***VIA MAIL***

[September xx, 2016]

[Mr. or Ms.] [insert name of MP], M.P.

House of Commons

Ottawa, Ontario K1A 0A6

Dear [Mr. or Ms.] [insert name of MP],

**Subject: Orphan Drug Regulatory Framework Urgently Needed**

I am writing to thank you for the important work you are doing for our constituency and to seek your support in implementing the federal Orphan Drug Regulatory Framework for the benefit of my family and the 3 million Canadians affected by a rare disorder.

Why must Canada implement an Orphan Drug Regulatory Framework? It has been 33 years since the USA, 20 years since Japan, and 16 years since the European Union implemented their Orphan Drug Acts. While Canadians eventually get access to many of the orphan drugs, Canadian physicians tend not to be included in early clinical trials, depriving them of cutting-edge experience and depriving Canadian patients of early access to innovative therapies. Even when an orphan drug is discovered in Canada (often with Canadian research dollars), the discovery is transferred for further development to a company in the USA or Europe, where there designated incentives. Canada loses in terms of expertise, investment, intellectual property, and, most importantly, timely access for Canadian patients.

**[Include a few sentences describing the rare disorder affecting you or your family and any challenge you have experienced accessing appropriate treatments.]**

In 2010, the Canadian federal government committed to developing an Orphan Drug Regulatory Framework. Since then, consultations with stakeholders have taken place and draft regulations have been ready for implementation for several years. We have been assured that there is no good reason for the delay. Sadly, without the Orphan Drug Regulatory Framework, Canada is a bystander and not a contributor to either the research or to the dialogue on appropriate sustainable access.

I ask for your support in calling on the federal Minister of Health, who is responsible for the implementation of this framework, to advance quickly and make this framework a reality. Can I count on your support? I would greatly appreciate a response to my letter.

Thank you in advance for your commitment to this critical healthcare issue. For more information, please visit www.raredisorders.ca.

Sincerely,

[Include your signature]

[Insert your name]

[Insert your address, phone number and email if you are willing to do so]