



**AAMAC**  
**ACAAM**

Aplastic Anemia & Myelodysplasia  
Association of Canada

Association canadienne de l'anémie  
aplasique et de la myélodysplasie

## Newsletter - Fall 2025

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

### Message from the Executive Director

How did you first get connected with AAMAC? If you are like many of our patients and care partners, you often did not find out about our services until well after your diagnosis. We are constantly trying to change that so patients and care partners find us when they need support most; right at the time they first hear they have MDS, Aplastic Anemia or PNH. We have new postcards that we are hoping to place in as many hospitals as possible. If you are able to assist with this distribution, please let us know [adminoffice@aamac.ca](mailto:adminoffice@aamac.ca).

We have many opportunities this fall for learning and connecting with others. All the meetings, both online and in person, are listed in this newsletter. We look forward to your participation.

Our AGM is coming up in October and we welcome anyone who is interested to join the online meeting on October 18, 2025. Information to register is found in the newsletter. Only members are able to vote, however, everyone is welcome to observe the meeting.

Thank you to Fiona Lewis for her continued work on the newsletter. There are some very interesting articles in this newsletter and we hope you find them helpful.

We welcome Kristin Reinhart to our Board of Directors. Kristin is our first Board Member from Saskatchewan and we hope to have a patient meeting in Saskatchewan in 2026. We are still recruiting Board Members. If you are interested in more information about this volunteer opportunity, please contact me.

I hope everyone had a wonderful summer.

Cindy Anthony

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## OCTOBER 25 IS MDS WORLD AWARENESS DAY



This year's focus is to raise awareness of MDS symptoms as their early recognition can help to get a timely diagnosis and appropriate care and treatment. The campaign tools address both the members of the public experiencing the symptoms as well as their loved ones who might help to notice that it could be MDS and encourage them to get a blood test.

Follow AAMAC on social media to share the message or access some of the tools yourself at: <https://www.mds-alliance.org/mds-world-awareness-day/>

## MDS SURVIVAL RATES

When patients are first diagnosed with MDS, they may be given a time frame for how long they can expect to live with the disease. We talked with haematologist, Dr. Rena Buckstein, to better understand how recent advances in treatment are impacting survival statistics.

### How have recent advances in MDS treatment affected the survival statistics?

While hypomethylating agents like azacitidine and decitabine are felt to improve survival in higher risk disease based on clinical trial data, population studies have not demonstrated the same results. Deployment of new drugs in the community is sometimes less than optimal and patients may be sicker in real life which can explain the differences between study results from drug companies and real-world data.

We are also seeing improvement in survival with allogeneic stem cell transplant using a conditioning regimen that includes treosulfan. We also can better identify the patients who need an early transplant using a better molecular based prognostic score (IPSS-M).

The potential biggest impact on survival right now may be occurring in patients with lower risk disease (which represents 50-60% of MDS patients) who are dependent on red blood cell transfusion. In a Phase 3 trial of Luspatercept targeting patients with ring sideroblasts who were red blood cell (RBC) transfusion dependent, the achievement of RBC transfusion independence (for a period of at least 8 weeks) was associated with a survival benefit. The IMerge<sup>1</sup> study showed that with Imetelstat, 38% of patients achieved RBC transfusion independence and they also saw improved survival compared with those that remained transfusion dependent. When looking at molecular level, researchers saw a decline in burden of disease in the clone. This anti-clonal affect may correlate with survival improvement (Imetelstat is not yet available in Canada). Lenalidomide also possesses anti-clonal activity in del5q MDS. It is probably improving survival but only in responding patients.

Overall, low-risk patients who achieve RBC transfusion independence do live longer but we are not sure if this is treatment-related or biology-related.

### **What is your message to patients who are disheartened by the prognosis they receive?**

A lot of the research we are doing in Canada shows that it is not just disease-related factors that should be incorporated into survival models. People who are frail will not fare as well as those who are physically fit. Most patients die from complications of the disease.

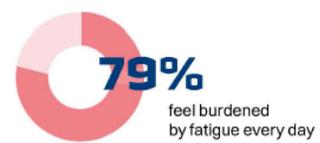
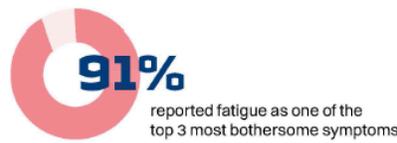
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1. **Imetelstat in patients with lower-risk myelodysplastic syndromes who have relapsed or are refractory to erythropoiesis-stimulating agents (IMerge): a multinational, randomised, double-blind, placebo-controlled, phase 3 trial.** Platzbecker, Uwe et al., *The Lancet*, Volume 403, Issue 10423, 249 - 260

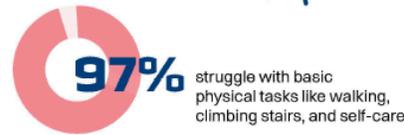
Cardiovascular disease is a major cause of death so modifying risk factors for that is recommended: manage weight and cholesterol, quit smoking, improve general health, stay physically active. Research would suggest that 25% of the prognosis has nothing to do with MDS factors but is more related to patient factors. So, I advise patients to not get entirely fixated on the number of years given to them which is a population statistic and may not be relevant to them.

## THE PNH ADVOCACY TOOLKIT

In 2024, Novartis collaborated with patient advocacy groups to run a study titled “The daily impact of fatigue in PNH” that aimed to explore in-depth the daily impact of fatigue in PNH patients and to understand how patients recognize, manage, and communicate fatigue, focusing on emotional and psychological aspects.



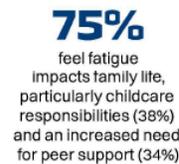
### Body & mind impact



### Mental well-being



### Family & social life



A combination of restricted physical, social and work activities severely impacts PNH patients' emotional and mental well-being.



91% of patients reported fatigue as one of the top 3 most bothersome symptoms and 79% felt burdened by it daily with:

- 97% struggling with basic physical activities like walking, climbing stairs, and self-care.
- 84% reporting that fatigue-related brain fog and mental exhaustion impacted their work lives.

- 75% stating that fatigue affected their family life, particularly childcare (38%) and the need for peer support (34%).
- 31% experiencing anxiety and depression due to fatigue.
- 41% feeling their doctor was unconcerned about their fatigue.
- 78% emphasizing that improving fatigue would be an extremely important consideration for new treatments.

As a result of this study, Novartis has developed a PNH Advocacy Toolkit to help patient advocacy groups such as AAMAC spread the word about the impact of fatigue on those living with PNH. The toolkit includes an infographic, a guidance document, and social media graphics, in English and French. These tools are intended to encourage conversations about fatigue between patients and their care team. If you would like to access any of the tools, please contact AAMAC: [info@aamac.ca](mailto:info@aamac.ca)

## GETTING TO KNOW AAMAC'S NEWEST BOARD MEMBER, KRISTIN REINHART

Kristin Reinhart is the newest member of AAMAC's board of directors. While Kristin has been living with Aplastic Anemia since 2001, she didn't hear about AAMAC until 2024. In a recent conversation, she explained how this has driven her to serve on AAMAC's board: "I saw that there was a knowledge gap about AAMAC in Saskatchewan and I saw that I could make AAMAC's presence known here."



**AAMAC's newest Board member,  
Kristin Reinhart**

Coming from a rural community, Kristin knows how isolating it can be to struggle with a rare disease.

After being stable for many years, Kristin's counts began to drop in 2022. She began the stem cell transplant process in early 2024. Now 14 months post-transplant, she is stable and feeling so much better. "It's incredible the difference. Even when I was stable before, I never felt 100% as I do now. Until I had the transplant, I didn't really understand how AA was affecting my well-being. As I'd had it since I was 19, I didn't really know anything different". Now that she is feeling well, she is looking for opportunities to get involved in advocacy and mentoring other patients.

Kristin brings her skills as a social worker to her Board role. She can see systemic barriers that get in the way of people accessing support and uses this knowledge to advocate for change. She has excellent listening skills and, now that she has been a patient herself, she sees healthcare from both sides. She feels this will enable her to bring a good balance of perspectives to board discussions. "I'm very eager to come in with fresh eyes and be part of AAMAC's future". AAMAC is very pleased to welcome Kristin to the Board.

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## **COPING WITH LOSS OF APPETITE**

Many patients report loss of appetite during chemotherapy treatment or after a stem cell transplant. Loss of appetite can be due to feeling ill or tired or because food and drink don't taste the same. Talk to your healthcare team about the issue. They may refer you to a dietitian and/or recommend food supplements.

Here are some tips you can try:

- Instead of having three big meals a day, try eating small, frequent meals or snacks. If you find certain times of the day are better for you to eat, try to eat then.
- Keep snacks handy to eat whenever you can. Nuts, chips, dried fruit or cheese and crackers are tasty and easy to grab. If these are hard for you to chew or swallow, try yoghurt, peanut butter or applesauce instead.



- Sometimes the smell of cooking can be enjoyable, but sometimes it can put you off eating. If you have family or friends who would like to help, ask them if they could cook for you. Or try to eat cold foods that do not need cooking, or ready-made foods that can go straight in the oven or the microwave.
- Everyone's appetite changes and you may have good and bad days. Make the most of the good days by eating well and treating yourself to your favourite foods.
- Make mealtimes relaxed and enjoyable in whatever way is meaningful for you. Maybe some music would lift your mood while you eat.
- If you have gone off your favourite foods, try a new food that appeals to you.
- Do not drink a lot of liquid with meals as it can fill you up.

### Protein Smoothie Recipe

1 cup almond milk (or dairy milk, oat milk, soy milk)

2 tbsp rolled oats

2-3 pitted dates (Medjool work best)

1 tbsp chia seeds

1 tbsp peanut or almond butter or tahini

$\frac{1}{4}$  tsp cinnamon

$\frac{1}{4}$  tsp vanilla extract

4 to 5 ice cubes



Blend all the ingredients in a high-speed blender until smooth.

If your blender has a difficult time pureeing the oats and dates, let them soak for 10-15 minutes in the milk to soften them before blending.

Contains 8 grams of protein when made with almond milk and peanut butter.

From: *The Oh She Glows Cookbook: Vegan Recipes to Glow from the Inside Out*, Angela Liddon, 2014.

## BECOME AN AAMAC AMBASSADOR

Are you a patient, care partner, or pharmaceutical representative visiting a hospital or clinic soon? Are you a health care professional who treats patients with MDS, aplastic anemia or PNH? We need your help to spread the word about AAMAC. We have created postcards that outline AAMAC's upcoming events.



### Upcoming 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	Western Canada	Atlantic Canada
Monthly at 6 PM EST	Monthly at 6 PM PST	Monthly at 7 PM ADT
September 10	September 15	September 18
October 8	October 20	October 16
November 12	November 17	November 20
December 10	December 15	December 18



Register at [www.aamac.ca](http://www.aamac.ca)



### Upcoming Webinars

MDS Classifications	PNH Treatments
Wednesday, September 24, 2025 7 PM EST	Wednesday, October 1, 2025 7 PM EST
Speaker: Dr. Karen Yee	Speaker: Dr. Marc Bienz

### Upcoming In-Person Meetings

CALGARY	WINNIPEG	OTTAWA
Saturday Oct. 25, 2025 9 AM - 1 PM Hotel 11	Saturday Nov. 8, 2025 8:30 AM - 1 PM Inn at the Forks	Saturday Nov. 15, 2025 9 AM - 1 PM Canadian Blood Services
Dr. Jennifer Grossman Overview of PNH and AA Dr. Michelle Geddes Overview of MDS	Dr. Lin Yang Overview of PNH and AA Dr. Brett Houston Overview of MDS Patient Experience Panel	Dr. Mitch Sabloff Overview of PNH and AA Dr. Ashish Masurekar Bone Marrow Transplants and Overview of MDS



Register at [www.aamac.ca](http://www.aamac.ca)



These include our virtual support groups and in-person educational conferences. We need your help in distributing these materials to reach more patients and families impacted by bone marrow failure disorders who can benefit from the support that AAMAC offers to navigate a diagnosis.

Please contact [adminoffice@aamac.ca](mailto:adminoffice@aamac.ca) and we will arrange shipment of these post cards.

Thank you for your invaluable contribution in increasing awareness about AAMAC!

## MEETINGS & EVENTS

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

### 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



## Upcoming In-Person Patient Education Conferences

### CALGARY

Date: Saturday, October 25, 2025

Time: 9:00 AM - 1 PM

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

#### 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: 9:00 AM - 1:30 PM

Location\*: Inn at the Forks, 75 Forks Market Road

#### 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, 1800 Alta Vista Drive

#### Speakers:

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

## 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, September 9

Time: 6 PM ET

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

\*This meeting will be streamed virtually. The meeting in Ottawa will also be translated in French.

\*\*AAMAC is offering a \$300 travel subsidy to offset the costs of travel for those who want to join the Winnipeg conference in person. Please contact [adminoffice@aamac.ca](mailto:adminoffice@aamac.ca) to learn more about the subsidy.



### Atlantic Patient Support Group

Date: Thursday, September 18

Time: 7 PM AT

This meeting is held on the third Thursday of each month

### Western Canada Patient Support Group

Date: Monday, September 15

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](http://CanadaHelps.org)

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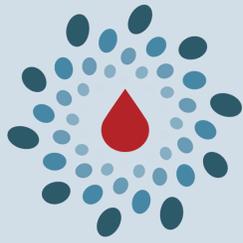
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# ANNUAL GENERAL MEETING



**OCT 18, 2025  
1 PM (ET)**

AAMAC's 2025 Annual General Meeting will take place virtually on **Saturday, October 18, 2025** at **1:00PM (ET)**. Please register on AAMAC's website or email [adminoffice@aamac.ca](mailto:adminoffice@aamac.ca) to be sent the details.

**Everyone is welcome to join the meeting!**