



Platelet Disorder Support Association

Empowering ITP Patients

November 20, 2019

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Hon. Christine Elliott
Minister of Health and Long-Term Care
Hepburn Block, 10th Floor
80 Grosvenor Street
Toronto, ON M7A 2C

Cc Angie Wong, Director Drug Programs Policy and Strategy
Patrick Dicerni, ADM and Executive Officer
Helen Angus Deputy Minister

Subject: Requesting urgent reform on existing policies surrounding drug access for patients in Ontario living with immune thrombocytopenia (ITP). Seeking updated policies reflective of accumulated solid evidence-based medicine to enhance and save the lives of patients living with this condition. Sharing patient stories to highlight the need for provincial government support.

Dear Hon. Minister Elliott,

The Platelet Disorder Support Association (PDSA) is a non-profit patient support organization dedicated to enhancing the lives of patients with immune thrombocytopenia (ITP) and other platelet disorders through education, advocacy, research and support. In Canada, PDSA is registered as a not-for-profit corporation and holds Canadian Regional Meetings on an annual basis and facilitates several PDSA support groups for patients and their families affected by this rare haematological blood disorder.

PDSA is reaching out with urgency to you and your team to update provincial policies on drug access for patients with immune thrombocytopenia (ITP).

ITP is an autoimmune condition that affects 3-5/100,000 individuals and causes the body to attack its own platelets drastically reducing the number of circulating platelets in the blood. Children and adults are at risk to bleed severely with minimal injury, and experience sometimes fatal bleeds spontaneously just on the basis of having a low platelet count. Access to treatment depends on what province you live in. Cost of treatment varies per province. Treatments that are covered under OHIP do not work for every ITP patient and they have long-term side effects often outweighing the benefit of using them. Current approved therapies include corticosteroids used often at extreme high doses, IVIG, and Anti-D therapy which comes with a black box warning. Splenectomy is also an approved therapy. For most chronic ITP patients, currently approved medical treatments only affect their platelet count for a few days or weeks following use. In many cases, surgical

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treatment (splenectomy) does not work, leaving the patient without a spleen and a forever compromised immune system.

New and more advanced non-surgical medications are available for ITP patients. These newer options have less side effects and will elevate platelet counts for a significant time. However, patients with ITP cannot access these treatments without private insurance due to the current processes in place. Most private insurance companies will not provide coverage, and those that do cover the entire cost of these medications. These newer medicines (monoclonal antibody therapy and thrombopoietin receptor agonists) are less expensive than a surgical splenectomy that also requires limited operation room bookings.

The lives of patient's living with ITP can be significantly improved with access to newer medicines such as Rituxan and TPO-RAs including eltrombopag and romiplostim. Revised ITP guidelines, soon-to-be published, recommend the use in specific situations of TPO-RAs in both adult and children with persistent and chronic ITP, however *the implementation of professional medical guidelines will not be possible in the province of Ontario.*

The PDSA requests the provincial government better support those in Ontario who are suffering with ITP by implementing the following:

- 1. Urgent reform of outdated policies and procedures in place for drug access for individuals with ITP.** Patients and their hematologist should be able to make a medical management plan that optimizes patient care and safety.
- 2. Provide OHIP coverage for established off-label therapies to be used in the treatment of ITP (i.e., Rituxan, romiplostim and eltrombopag).** Significant scientific evidence is available to support the use of Rituxan to treat ITP. Patients with ITP living in Ontario cannot afford to pay out-of-pocket for this medication and private insurance companies may not cover the cost since Rituxan would be used 'off-label'. OHIP will only cover the use of Rituxan through the exceptional access program and this is only available once other less effective and toxic treatments have been tried and failed. Ontario patients have to subject themselves to significant side effects from medications with short-term benefit instead of using safer newer medicines that work for a longer period of time with fewer side effects. Some patients cannot access TPOs until Rituxan has been used and failed. Revised guidelines suggest using TPOs over Rituxan to avoid immunosuppression. Thus, Ontario policy is in direct conflict with medical management guidelines about to be published.

On October 23, 2019 the CBC published an article highlighting the experience of a Canadian with ITP who could not access safer treatment through the province of British Columbia <https://www.cbc.ca/news/health/itp-drug-1.5326930>. We want you to hear how a few of our PDSA members living in Ontario have been negatively impacted by the current drug coverage policies in place (see enclosed).

A letter has recently been submitted to you from a group of hematologists across the province of Ontario. Our wish is to support that letter and enhance its impact. We ask that you make the necessary changes to drug access to enhance and save the lives of patients with ITP.

Sincerely,
Jennifer DiRaimo, MS, CCGC
Genetic Counsellor/Research Coordinator
Platelet Disorder Support Association

Caroline Kruse
President and CEO
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Enclosed: Patient Stories