



AAMAC
ACAAM

Aplastic Anemia & Myelodysplasia
Association of Canada

Association canadienne de l'anémie
aplasique et de la myélodysplasie

Newsletter - Spring 2025

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

Message from the Executive Director

We are happy to share with you our Spring Newsletter. I am sure everyone is looking forward to spring and the warmer weather, and we have lots of information to share with you in this newsletter.

Did anyone enjoy a winter vacation? Planning a summer holiday somewhere special? Thank you to Fiona Lewis, our newsletter editor for putting together some helpful information about traveling with a bone marrow failure disease.

We are excited to share information about our upcoming meeting on March 29th. As a result of feedback from last year's meetings we will be offering this meeting in person in Vancouver and online. The online participants will have the opportunity to ask questions of the speakers. We thank Canadian Blood Services for their support in assisting us with the online logistics for the meeting. Registration details can be found on the website www.aamac.ca.

AAMAC has many wonderful volunteers who assist in many ways. In November we lost one of our volunteers, Philip Veness. Philip was a great ambassador for AAMAC and you can read more about Philip in this issue. We are always looking for volunteers and some of the areas of need are outlined in the article. As we celebrate Volunteer Week in April, it would be great if you could give consideration to how you might volunteer with AAMAC.

Thank you.

Cindy Anthony

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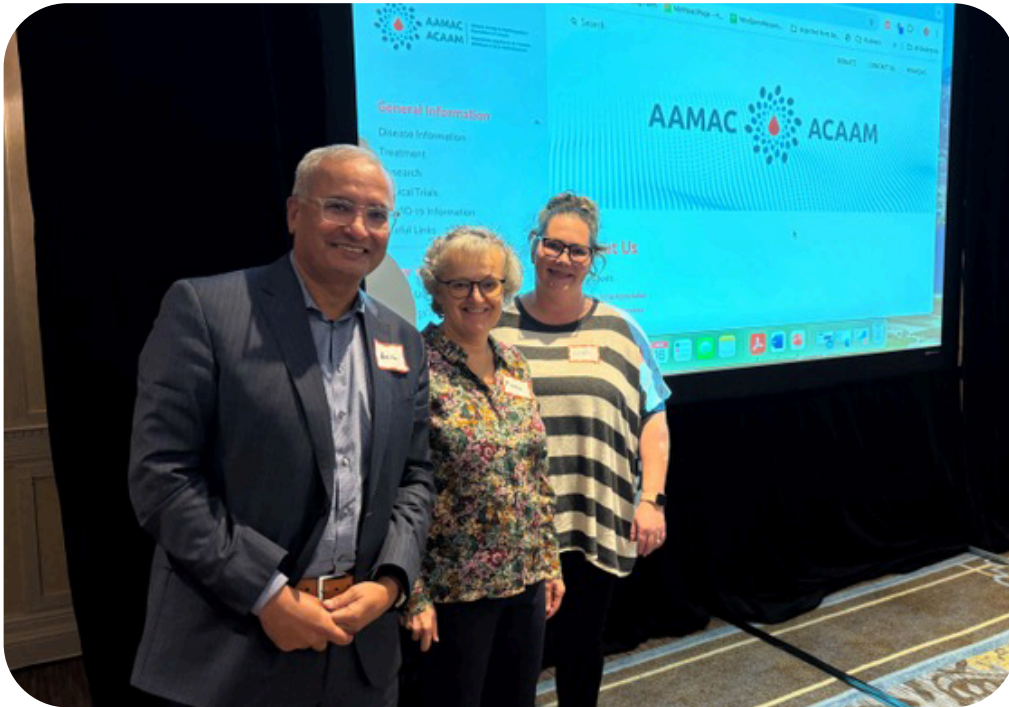
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PATIENT EDUCATION DAY IN WINNIPEG



Sobi team members Anil Kaul and Leah Kennedy are pictured with AAMAC staff Fiona Lewis at our recent Patient Education Day in Winnipeg.

REMEMBERING A SPECIAL VOLUNTEER

In November of 2024, the AAMAC team was very saddened to learn that volunteer Philip Veness had passed away. Philip was diagnosed with severe aplastic anemia (SAA) in 2020 and discovered AAMAC shortly after that. He joined our Western Patient Support group and in 2022 also joined our board as a volunteer, providing a valuable patient perspective.

As a Winnipeg resident and retired social worker, Philip was interested in ensuring that AAMAC's resources were available at Manitoba Cancer Care. He left the board after one term and decided to focus on raising awareness in the community. AAMAC executive director, Cindy Anthony, recalls that Philip "was one of those volunteers who always had AAMAC front of mind." Philip was a true ambassador for AAMAC, always looking for a chance to raise awareness. For example, he noticed that there was an opportunity to promote AAMAC's patient education meeting in the Manitoba Cancer Care newsletter and acted quickly to submit the information.

When the medication Eltrombapag was up for review with CADTH, AAMAC had an opportunity to have a patient appear before their board to provide patient input. Philip went and spoke persuasively about his experience with the drug.

In remembering Philip, Anthony commented that, “on support group calls, Philip demonstrated an exceptional ability to really listen to people and to remember the important details of their lives. He always made people feel heard and supported, in a very gentle way.”

Beyond AAMAC, Philip also volunteered with the Dalnavert Museum, the Winnipeg Art Gallery, and the Autism Society of Manitoba. Philip’s loss leaves a huge void in Manitoba for AAMAC. Our strength comes from community-minded people like Philip.

If Philip’s story inspires you to volunteer as an AAMAC Ambassador in your community, please contact us at the AAMAC office.

RARE DISEASE DAY 2025

Every February, AAMAC joins millions of people around the world in recognizing Rare Disease Day.

Rare Disease Day is the globally-coordinated movement on rare diseases, working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease.

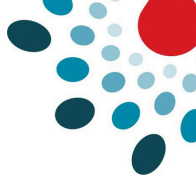


RARE DISEASE DAY®

Since its creation in 2008, Rare Disease Day has played a critical part in building an international rare disease community that is multi-disease, global, and diverse—but united in purpose.

AAMAC contributes by raising awareness of bone marrow failure diseases among individuals, families, caregivers, healthcare professionals, researchers, clinicians, policy makers, industry representatives and the general public.

You can join the effort by sharing your story with others or posting it to the Rare Disease Day [website](#).



HEMATOPOIETIC CELL TRANSPLANTATION TRENDS AND OUTCOMES IN CANADA: A REGISTRY-BASED COHORT STUDY

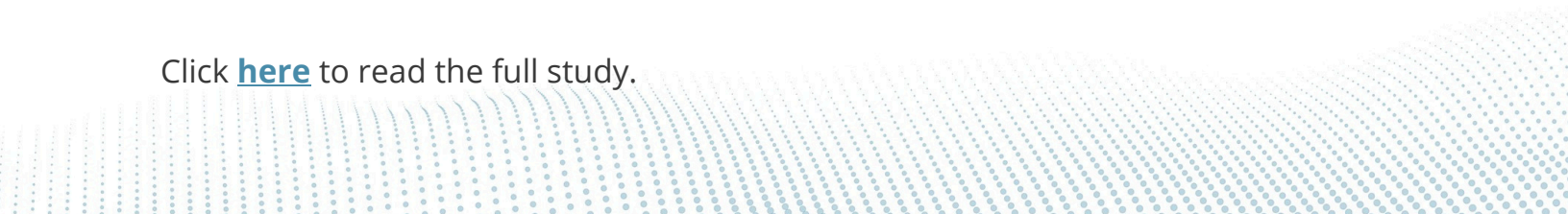
This recently published study looked at quantity, trends, and clinical outcomes of hematopoietic (stem) cell transplantation (HCT) over time in Canada. The researchers examined these issues using Canadian registry data. To determine whether patient characteristics have changed and whether outcomes have improved over time, patients were grouped into two periods: 2000 to 2009 (early era) and 2010 to 2019 (later era). Both children and adults were included in the study.

The researchers observed an increasing number of transplants being offered to Canadians, which they attributed to improvements in health care access, a greater awareness of the potential benefits of HCT, and a higher number of medically eligible patients as HCT can be delivered more safely. They also noted a shift towards older adults receiving both allogeneic and autologous HCTs, with a 5-fold increase in older adults (>64 years old) accessing allogeneic transplants. Comparing the two eras, allogeneic transplants increased in number by 22.3%, with greater use of matched unrelated donors in the later era. Autologous transplants increased by 10.9%.

In terms of key clinical outcomes, there were significant temporal improvements in overall survival (OS) that benefited both pediatric and adult allogeneic HCT recipients. In particular, autologous HCT recipients experienced improved 5-year OS in the later era. The study also looked at non-relapse mortality (NRM) which refers to death from any other cause other than the relapse of the underlying disease. Age-related differences in NRM after allogeneic HCT were apparent, with higher NRM in adults compared to children, suggesting that adult patients are more vulnerable to the adverse effects of allogeneic HCT. However, there were temporal improvements in NRM in the 2010–2019 (later) era for both adult autologous and allogeneic HCT recipients.

In conclusion, researchers found that over the 20-year study period, transplant activity has increased and key clinical outcomes have generally improved for adult and pediatric patients receiving HCT in Canada. The landscape of HCT in Canada has also evolved to serve older patients, with increased reliance on volunteer unrelated donors. Despite offering allogeneic HCT to older patients, OS rates in adults remained stable.

Click [here](#) to read the full study.





TRAVELLING WITH BONE MARROW FAILURE

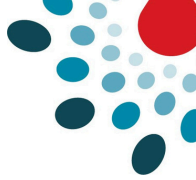
When you are diagnosed with bone marrow failure or after an acute episode of your illness, you may feel that your travelling days are over. However, many patients do travel with MDS, AA and PNH, both locally and overseas. We've pulled together some tips for travelling with bone marrow failure and spoke to a seasoned traveler about her experiences.



Gwen Barry in Hawaii

Before a trip:

- Consult your hematologist as you start planning a trip. They will make you aware of any specific precautions you need to take and can help you schedule treatments around your trip dates, if needed.
- Research your destination so that you are aware of what medical facilities are available and whether any infectious diseases are present in the area.
- Gather all the necessary documentation. This may include:
 - A 'fit-to-travel' letter from your doctor
 - Your AAMAC wallet card or similar document outlining the basic details of your condition
 - A list of all your medications and dosages
 - Your AAMAC Progress Tracker or similar record of your test results, in case of an emergency hospitalization
- Pack sufficient medication (both prescription and over-the-counter) in your carry-on bag, using cold packs if refrigeration is required. Check that original labels are intact. Make sure that none of your drugs are a controlled substance in your destination country.
- Ensure you have adequate travel insurance
 - Even if your condition is stable, you may want to take out a medical travel insurance policy that covers your pre-existing condition. Carefully review the insurance company's definition of "stable" to ensure you are adequately covered. Alternatively, you may be able to find a more expensive policy that does not have a stability clause.
- Ensure you have any recommended vaccinations, in consultation with your hematologist
- If you require any mobility equipment, investigate whether you can rent it at your destination. This may avoid any potential damage of your own equipment by airlines. You can also request mobility assistance at the gate in the airport if you have trouble walking long distances.



During a trip:

- Pace yourself – build some downtime into your travel schedule and manage expectations so that you don't over-exert yourself
- Wear comfortable shoes as most forms of travel involve a lot of walking
- Keep up good hygiene practices:
 - Wash your hands frequently
 - Wear a mask on a plane and in crowded places
 - Use bottled water if the safety of tap water is uncertain
 - Use hand sanitizer and carry disinfectant wipes to clean surfaces

With a little planning, you can have an enjoyable and worry-free trip while living with bone marrow failure. AAMAC board member, Gwen Barry, says this about her experiences:

"I have had MDS for 20 years, and Eprex kept me away from blood transfusions, except when I got a viral or bacterial infection. Those conditions caused me to need a few transfusions here and there. But now on Reblozyl, and 83 years old, (MDS) hasn't stopped me from traveling. Every year for the past 20 years, I have taken a trip somewhere and probably will next year. I have travelled to Europe, the USA, Hawaii, and to the Caribbean on many cruises, and have learned along the way how to travel safely."

CAMP QUALITY REGISTRATIONS OPEN

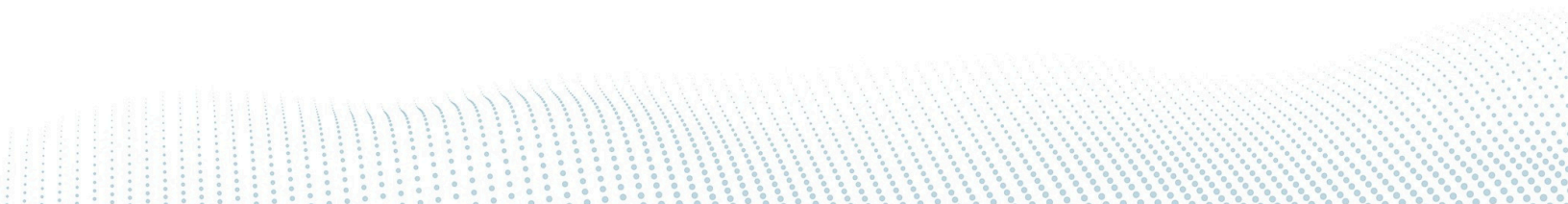
For children ages 7-17 with cancer and blood disorders, Camp Quality provides free 1-week overnight summer camps that support the whole family through fun camp adventures. Camps are taking place across Ontario, Alberta, and Manitoba and registrations are now open.

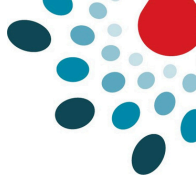


For more information and to register please visit <https://www.campquality.org/>

SPRING MEETING IN VANCOUVER

We are excited to announce, that in response to your feedback, the upcoming Patient Education Meeting in Vancouver will be *live streamed virtually* across Canada. If you can't join us in person, you can listen to the presentations from the comfort of your home. Please see the following page for details and contact us to register.





MEETINGS & EVENTS

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

Upcoming In-Person Patient Education Meetings

VANCOUVER

Date: Saturday, March 29, 2025

Time: 8:30 AM - 1:30 PM*

Location: Holiday Inn Express Vancouver-Metrotown (Burnaby)
4405 Central Blvd, Burnaby

*The virtual program will begin at 9:15 AM.

Virtual streaming:

This in-person meeting will have a virtual streaming option, giving patients and caregivers across Canada the opportunity to attend presentations from experts in the field.

Speakers:

- Dr. Chris Patriquin: PNH - Overview & Treatment Options
- Dr. Ryan Stubbins: Transplantation & Cellular Therapy
- Dr. Heather Leitch: Iron Overload
- Dr. Wendy Davis: Community Cross Matches - Transfusions

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, February 12

Time: 6 PM ET

This meeting will be held on the second Wednesday of each month

Atlantic Patient Support Group

Date: Thursday, February 20

Time: 7 PM AT

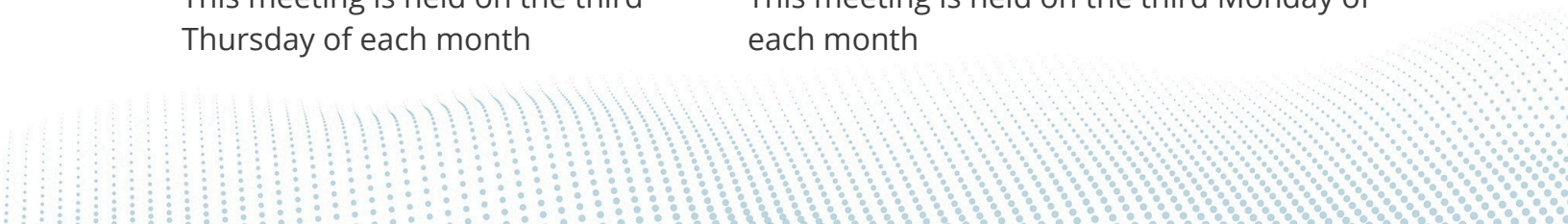
This meeting is held on the third Thursday of each month

Western Canada Patient Support Group

Date: Monday, February 17

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

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