



AAMAC
ACAAM

Aplastic Anemia & Myelodysplasia
Association of Canada

Association canadienne de l'anémie
aplasique et de la myélodysplasie

Newsletter - Winter 2024

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

Message from the Executive Director

We just held our Annual General Meeting for AAMAC and how wonderful it is to look back over a year of successful patient meetings where we could meet with so many wonderful patients and families. Our new resource books have been widely distributed and we have had very positive feedback on them. Our support groups continue to meet monthly welcoming new members and continuing to support others who have been with us for some time and now offer advice and support to newly diagnosed patients.

At our AGM this year we are saying goodbye to two Board Members, Jesse Prager and Vivian Do. Both Jesse and Vivian have been with the Board for a long time and each have given so much of their time and expertise to assist AAMAC. We will miss them both very much and wish them both all the best.

Awareness continues to be key in ensuring patients hear about AAMAC as soon as possible so we can play a role in supporting patients right from the beginning. We are always so appreciative of patients who are able to share AAMAC's information at their hospital or clinic. If you feel you would like to assist please email info@aamac.ca and we can discuss what might work best in your area.

Thank you once again to Fiona Lewis and Maria Dimancheva for writing and editing the newsletter each month. There is a lot of work that goes into each issue and we appreciate all the work they do. Thank you to Gwen Barry our Board Secretary who assists in proof reading each issue on top of all the work she does on the Board.

Enclosed in this issue you will find our annual donation request. We thank you for your consideration in supporting our ongoing support of ongoing work.

Wish all of you a wonderful holiday season,

Cindy Anthony

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SUPPORT GROUPS: BENEFITS AND CHALLENGES

“I want to extend thanks to... all those who participated in the online meeting last night. Given the recent changes in my condition I found it extremely helpful and comforting. I appreciate everyone's patience given the time afforded me to share my information.”

Those are the words of a recent participant in one of AAMAC's patient support groups, conducted monthly via Zoom, across the country. Our support groups are led by AAMAC staff and include both patients and care partners. We know from both participant feedback and from recent research* that support groups have many benefits for participants.

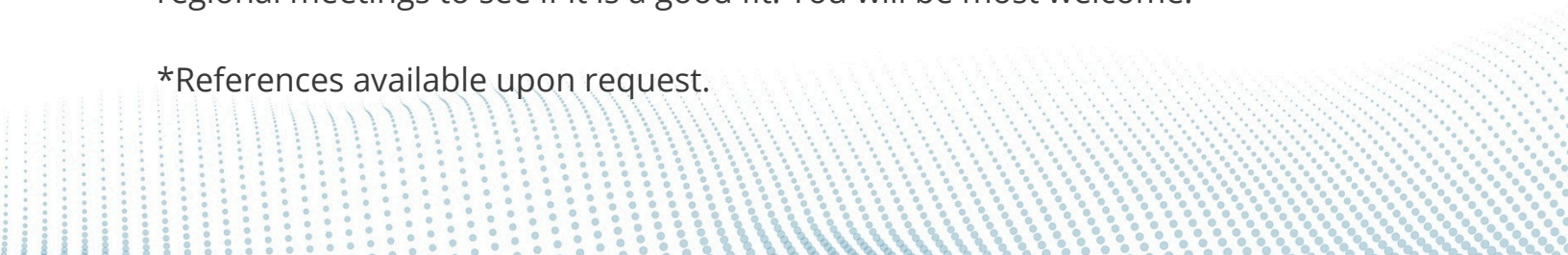
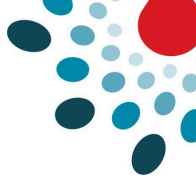
Many group members appreciate the information sharing aspect of the meetings. This can include getting advice on what to ask doctors, obtaining practical information about the healthcare system and learning about treatment options.

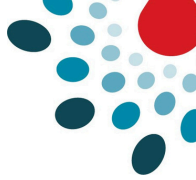
For some members, sharing personal experiences can be most beneficial. Support groups can enable partners to gain greater understanding of the disease by hearing from others. They can also offer a place of comfort, hope, and, often, humour. Support groups can also give participants a sense of usefulness as they help others by giving information or sharing their own journey.

Notwithstanding these benefits, some members may find aspects of the group challenging. The deteriorating health or even death of a member can lead to survivor guilt and/or depression. Sometimes the coping strategies of other members (such as extreme optimism) may not work for everyone. A third challenge is that the information needs of the members may differ: a newly diagnosed member may want information about the disease and treatment whereas long term members are likely more interested in new research. A skilled leader can help the group manage these challenges and ensure it benefits everyone. In AAMAC's support groups, members are free to leave and rejoin the group, as appropriate to their needs.

If you are not sure if a support group is right for you, consider joining one of our 4 regional meetings to see if it is a good fit. You will be most welcome!

*References available upon request.





UPDATE ON PLANNING WITHIN AAMAC

In 2023, the AAMAC board of directors approved a new and ambitious strategic plan for the organization. This was the first major update to the organization's planning process in many years. We checked in with Executive Director, Cindy Anthony, to get an update on how the implementation of the plan is going:

How is the organization progressing with regards to achieving the goals in the plan?

We have completed the goals set out in the plan; however, there is still work to be done in the communications area with the continued challenge of raising of AAMAC among newly diagnosed patients. Also, the board needs to do a search for 2 new board members.

What accomplishments are you most proud of, so far?

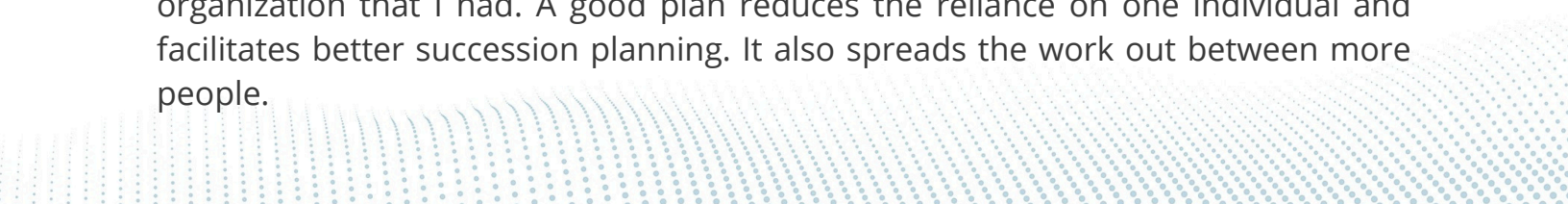
The greatest accomplishment with this plan was the creation of several board committees. This allowed board members to better use their areas of expertise and become more engaged with organization. It also has helped and will continue to help with further planning and succession planning for both board members and staff. One example is the research committee, which has allowed AAMAC to put in place a research plan. The research plan helped us promote research funds to potential researchers. Under Dr. Egan's guidance, we're better able to critically review the applications we receive. It's allowed us to get involved in some important research projects.

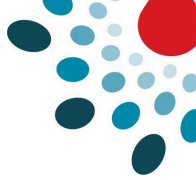
What has proven to be the most challenging goal to implement?

The communications area has been a challenge in terms of getting the right committee membership from the board. We've recently added two new members to the board, who are very skilled in this area. Awareness of AAMAC within the medical community has always been and continues to be a challenge but the committee is helping with this. The willingness of committee members to attend conferences has helped us to raise our profile and create awareness.

What are the benefits to the organization in having such a detailed plan?

I think it was good to take a step back and review all the areas covered in the plan. It helped to highlight areas that we needed to focus on more. The plan made our goals more doable and practical. It brought us all together to focus on the same goals. It also gave the board members the same broad overview of the organization that I had. A good plan reduces the reliance on one individual and facilitates better succession planning. It also spreads the work out between more people.





When will the plan next be updated?

Our next planning session is scheduled for November 2025. We will conduct a full review of the existing plan then create a new one.

What are some of the external factors that will likely impact the next plan?

As I mentioned, there’s always the need to attract new board members to the organization. We need people with the right skills to engage with our vision and mission. Funding is always an issue that we must consider, in terms of our capacity. I think that things are going to continue on the upswing for AAMAC and our patients: there are more treatments coming out and more research happening. I anticipate better outcomes for our patients as we move forward.

We are looking to add a couple more Board members in advance of our next planning session, particularly with experience in finance and/or governance. I invite anyone who is interested to contact me for more information at cindyanthony@aamac.ca.

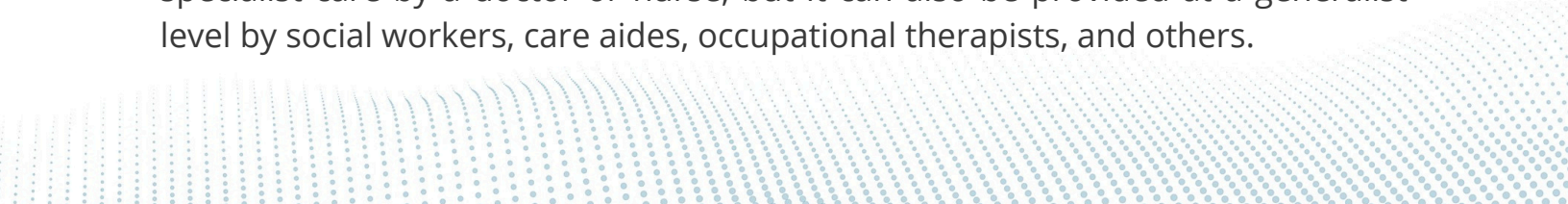


PALLIATIVE CARE: DISPELLING THE MYTHS



“Palliative care” is a term that is often misunderstood, which, unfortunately, may lead to fear, anxiety, and avoidance when it is offered as a care option. In this article, we correct some myths about palliative care and explore its availability in Canada.

Palliative care focusses on improving quality of life for people with a life-limiting illness. It differs from end-of-life care which occurs in the last part of a person’s life, usually in the last days, weeks or months. Contrary to what many believe, palliative care can benefit people of any age, at any stage of an illness, and can be provided in a variety of settings ranging from home to residential care facilities to hospices to hospitals. Many people think of palliative care as specialist care by a doctor or nurse, but it can also be provided at a generalist level by social workers, care aides, occupational therapists, and others.





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Perhaps most importantly, palliative care is a holistic approach to care which focusses not only on physical well-being, but also on spiritual, psychological, and social support. In addition, it goes beyond the individual to provide support to families and care partners, both before and after a loss.

Since 2018, the Government of Canada has been working to improve equitable access to palliative care in Canada. A 2023 review by the Canadian Institute for Health Information found that even though more people are receiving palliative care than 5 years ago, some people still have trouble accessing palliative care because of their age, where they live or their disease diagnosis. Additionally, while some people do receive palliative care, they do not receive it early enough in their disease progression or they cannot access it in the setting they would like.

The 2023 review found that Canadians age 85 and older who died were less likely to receive palliative care than younger people. Palliative patients living in rural areas were more likely to be hospitalized primarily for palliative care compared with those living in urban areas and patients with cancer were more likely to be considered palliative versus patients with other illnesses.

So, what does this all mean for patients with bone marrow failure? Palliative care is a care option that can and should be discussed with the health care team, like any other care option. Through these discussions, patients can explore what the benefits might be for them as well as how palliative care is delivered in their province. By gaining an understanding of this early in the disease process, patients and their families will be in a better position to request palliative care services if and when they need them.

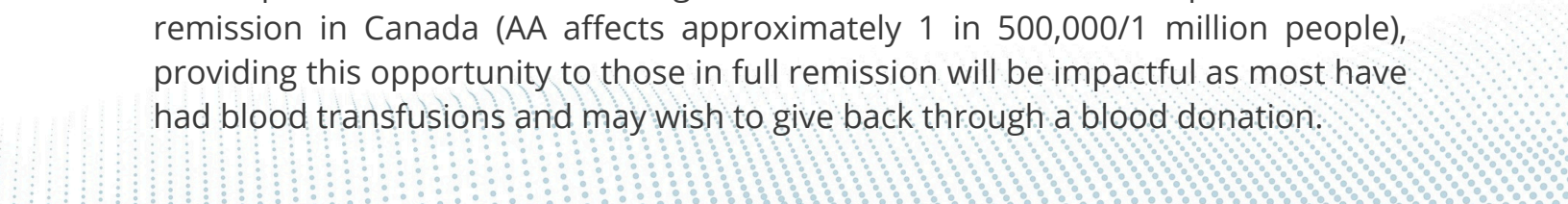
For more information about palliative care, visit virtualhospice.ca

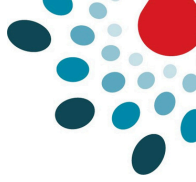
*References available upon request



POTENTIAL CHANGE TO BLOOD DONOR CRITERIA

AAMAC is supporting a Canadian Blood Services (CBS) submission to Health Canada, seeking to change the blood donation criteria and eligibility for patients in full remission with Aplastic Anemia (AA). CBS proposes that eligibility for these donors be considered on a case-by-case basis with an assessment by a CBS doctor, if the donor passes their hemoglobin screen and if they are not on any unacceptable medications. Although there are a limited number of patients in full remission in Canada (AA affects approximately 1 in 500,000/1 million people), providing this opportunity to those in full remission will be impactful as most have had blood transfusions and may wish to give back through a blood donation.





EDMONTON PATIENT EDUCATION DAY



Presenters Dr. Monika Oliver and Dr. David Page (left) and patient panel speakers Charlotte Stel, Melissa Nalder, and Tracie Reed (right) at the October 5th education meeting in Edmonton.



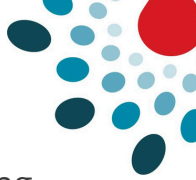
MARILYNNE CONVEY AAMAC AWARD RECIPIENT FOR 2024



Camilo Sierra Herrera

My interest in a career in nursing began while volunteering for the Neurosurgery Kids Fund (NKF), a non-profit organization in Edmonton, Alberta. Before then, I knew little about the profession. The NKF consists of medical professionals and volunteers, including nurses, doctors, and therapists, who care for children undergoing complex brain and spinal surgeries at Edmonton's Stollery Children's Hospital.

During the completion of my Master of Science (Applied) at McGill University, I embraced various roles beyond my coursework. Serving as President of the Nursing Graduate Student Association and as a Graduate Representative of the Faculty of Medicine & Health Science, I supported my peers and fostered a sense of community.



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These experiences deepened my passion for guiding future leaders, lifelong learning, and viewing challenges as growth opportunities.

My journey in oncology has been diverse and enriching. I have collaborated with organizations like the Canadian Association for Nurses in Oncology (CANO) while leading psychosocial oncology research projects at McGill and the McGill University Health Centre (MUHC). These experiences have strengthened my dedication to evidence-based, patient-centered care.

Looking ahead, I am excited to continue my career in Hematology-Oncology-Stem Cell Transplantation, promoting the highest standards of care for patients and families.

I am profoundly grateful to the Canadian Nurses Foundation and the Aplastic Anemia & Myelodysplasia Association of Canada (AAMAC) for this honor, which inspires me to strive for excellence in all that I do.



GIVING TUESDAY IS DECEMBER 3



Giving Tuesday is the world's largest generosity movement, founded right here in Canada. We invite you to participate on December 3rd by supporting the work of AAMAC. There are many ways to get involved. You can share our posts on social media, tell your family and friends about our work, and donate via our website or [CanadaHelps](#). You may wish to consider making a **legacy gift**, which can have a significant impact in the work we do to fund research, share information, and provide support to patients and their families. To find out more about how to include AAMAC in your estate planning, please contact our Executive Director, Cindy Anthony, cindyanthony@aamac.ca or call 1-888-840-0039.



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

WATCH OUT FOR

Upcoming Spring 2025 meetings.
 Details about the locations and
 speakers will be announced on our
 website.

Speakers:

To be announced on our website.

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!

French Speaking Patient Support Group

Date: Wednesday, December 4
 Time: 7 PM ET
 This meeting will be held on the first
 Wednesday of each month

Central Canada Patient Support Group

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

Atlantic Patient Support Group

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

Western Canada Patient Support Group

Date: Monday, December 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

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390 Beach Drive,
Brighton, ON
K0K 1H0

Phone: 1-888-840-0039

Email: info@aamac.ca

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Phone: 1-888-840-0039

Central Canada:

ontariosupport@aamac.ca

Atlantic Canada:

atlanticsupport@aamac.ca

Western Canada:

bcsupport@aamac.ca

French Speakers:

soutienfrancophone@aamac.ca

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