**SUBJECT LINE: *CONSTITUENT MEETING REQUEST:*** *Urgent access needed to an effective treatment for rare blood disorder*

Date

(MPP Name)

(Address 1)

City, Province

Postal Code

Dear MPP (name)

I am a constituent of yours and I am writing to request a meeting with you to discuss an important issue affecting the treatment of a rare blood disorder – aTTP, or Acquired Thrombotic Thrombocytopenic Purpura (aTTP).

ATTP is a serious and rare blood disorder affecting only 2-6 per million people per year. A deficiency of an enzyme causes small blood clots to form throughout the body and prevents oxygen-rich blood flow to critical organs. The medical community has characterized an aTTP crisis as a true medical emergency because damage to critical organs from the small blood clots happens quickly, is unpredictable, life-threatening, and can be irreversible. It takes time for standard untargeted treatments to kick-in. As a result, each aTTP crisis carries a 20% mortality rate with standard treatments alone. BUT there is hope.

A new targeted treatment, caplacizumab, can shield patients from the formation of clots, giving standard therapies the critical time they need to work. Caplacizumab saves lives and prevents disability. But aTTP patients in Canada do not have access to this life-saving therapy.

In January of 2021, Lorraine suffered a second aTTP relapse after contracting COVID19 from her end of life dying comatose father who had tested negative days before. After receiving standard aTTP treatment her case took a nosedive and she became very scared that maybe she would not dodge the bullet this time. Caplacizumab was added to her treatment regime and she was released from hospital two weeks later, half the time as what she spent during her less severe first two aTTP episodes. Lorraine is grateful to be alive.

Treatment for aTTP is grueling. When an episode begins, patients must be hospitalized and undergo blood plasma exchange, and immunosuppression. Plasma exchange is a frightening, risky and unpredictable treatment. Utilization of this untargeted treatment for aTTP dates back to the 1980s. The treatment replaces a patient’s blood plasma in an attempt to rebalance enzyme levels and remove antibodies. This untargeted treatment is repeated at least daily and then tapered-off as tolerated. Sudden life-threatening flares during tapering, or soon after, is not uncommon and requires the process to start again with daily treatments. Plasma exchange can only be administered to hospital in-patients and may require weeks and sometimes months of hospital stays. For the duration of this time, patients remain at risk of severe complications and death. Stats don’t lie, even with timely treatment and access to standard care, up to 20% of patients in an aTTP crisis still die.

As you can imagine, this disease also has real mental health consequences. The uncertainty of the severity and timing of the next relapse brings about real mental stress. A high prevalence of PTSD and depression in aTTP survivors has been reported and a study found that 80.8% of individuals with aTTP have mild depressive symptoms, compared 10.5% found in the general population.

The Canadian aTTP community was thrilled to hear of an improved treatment recently approved in Canada: caplacizumab. When added to the standard of care, caplacizumab is proven to prevent blood clots from forming in the body while standard therapies kick-in. This helps to buy critical time for an aTTP patient’s treatments to work while being protected from additional long-term health consequences.

For aTTP patients, caplacizumab is undoubtedly life-saving and this is where we need your help. While caplacizumab was deemed a priority review by Health Canada and approved in March 2020, the good news ends there. In September 2020, The Canadian Agency for Drugs and Technologies in Health (CADTH) issued a negative recommendation for the drug and while the reviewers noted caplacizumab’s efficacy and ability to provide better care for patients, they cited issues with the way that the manufacturer designed its clinical trial for a rare disease population.

Our community is currently at a loss. Other peer countries across the world are already covering caplazicumab, including the United Kingdom, Austria, Belgium, Denmark, Netherlands, Finland and Italy – leaving Canada as an outlier among its peer countries across the world and Canadian aTTP patients in life-threatening condition. It is also puzzling to us that caplacizumab was recommended for reimbursement by the United Kingdom’s National Institute for Health and Care Excellence (NICE) with the same clinical study reviewed by CADTH.

**I would appreciate the opportunity to speak further with you on this issue, and how we can ensure that aTTP patients identified by their physicians to benefit from this life-saving treatment, can receive access to it.**

I am available at your convenience – please let me know when you are available to meet either virtually or in person.

Sincerely,

(insert your name)