



**AAMAC**  
**ACAAM**

Aplastic Anemia & Myelodysplasia  
Association of Canada

Association canadienne de l'anémie  
aplasique et de la myélodysplasie

## Newsletter - Winter 2025

*for patients living with AA, MDS, PNH and those who support them*

### Message from the Executive Director

The definition of support is **“To help someone or something in an emotional or practical way”**.

AAMAC's vision and mission both contain the word support.

#### Mission

*To provide a seamless **support** network for every Canadian patient, family member, friend, and concerned healthcare provider dealing with aplastic anemia, myelodysplasia and paroxysmal nocturnal hemoglobinuria.*

#### Vision

*To support all Canadians and their families and friends through diagnosis, treatment and remission stages of these diseases.*

This issue of our newsletter contains articles about different types of **support**. We are looking at getting feedback on our current online **support** groups. Do we need more? Do we need to have groups that **support** different disease groups? Do we need a group for care partners as they **support** their loved ones? We want to hear from you, our patients and care partners, on how AAMAC can best **support** you.

Financial **support** for AAMAC is necessary for us to continue to offer the many programs. We so appreciate everyone who contributes each year.

As 2025 draws to an end we wish each of you a wonderful holiday season and look forward to continuing **supporting** you and your families in 2026.

Cindy Anthony

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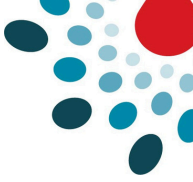
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## LETTER TO THE EDITOR

We were pleased to receive this letter in response to the article in the last newsletter regarding MDS Survival Rates:

*I smiled when I read the article about survival rates. At the time I was diagnosed with MDS, the median life span was 8.3 years. I was diagnosed 22 years ago! The new drug Reblozyl (Luspatercept) is probably making a difference in the survival rate for MDS RARS. Although, where I go to get Reblozyl injected, there were 5 RARS patients taking the drug besides me. It didn't work for 4 of them, and 2 newer patients are struggling with the drug. I've been on Reblozyl for 1 year, and it's working so far.*

*Gwen Barry*

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## THE HIGHS AND LOWS OF BEING A CARE PARTNER

At AAMAC, we use the term “care partner” to recognize that many patients have someone in their life who is a partner with them in their illness journey. While this partner may not do a lot of hands-on physical care, they support their loved one in many ways. AAMAC care partners have described their role as follows:

- Being a notetaker and/or second ‘ear’ at medical appointments
- Assisting with the tracking of test results, blood counts, medication dosages and other medical information
- Picking up prescriptions and other supplies
- Ensuring meals are balanced and nutritious
- Keeping other family members and friends in the loop
- Taking on a larger share of household tasks when their loved one is fatigued or low energy
- Helping to navigate the health care system and advocate for services as needed
- Providing emotional support and encouragement



The role of care partner can be both satisfying and challenging. Some care partners report that they appreciate the opportunity to support their loved one at medical appointments and to be together on the journey of learning more about bone marrow failure.



Navigating the health care system is often a challenge for both patients and care partners, who need to learn new jargon, understand the roles of various health care professionals, and discover who to contact when issues come up. Treatment funding can also be complicated and require a lot of form completion and record-keeping. Good communication between patient and care partner(s) can help to share information and reduce duplication of effort.

Another common challenge for care partners is supporting the patient through the emotional highs and lows of chronic illness. Blood work day can be either uplifting or disheartening, depending on results, and care partners are often able to prevent catastrophizing or offer another perspective. Care partner(s) can also help patients manage expectations when they are undergoing treatment and not seeing results quickly enough.

However, care partners also have their own emotions to manage. They, too, can feel down, worried or confused. It's important to recognize these feelings and seek out support, too. AAMAC care partners have found our patient support groups to be helpful (see the article in this newsletter for more information about these groups). Others have accessed therapy, developed their own wellness routines and/or relied on family and friends for emotional support.

We asked some care partners for their tips for others. Here are their suggestions:

“One practical tip that helped me was setting up a ‘chain of communication.’ I couldn’t keep up with everyone’s messages and care, so I chose one point of contact on each side of the family to share updates. That way loved ones stayed informed without me having to retell the same difficult news over and over.”


“Listen to your partner and don’t take control too much. If you have a concern, try not to freak out and go over the head of your loved one. Watch out for information overload also. Step back and remember you’re a family member, not his caregiver. Don’t make your loved one feel like a patient.”

“Since this was a marathon, not a sprint I learned that I needed to talk about what we were going through, while my partner preferred to keep things private. We had to find a balance and understand that his diagnosis affected our whole family, not just him.”

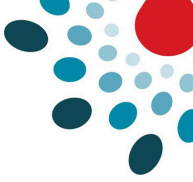
“Most of all, know that it’s okay to feel scared, upset, or uncertain. You’re doing your best in a situation no one is ever fully prepared for.”

## Care Partner Resources

Visit the [Canadian Centre for Caregiving Excellence](#) to find a range of provincial and national resources. These sites include resources such as:

- Newsletters
  - Videos
  - Podcasts
  - Tip sheets
  - Caregiver wellness assessments
  - Planning tools
- 





## **PATIENT SUPPORT GROUP FEEDBACK OPPORTUNITY**

AAMAC patient support groups take place over Zoom twice monthly. Patients, care partners, and family members are welcome to join these video calls. Here are some comments from recent participants:

"I appreciate that I can talk honestly about how I am feeling at these meetings."

"The information and advice from this group has really helped us in our decision-making."

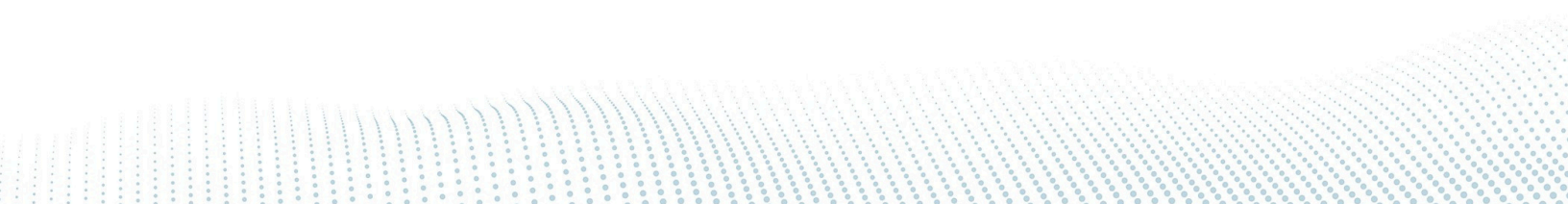
"The people in this group really understand where I am coming from as they have had similar experiences."

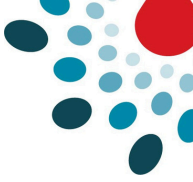
"The monthly support groups are incredibly welcoming and filled with people who truly understand what you're going through."

"I like that we (care partners) can join the patient support groups. It really helped me feel that this is going to be OK. Until you listen to others' stories, you don't really realize how much you have in common. Just one call made a huge difference to me – I didn't feel as scared when I got off the call. I realized he had other supports besides me."

This month, AAMAC is conducting a survey to find out how our patient support groups can better meet your needs. The survey is open to both patients and family members, whether you have participated in a patient support group or not. Please follow the URL below to access the survey between November 1st and 28th, 2025.

**<https://www.surveymonkey.com/r/RVVFFQK>**





## Peer Support Program

Perhaps support groups are not for you? If so, you may find that our peer support program can provide many of the same benefits in a one-to-one setting. Patients in our peer support program are matched with patient volunteers who may have a similar bone marrow failure disease and/or treatment experience. Contact can be by phone, text, or email and may be one-time or ongoing. To request a match with a peer support volunteer, please contact the AAMAC office at [info@aamac.ca](mailto:info@aamac.ca)

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## 2024 FOLLOW UP TO MDS ALLIANCE GLOBAL PATIENT SURVEY

The MDS Alliance has issued a follow up survey to its 2022 global patient survey. This year's survey focused on access to care and had three main aims:

- 1.To better understand patient access to medications, treatments, and care.
- 2.To identify barriers and facilitators to access across different health systems.
- 3.Based on the findings above, to develop clear, actionable recommendations for stakeholders.

The survey findings were based on 628 respondents from 31 countries. Key findings include:

- 48% of patients also have autoimmune or inflammatory disease.
- 45% of patients do not know their MDS subtype.
- 1 in 10 patients do not feel involved with treatment decisions.
- Offers of a bone marrow transplant are low but more common in younger patients.
- Only half of MDS patients is looked after by a multidisciplinary team.
- Nearly a quarter (23%) reported that patients' symptoms have gotten worse after treatment.

- Over half (57%) reported delays in accessing services with the biggest challenge being accessing appointments with specialists.

You can read the full survey report and recommendations [on our website](#).

## GIVING TUESDAY IS DECEMBER 2

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](mailto:cindyanthony@aamac.ca) or call 1-888-840-0039.

GIVINGTUESDAY

**December 2, 2025**

One day. Huge impact.



## MEETINGS & EVENTS

Visit [AAMAC.CA](https://aamac.ca) for all meetings, event details, and registration.

### Upcoming In-Person Patient Education Conferences

#### CALGARY

Date: Saturday, April 25, 2026

Time: 9:00 AM - 1:00 PM

Location: Hotel 11, MOD A Sonesta Collection, 11 Freeport Crescent NE

#### Speakers:

- To be announced – Overview of PNH and Aplastic Anemia, New Treatments
- Dr. Michelle Geddes – Overview of MDS, New Treatments

#### VANCOUVER

Date: Saturday, April 25, 2026

Time: 9:00 AM - 1:00 PM

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

#### 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!

#### Monday Patient Support Group

Date: Monday, December 15

Time: 6 PM (PT), 7 PM (MT), 9 PM (ET), or 10 PM (AT)

This meeting is held on the third Monday of each month

#### Wednesday Patient Support Group

Date: Wednesday, December 10

Time: 7 PM (AT), 6 PM (ET), 4 PM (MT), or 3 PM (PT)

This meeting will be held on the second Wednesday 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](https://CanadaHelps.org)

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