

THE PULSE

for patients living with AA, MDS, PNH and the caregivers who support them



AAMAC Newsletter - Spring 2020



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UPDATE ON THE PMPRB DRAFT GUIDELINES

We know you're probably thinking, oh no, not another acronym! What is PMPRB? Well, it stands for Patented Medicine Prices Review Board. This quasi-judicial body has a regulatory mandate to protect consumers from excessive pharmaceutical prices during the company's monopoly period for a new drug.

After 30 years, the government has decided to modernize the Patented Medicines Regulations to adapt to shifts in how the pharmaceutical industry handles research and development. The Draft Guidelines are intended to operationalize the Regulations, which were amended in August 2019. The government began a 60 day consultation period on the Draft Guidelines on November 21, 2019.

The Draft Guidelines propose a new approach for monitoring and reviewing patented medicine prices. Information about the Draft Guidelines and a Q and A can be found on the [Government of Canada webpages](#).

Both patient groups and pharmaceutical companies have raised concerns about the proposed changes.

There are concerns that the changes may negatively impact:

- Launching of new drugs in Canada
- Availability of clinical trials in Canada
- Patient support programs that are currently funded by pharmaceutical companies, such as compassionate access, infusion clinics, and nursing support

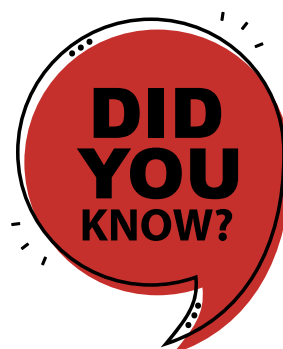
The PMPRB recently responded to these concerns in a [presentation posted on its website](#).

You can read more about industry concerns on the website of [Innovative Medicines Canada](#)

You can read about the concerns of the Canadian Organization for Rare Disorders [here](#).

AAMAC expressed its concerns in a [letter to the Prime Minister](#) in May 2019 and will continue to monitor and respond to this issue.

**AAMAC offers
free telephone
and email peer-
to-peer support**



A PATIENT'S JOURNEY: INTERVIEW WITH CHLOE PEARSON

by Fiona Lewis



Chloe Pearson was recently diagnosed with Severe Aplastic Anemia (AA) and lives in Victoria, B.C. She spoke to AAMAC about her journey from diagnosis to treatment.

Can you tell me about your experience of getting diagnosed with AA

I didn't feel well for a couple of weeks, was burned out, experiencing heart palpitations and breathlessness. One day in August I went to work and took the stairs as the elevator was down. I felt terrible going up 4 flights so I went to hospital. Once there, I had a bone marrow biopsy within hours because my hemoglobin, platelets and neutrophils were all so low. I spent 4 nights in hospital and received a definitive diagnosis within 5 days. By August 23rd, it was confirmed by a hematologist at Vancouver General Hospital. I immediately received 3 blood transfusions and my wife noticed right away that my sun tan had returned! I was having transfusions every 2 weeks after that for a couple of months.

What challenges have you faced in adjusting to your diagnosis?

The biggest challenge was waiting for news on what my treatment plan would be: being in limbo was the hardest. It took six weeks to determine that my sister was not a match for a transplant. My doctor recommended trying ATG rather than going with an unrelated bone marrow donor. The ATG is working well for me. I had a lot of side effects at first but now all of my counts are very close to the normal range. I was lucky to be able to stay at home while they figured out my treatment plan. The other major challenge was having to spend two months in Vancouver during treatment. My friend started a GoFundMe campaign to assist with my living expenses. I found it very challenging to have to ask friends and family for this support but their response was incredible. We ended up renting a bachelor suite in Vancouver, found through word of mouth. My wife took unpaid caregiver leave, my mom took an unpaid leave and my dad and his wife came out from the U.K. to support us. There was a financial ripple effect through the family.

What about your family and friends? How did they handle the news?

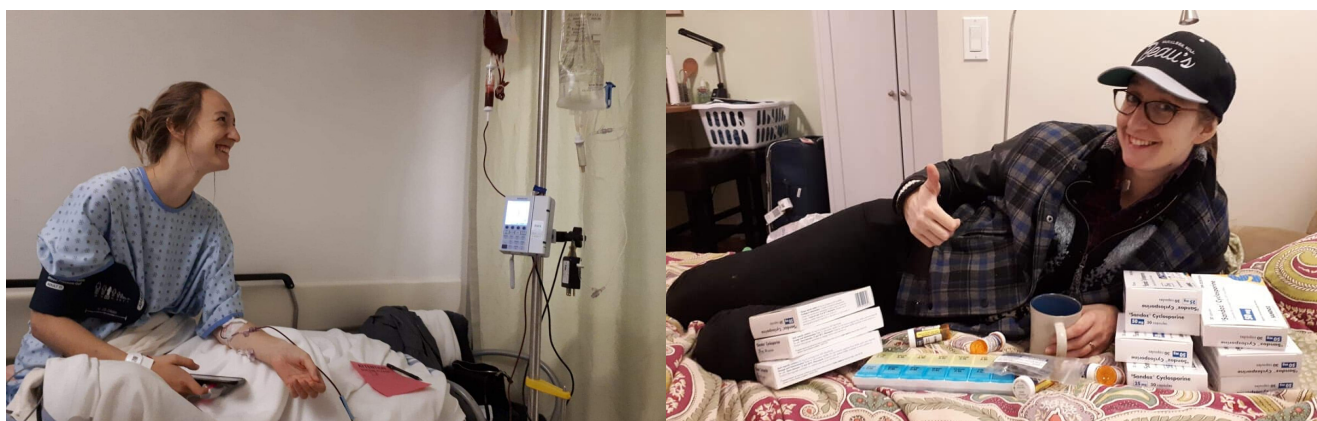
As soon as people hear anemia, they think it's just low iron. I find it helps to lead with "bone marrow failure". Generally, people were shocked – I'd just graduated, married, and moved across the country so there was a feeling that I was getting settled, then this happened. The unknown is the worse. I wondered if the treatment would work for me. You read the survival statistics and wonder which statistic you will fit into. We worried about catching germs: my wife at work or my mom on a plane. We cleaned the house like crazy.

What resources or supports have been the most useful for you?

AAMAC's web resources prevented me from going down a Google wormhole. It helped me get things straight right away. Now, I'm part of an AA Awareness Facebook group. I find it really helpful to connect with others as this disease is so rare. Support group meetings are helpful, too, in terms of hearing from others with same condition. Instagram hashtags also help us connect (#AplasticAnemiaAwareness). It is encouraging to read about others who have returned to normal life.

What advice would you give to someone just receiving a diagnosis like this?

I recommend using your support system and letting people help you. They want to get involved so don't be too proud to accept help. Also, keep trying to have a good time and spend time with people you care about. Keep a positive attitude to help you push through difficult times. Avoid Google wormholes and worrying about the worst outcomes. Bring someone with you to appointments to take notes. Don't be afraid to email your doctors with questions.



MEETINGS & EVENTS

Visit AAMAC.CA for all meeting and event details and registration

Ottawa Patient Support Group Meetings

Join us every second Wednesday of each month (except July, August & December) for a FREE Patient Support Meeting. Meetings run from 6-8pm and are held at the Maplesoft Centre, Ottawa Regional Cancer Foundation, 1500 Alta Vista Dr.

Calgary Patient Support Meeting

Date: March 21, 2020

Speaker: Reanne Booker, Nurse Practitioner

London Patient Support Meeting

Date: April 18, 2020

Speaker: Chris vanDoorn,
Canadian Blood Services

What happens at a support group meeting?

Share stories, compare notes, learn how others are coping and responding to treatments. In these meetings, patients and caregivers come together in a safe environment to share and learn from one another and access various resources through AAMAC.

Annual Patient Education Day

The 2020 Patient Education Day will be held in Halifax on October 17th. All AA/MDS/PNH patients and caregivers from the four Atlantic Provinces are invited to attend. Notice of the event, and registration forms will be sent to Blood Collection Units throughout communities of Nova Scotia, New Brunswick, Prince Edward Island, and Newfoundland and Labrador. A limited number of travel bursaries will be available up to a maximum of \$500 per family.

CHRISTMAS IN THE ATLANTIC

The Atlantic Region held it's Annual Christmas gathering at the home of Jennifer Moss in December 2019, including a pot luck lunch, and Christmas Carol singing, accompanied on the piano by the skilled pianist, Jennifer Moss



RARE DISEASE DAY - FEBRUARY 29, 2020

Rare Disease Day takes place on the last day of February each year. The main objective of Rare Disease Day is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives.



GET INVOLVED!

Register for AAMAC's Rare Disease Day webinar or check out CORD's breakfast event in Toronto. You can also visit www.RareDiseaseDay.org to find other ways to participate.

Webinar - A Review of the Stem Cell Registry

Join AAMAC on Rare Disease Day for an informative webinar featuring Dr. Heidi Elmoazzen from Canadian Blood Services. She will be discussing how the Stem Cell Registry is managed. Visit AAMAC.CA to register

Breakfast Reception at Queen's Park

On March 3, 2020, The Canadian Organization for Rare Disorders (CORD) is hosting a breakfast reception at Queen's Park in celebration of Rare Disease Day. This will be an opportunity for patients, families, and advocates to meet with members of Provincial Parliament and other supporters. This event is open to the public. Please visit CORD's website to learn more. www.RareDisorders.ca

Members of the AAMAC team will be attending the following private events:

Alexion Pharma Canada has invited a member of the AAMAC team to an open house at their office headquarters in Vaughan, Ontario. The event features an opportunity to meet with Alexion team members, share personal stories and learn more about AAMAC diseases and other rare diseases from experts and patient advocacy organizations.

Le Regroupement Québécois des Maladies Orphelines (RQMO) has invited a member of the AAMAC team to an event in Montreal in celebration of Rare Disease Day as well as recognizing the RQMO's 10th anniversary.

UPDATE ON THE CANADIAN APLASTIC ANEMIA AND MYELODYSPLASTIC SYNDROME STUDY (CAMS)

Dr. Yigal Dror, Hospital for Sick Children, reports that work on building the CAMS registry continues with the involvement of 14 pediatric hematology/oncology referral centers from all provinces in Canada. The ultimate purpose of CAMS is to improve outcomes for children and their families with acquired/idiopathic AA/MDS/PNH conditions by investigating the causes, clinical outcome and mechanisms of the disease and complications. CAMS is the only registry for acquired/idiopathic AA in Canada and the only registry for acquired/idiopathic AA/MDS/PNH in children.

Funding from AAMAC supports CAMS in the work of enrolling patients in the registry. As of December 2019, 76 patients have enrolled, 71 with AA and 5 with MDS. In 2020, CAMS will be involved in a project investigating the response of very young children with AA to immunosuppressive therapy. Dr. Dror and his colleagues will also soon be publishing the results of research into the "Reduction of extramedullary complications in patients with myelodysplastic syndrome treated with Azacitidine".

PANCAKE BREAKFAST SUPPORTS AAMAC

Thank you once again to Gary and Sylvia Scows for their generous donation following their annual Open House Pancake Breakfast fundraiser.

They hold the fundraiser at their home the Saturday before Christmas. It all started in 1992 as a way to include friends and family in Christmas activities. After their son was diagnosed with aplastic anemia they wanted to give back especially given the rare nature of the disease. Anywhere from 25 - 40 people stop by for the fundraiser.

If you feel inspired to organize a third-party fundraiser, please contact our office and speak to Robyn for guidance. Any donation, big or small, assists AAMAC in continuing to fund programs, services and research studies to support our patients and their caregivers.

Volunteer with us

AAMAC is grateful to our volunteers who donate their time and expertise.
Contact us if you are interested in learning about volunteer opportunities





Aplastic Anemia & Myelodysplasia
ASSOCIATION OF CANADA
ASSOCIATION CANADIENNE
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DONATE

You can help someone living with AA, MDS & PNH by making a donation. Patient support meetings, resources and programs are made possible by your thoughtful & generous donation. Thank-you.



Donate a Car Canada

Donate a Car Canada accepts vehicle donations for AAMAC. When you donate your car, truck, RV, boat, or motorcycle it will either be recycled or sold at auction. Visit our website to learn more.



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