



AAMAC
ACAAM

Aplastic Anemia & Myelodysplasia
Association of Canada

Association canadienne de l'anémie
aplasique et de la myélodysplasie

Newsletter - Summer 2025

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

Message from the Executive Director

I hope you are enjoying some sunshine and warmer weather when you receive our Summer Newsletter. We are already busy starting to plan for the fall meetings and webinars and we hope we will see many of you participating online or in person at those. Past presentations are all available on our website so please take the opportunity to see if any of the recordings would be of interest to you.

One of AAMAC's biggest challenges is ensuring that patients and their families learn about AAMAC at the time of their diagnosis when there are so many questions and concerns to be answered. In this issue you will see a study I was involved in asking Health Care Professionals about their knowledge of Patient Advocacy Groups and whether they advise their patients of our support services. This is an area where patients can assist AAMAC by asking their doctor or clinic if they would be open to having information about AAMAC available in order for patients to be able to access our services. If this is something you feel you could help with there is more information in the newsletter.

Fiona Lewis has put some information together on the impact the tariffs may have on medications. The information she received of course could be subject to change but will give you an idea of some of the potential challenges.

We wish you all a relaxing summer and hopefully some time with family and friends. Hope to see many of you in the fall.

Cindy Anthony

IN THIS ISSUE

Impact of Tariffs on
Healthcare 2

Research Update:
Doctor Awareness of
Patient Advocacy
Groups 4

Volunteer with
AAMAC 5

PaRX Program 6

Meetings and Events 7

IMPACT OF TARIFFS ON HEALTHCARE

Many of you may be wondering how the trade war between the United States and Canada will impact access to prescription medications, the price of medications, and the exchange of research knowledge across borders. Although the situation is still very fluid, this is what we know so far:

Medications

The Canadian Medical Association surveyed doctors in early February 2025 and found that almost 9 in 10 respondents are moderately to very concerned about the effect of tariffs on patients. They were most concerned about the cost of living for patients (83%), the cost of medications (70%) and a potential shortage of medications (71%)¹.

Prescription medications have so far been exempted from the trade war between the two countries. However, tariff threats are putting pressure on pharmaceutical companies to repatriate production to the US; this could result in higher production costs and an inflationary effect on medicine prices². Although World Trade Organization rules exempt most pharmaceuticals and their starting materials from tariffs, it is unclear whether the White House will continue to abide by this 30-year-old agreement.

There is a further concern that tariffs can lead to hoarding of pharmaceuticals as drug distributors and manufacturers may seek to stockpile raw materials to mitigate supply chain disruptions. As we saw during the Covid-19 pandemic, hoarding can drive up prices due to reduced availability and increased demand³. However, the [Canadian Pharmacists Association \(CPhA\)](#) advises that there is no need to panic as Canada's drug supply remains stable with pharmacies maintaining their usual medication supply levels.

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1. <https://www.cma.ca/latest-stories/eight-10-doctors-concerned-about-impact-tariffs-patients>
 2. <https://www.pharmaceutical-technology.com/analyst-comment/trump-tariffs-pharma-manufacturing/?cf-view>
 3. <https://www.forbes.com/sites/stephenbrozak/2025/03/04/as-tariffs-begin-what-will-they-do-to-drug-prices-and-availability/>



Other experts have expressed concern about Canada's supply of medications. Mina Tadrous, an assistant professor at the University of Toronto's Leslie Dan Faculty of Pharmacy, told Global News that, "any sort of tariff war on this space could send ripples throughout the supply chain.

Similar to automobiles, each drug crosses multiple borders before Canadians get the finished product from their local pharmacy, so tariffs may add to drug prices in Canada⁴. Some 16% of Canada's drug supply is imported from the United States. Overall, Canada imports about \$30 billion a year of pharmaceuticals from around the globe⁵.

Groups such as the CPhA are calling on the federal government to exclude pharmaceutical products from any retaliatory trade measures⁶.

Research

Overall, there is concern that cuts in the United States to the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), Food and Drug Administration (FDA), and other key federal health agencies threaten to stall research on promising drugs and treatments. Canada has long benefitted from the US's investments in biomedical research. The Trump administration's cuts to NIH funding are dismantling key research programs and forcing universities to absorb additional costs, disrupting a critical pipeline that drives new treatments and clinical breakthroughs⁷.

The long-term consequences of these cuts remain to be seen, particularly as some are now the subject of court challenges in the U.S. AAMAC will continue to monitor the situation and highlight potential impacts on Canadians with bone marrow failure.

4. <https://globalnews.ca/news/11004781/donad-trump-tariffs-drug-supply-canada/>

5. <https://edmontonjournal.com/news/world/trump-tariff-pharmaceuticals-canada-united-states>

6. <https://montreal.citynews.ca/2025/04/02/retaliatory-tariffs-canada-medication-pharmaceutical/>

7. <https://www.pharmasalmanac.com/articles/science-under-siege-the-devastating-consequences-of-public-health-and-research-cuts>





RESEARCH UPDATE: EVALUATION OF HAEMATOLOGY PHYSICIANS' AWARENESS OF AND REFERRAL TO APLASTIC ANEMIA PATIENT ADVOCACY GROUPS

This recent study aimed to evaluate haematology physician's awareness of Patient Advocacy Groups (PAGs) and assess their referral practices to PAGs. Awareness of PAGs among healthcare professionals is critical for ensuring patients with rare diseases get early access to the services PAGs provide.

Data was gathered from haematologists in six countries: the United States, Germany, Japan, France, the Netherlands and the United Kingdom. To be eligible to participate, physicians must have seen at least one Aplastic Anemia (AA) patient in the preceding six months.

The findings were as follows:

- 54% of respondents indicated that their centres inform patients/caregivers about PAGs
- The most common timepoints for informing patients/caregivers about PAGs were following treatment discussions and at initial diagnosis
- Factors influencing decisions to discuss PAGs included patient/caregiver requests for information about PAGs and the physician's familiarity with the PAG

Although Canada was not included in this study, AAMAC Executive Director, Cindy Anthony, reports that she believes the results here would be similar. This suggests that there is a gap in getting information about PAGs in a timely manner. AAMAC builds relationships with Canadian haematologists to ensure they are aware of our services and can refer patients easily.



VOLUNTEER WITH AAMAC

From April 27 to May 3, Canada celebrates the 24 million Canadians who contribute to improving the health, well-being, education and safety of the Canadian population and enhancing Canadian communities. As a non-profit patient advocacy group, AAMAC relies on the work of volunteers to extend our reach and maximize our resources. We have several volunteer roles available for someone who is looking to contribute to our mission.

- **AAMAC ambassador** – this volunteer works in their local community to ensure that hematologists and other health professionals are aware of us and our services. If you take on this role, you will be asked to distribute posters and information sheets to hematology clinics and offices.

- **Peer-to-peer support** – as a patient, you will connect with other patients, many newly diagnosed, to answer their questions about bone marrow failure and to provide support. The time commitment varies as some patients may just want to have one phone conversation while others appreciate a longer-term connection.

SUPPORTING CANADIANS WITH **Bone Marrow Failure Disorders**

If You or Someone You Love Are Living With:

- Myelodysplastic Syndromes (MDS)
- Aplastic Anemia (AA)
- Paroxysmal Nocturnal Hemoglobinuria (PNH)



We Offer Support Through:

- Monthly Virtual Patient Support Meetings
- In-Person Educational Days
- Educational Materials
- Connecting Patients Across Canada



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is here to
support you



1-888-840-0039

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AAMAC promotional materials



- **Board member** – AAMAC is looking for volunteer board members who have some experience serving on a non-profit board of directors. People with professional skills in accounting, communications, or management are needed.

We have other roles available as well. If you are interested in giving back, please contact our Executive Director, Cindy Anthony, to explore the possibilities: cindyanthony@aamac.ca

NATURE PRESCRIPTIONS

Are you looking for an inexpensive and enjoyable way to improve your health? If so, you might benefit from a nature prescription. Health care providers in Canada are joining a new program called PaRx, which encourages them to write nature prescriptions for patients who would benefit from being outside in nature more often.

Scientific research indicates that connecting to nature is one of the best things you can do to improve your health. According to PaRX, research shows that:

- People who spend at least 2 hours in nature each week report significantly better health and wellbeing
- Nature therapy improves the psychological well-being of cancer patients
- Seniors who live close to walkable green spaces live longer
- Spending time in nature boosts memory, creativity and work satisfaction



Fiona Lewis enjoying a walk in a BC forest



- Increasing nature time reduces your risk of developing heart disease, high blood pressure, and diabetes

You can realize many of these benefits by spending 2 hours a week in nature, for 20 minutes at a time. The health benefits can start to add up whenever you feel like you have spent meaningful time in nature.

Receiving a written prescription for connecting to nature may not only help you prioritize nature in your weekly schedule but may also lower some of the cost barriers associated with the use of green spaces. PaRx has partnered with groups such as Parks Canada to offer discounts to patients with nature prescriptions. Visit the [PaRx website](#) to find out about other partners in your region. The website also explains how your regulated health care professional can participate in the program.



MEETINGS & EVENTS

Visit AAMAC.CA for all meetings, event details, and registration.

Upcoming In-Person Patient Education Meetings

CALGARY

Date: Saturday, October 25, 2025
 Time: 9:00 AM - 1 PM
 Location: Hotel 11, MOD A Sonesta Collection

Speakers:

- Dr. Jennifer Grossman – Overview of PNH and Aplastic Anemia, New Treatments
- Dr. Michelle Geddes – Overview of MDS, New Treatments

WINNIPEG

Date: Saturday, November 8, 2025
 Time: 8:30 AM - 1 PM
 Location*: Inn at the Forks

Speakers:

- Dr. Brett Houston – Overview of MDS – New Treatment Options
- Dr. Lin Yang – Overview of PNH and AA – New Treatment Options
- Patient Experience Panel

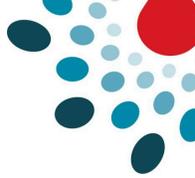
OTTAWA

Date: Saturday, November 15, 2025
 Time: 9:00 AM - 1:30 PM
 Location*: Canadian Blood Services

Speakers:

- Dr. Mitchell Sabloff – Overview of PNH and Aplastic Anemia, New Treatments
- Dr. Ashish Masurekar – Bone Marrow Transplants and Overview of MDS





*This in-person meeting will be streamed virtually, allowing patients and caregivers to attend if otherwise unable to join us in person. The meeting in Ottawa will also be translated in French.

**Travel subsidy for Winnipeg meeting: AAMAC will offer a \$300 travel subsidy to offset the costs of travel for those who want to join the conference in person. Please contact adminoffice@aamac.ca to learn more about the subsidy.

Upcoming Webinars

MDS Classifications

Date: Wednesday, September 24, 2025
Time: 7 PM (ET)
Speaker: Dr. Karen Yee

PNH Treatments

Date: Wednesday, October 1, 2025
Time: 7 PM (ET)
Speaker: Dr. Marc Bienz



Virtual Patient Support Group Meetings

AAMAC offers monthly virtual patient support group meetings. Join us from the comfort of your home - patients and care partners welcome!

Central Canada Patient Support Group

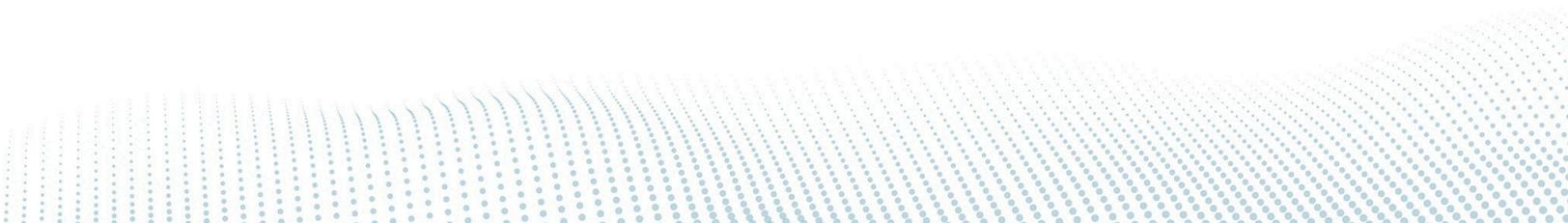
Date: Wednesday, June 11
Time: 6 PM ET
This meeting will be held on the second Wednesday of each month

Atlantic Patient Support Group

Date: Thursday, June 19
Time: 7 PM AT
This meeting is held on the third Thursday of each month

Western Canada Patient Support Group

Date: Monday, June 16
Time: 6 PM PT
This meeting is held on the third Monday of each month





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 and generous donation. Thank you.

There are many ways to donate to AAMAC:



Call the National Office to donate by phone.



Click the 'DONATE' button on our website



Visit CanadaHelps.org

AAMAC NATIONAL OFFICE

390 Beach Drive,
Brighton, ON
K0K 1H0

Phone: 1-888-840-0039

Email: info@aamac.ca

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