

# TTP Treatment in Canada

Community meeting focusing on the impact of NOT having access to caplacizumab in Canada.

# Access to Caplacizumab in Canada



March 2020 Health Canada approval means **you can get it.**



August 2020 evaluation bodies publish *DO NOT REIMBURSE* recommendation which means **it is not funded.**

# The Foundation Has Written Letters

The letters to CADTH and INESSS emphasize the enormous challenge of rescuing an aTTP patient without caplacizumab. Three main messages of campaign.

1. Caplacizumab saves lives and prevents disability. Canada's inability to adopt caplacizumab is causing undo suffering and death.
2. Caplacizumab prevents the formation of clots that cause organ damage, allowing patients to survive long enough for standard therapies to take effect.
3. Peer nations have recognized its evidence-based utility by updating their international treatment guidelines to include the use of caplacizumab.

**This isn't enough.  
We Need Your Voice Now!**

# Your Next Steps for the Community

## 1. TODAY Participate and Share Our Letter Writing Campaign



You will be provided a link to write your provincial Health Minister and local elected provincial representative (MPP or MLA) with a few mouse clicks or phone taps.

Share the link with your network – family, friends, co-workers, neighbours. You are the tip of the iceberg in the success of this movement.



## 2. Discuss the use of caplacizumab with your physician

The very nature of TTP is that it is a true medical emergency. Patients may be admitted to hospital unable to discuss care with their physician due to the severity of disease. The time to talk through treatment scenarios with your TTP treatment team is now.

Writing your Health Minister and MP is as easy as a few mouse clicks...



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## Caplacizumab Letter Campaign

I was very sick and very scared, my husband and parents were told I might die, which was very scary for them.

[Read Vickie's Story »](#)

Caplacizumab was approved by Health Canada in 2020, but is not funded for use in Canada despite being a standard of care in peer nations. Caplacizumab is our only immediate defence against the potentially life-altering blood clots that characterize a TTP crisis. Standard treatments are designed to control the underlying mechanism of disease, but require time to take effect, time that a TTP patient does not have. Caplacizumab can shield patients from the formation of clots, giving standard therapies the time they need to kick-in. Caplacizumab saves lives and prevents disability.

### Answering TTP Community

**We are stronger TOGETHER!**

Register online to be part of the unified voice for TTP. Receive the quarterly newsletter, updates and surveys.



Enter your email address: \*

Register NOW

# Access to life-saving treatment: caplacizumab

TEST MODE

Thank you for lending your voice! Please fill in the details

Thank you for taking action for aTTP patients! 🔍 Inbox x Contact@answeringttp.org x



AnsweringTTP via [advocacyvoice.com](https://advocacyvoice.com)

6:30 AM (10 minutes ago) ☆ ↶ ⋮

to me ▾

Thank you for taking action, Sydney!

Please help us spread the word by sharing this campaign with your network:

Post to Facebook ▶

Share on Twitter ▶

Share by email ▶

We have included your message below for your reference.

— The AnsweringTTP team

Dear Minister of Health Christine Elliott,

Selena, a 19-year-old from Ottawa, suffered her third stroke in a few days in the intensive care unit, before receiving caplacizumab for TTP and stabilizing almost overnight. Her doctor was shocked: "We had heard about this treatment, but we didn't know it worked this well or this fast."

I am writing to urge you to make caplacizumab accessible to all Canadians with TTP (thrombotic thrombocytopenic purpura).

TTP is an ultra-rare blood disorder that rapidly turns fatal without immediate treatment. A TTP crisis is a true medical emergency where blood clots quickly form throughout the body and block the flow of oxygen-rich blood to vital organs. Caplacizumab works immediately to keep patients like Selena safe from those clots so that existing treatments have the time they need to "kick in".

Up to 20% of patients with aTTP will die before standard therapies have time to work. Other patients needlessly suffer irreversible and life-altering complications due to clots that could be prevented.

Caplacizumab was the turning point for Selena, but this life-saving treatment is not available to most Canadians with TTP, despite Health Canada's approval following Priority Review.

International guidelines recommend the use of caplacizumab in patients with TTP. It has been approved for reimbursement in the UK, United States, Austria, Belgium, Denmark, Netherlands, Finland, and Italy. For a country that pioneered TTP treatment by establishing the use of plasmapheresis 30 years ago, Canada's delay in adopting caplacizumab is inexcusable.

On behalf of Canadians who have survived an episode of TTP, and those who have not, I urge you to save lives by making caplacizumab accessible to Canadian patients by adding it to our provincial formulary.

Sincerely,  
Sydney Kodatsky  
[contact@answeringttp.org](mailto:contact@answeringttp.org) M9A 1Y1

Your confirmation  
email will arrive in  
your inbox...

# Discuss the use of caplacizumab with your physician.



- Your approach to the discussion is important.
- Follow up appointments are for checking in and asking questions. Physicians expect questions from their patients, and should be open to discussing treatment scenarios.
- Handout is not intended to be given to your physician.

# Be Prepared. In Case.

Talk through treatment scenarios with your TTP treatment physician now.

The very nature of TTP is that it is a true medical emergency. Patients may be admitted to hospital unable to discuss with care with their physician due to the severity of disease. The time to talk through treatment scenarios with your TTP treatment team is now.

**If your TTP is not responding to the standard therapy of plasmapheresis and immunosuppression consideration for adding caplacizumab to your treatment regime should be considered.**

Once administered, caplacizumab is proven to buy patients time by acting against these potentially life altering clots before they cause further damage. Many peer reviewed, scientific studies have shown that caplacizumab saves lives, reduces time in the ICU and in the hospital, and prevents lifelong disability.

International guidelines recommend the use of caplacizumab in patients with TTP. It has been approved for reimbursement in the UK, United States, Austria, Belgium, Denmark, Netherlands, Finland, and Italy. For a country that pioneered TTP treatment 30 years ago by establishing the effectiveness of the current therapy, plasmapheresis, Canada's delay in adopting caplacizumab is inexplicable.



**Answering T.T.P.**

Thrombotic Thrombocytopenic Purpura Foundation  
www.AnsweringTTP.org

## T.T.P. Thrombotic Thrombocytopenic Purpura

*TTP is a medical emergency causing small blood clots and potentially fatal complications. Early diagnosis is key to survival. TTP can strike anyone, at any stage of life. Three in one million people are diagnosed each year.*

From the NEW ENGLAND JOURNAL OF MEDICINE  
January 24, 2019  
[New England Journal of Medicine](#)

Among patients with TTP, treatment with caplacizumab was associated with faster normalization of the platelet count; a lower incidence of a composite of TTP-related death, recurrence of TTP, or a thromboembolic event during the treatment period; and a lower rate of recurrence of TTP during the trial than placebo. (Funded by Ablynx; HERCULES ClinicalTrials.gov number, NCT02553317)

International guidelines recommend the use of caplacizumab in patients with TTP.

The International Society on Thrombosis and Haemostasis (ISTH) has published new clinical practice guidelines for the diagnosis and treatment of thrombotic thrombocytopenic purpura (TTP). Developed in partnership with McMaster University, the ISTH TTP Guidelines are the product of a rigorous, systematic review of evidence by a guideline panel comprised of clinical experts, methodologists and patient representatives.

[ISTH TTP Treatment Guidelines](#)

The United States Thrombotic Microangiopathy (USTMA) Consortium of physicians have collaborated and created a document giving guidance on the diagnosis, treatment, and outpatient follow up of patients with TTP. Drs. Mazepa and Cataland formed the United States Thrombotic Microangiopathy (USTMA) Consortium in 2014 as a grassroots effort to organize research efforts in the thrombotic microangiopathies.

[USTMA Treatment Guidelines](#)

Charitable Registration # 84600 4802 RR0001  
The content herein is intended for informational purposes only, and is not meant to substitute consultation from a recognized health professional.

## New Treatment for TTP Patients Not Responding to Standard Therapies

**Caplacizumab** is the first targeted treatment for TTP. Once administered, caplacizumab is proven to immediately buy patients time they need, by protecting them from blood clots, while standard therapies "kick in". Many peer reviewed, scientific studies have shown that caplacizumab saves lives, reduces time in the ICU and in the hospital, and prevents lifelong disability.

### Selena's Story

Thanksgiving 2020 was difficult enough with the COVID-19 pandemic, but when my 19-year-old daughter who is usually full of life and energy, came home from work looking jaundiced, feeling tired and had no appetite, I knew it was something more than a bad day at work. I took her to the emergency room where she had a round of lab tests done and they indicated her platelets (Platelets/thrombocytes) are colorless blood cells that help blood clot -were dangerously low. The doctor had already spoken to a hematologist and they promptly began a blood transfusion while they ran more tests which came back to confirm that Selena had something called TTP.

Selena responded well to the first 5 days of standard TTP treatment in hospital, but then she started getting worse again. Her health declined for another week even after doubling the standard plasmapheresis treatments and adding additional immunosuppressive therapy. I asked Selena's physician about a new treatment I'd heard about called caplacizumab. I'd learned that it is used to keep patients safe from blood clots until standard treatments have time to "kick in". I was told that the therapy had been approved in Canada in March 2020 but it wasn't actively being used as it was expensive and outside the Canadian standard treatment for TTP.



Seeing my daughter complete hours of treatment with a needle in her neck, being in the hospital for weeks during a pandemic, then bottoming out with a heartbreaking series of strokes from clots resulted in Selena being moved to the ICU. As a Mom, I felt helpless that I couldn't take this away from her. A new hematologist's shift started on Selena's case and mentioned caplacizumab. Not sure where the money would come from, and knowing no one had received this drug at his hospital, he put in a stat request to see if there was anything they could do to bring it in for her.

The next day Selena suffered her third stroke and I was desperate. TTP was taking my 19-year-old daughter. Tapping into all resources, the medicine arrived to the hospital at 4 pm that day and Selena had her first dose that night.

Caplacizumab was the turning point for Selena. Within 4 days Selena told me "Mom, I am feeling great again." and was soon able to go home. It worked!! Selena is now in remission. Our daughter was given a second chance!



**Answering T.T.P.**

Thrombotic Thrombocytopenic Purpura Foundation

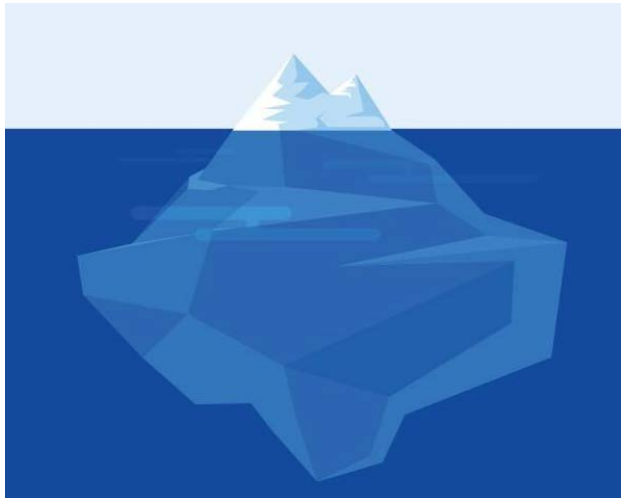


# Please do these 2 things,

## 1. TODAY

Write your Provincial Health Minister NOW.

Share the link with your network. You are the tip of the iceberg. Let's be heard!



## 2. NEXT APPOINTMENT

Start the conversation with your physician. It may save your life.

