altering therapy because of bureaucratic timing.** There are many arguments in favour of Zolgensma: it is substantially more cost effective than Spinraza ($2.8M vs $6.7M), has better health outcomes, would reduce use of the healthcare system, reduced infant & parental stress, and the list goes on. **Please help these infants access Zolgensma as quickly as possible. The quality and quantity of their lives depend on it.**

Thank you for your time. I look forward to hearing from you regarding your actions on this.

Sincerely,

[*insert your NAME]*

*resident of [ insert your PROVINCE & POSTAL CODE]*