



**AAMAC**  
**ACAAM**

Aplastic Anemia & Myelodysplasia  
Association of Canada

Association canadienne de l'anémie  
aplasique et de la myélodysplasie

## Newsletter - Summer 2026

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

### Message from the Executive Director

Happy Spring!! By the time you receive this newsletter we hopefully will be well on our way to some summer weather.

We enjoyed seeing many of you at our Spring meetings either in person or online and we are always grateful to the doctors who give of their time to give presentations and answer questions from the participants. We have already started plans for the fall meetings this fall we will be hosting meetings in Halifax and in Saskatoon. We are also grateful to our sponsors for their financial support to assist AAMAC in offering these opportunities for our patients.

We recently hosted a webinar on Shared Decision Making. I am sure this is an important topic for both patients and their families as they receive their diagnosis and make subsequent decisions on treatment. The webinar is available on our website for those who are interested in listening.

We were so happy to welcome Nina to our Board of Directors. Nina has become very involved very quickly and is currently assisting in recruiting some new board members. If you would like more information about this opportunity, please email me at [cindyanthony@aamac.ca](mailto:cindyanthony@aamac.ca).

Thank you to Fiona and Maria for putting the newsletter together for us four times a year. We hope you enjoy this issue.

Enjoy summer.

Cindy Anthony

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## SHARED DECISION MAKING IN RARE DISEASES

People with bone marrow failure are often faced with making difficult decisions about treatment options. Making these decisions can be even harder when the patient and/or family feel rushed, uninformed, or pressured by the opinions of others. Fortunately, there is new process being introduced into healthcare that is called Shared Decision Making (SDM).

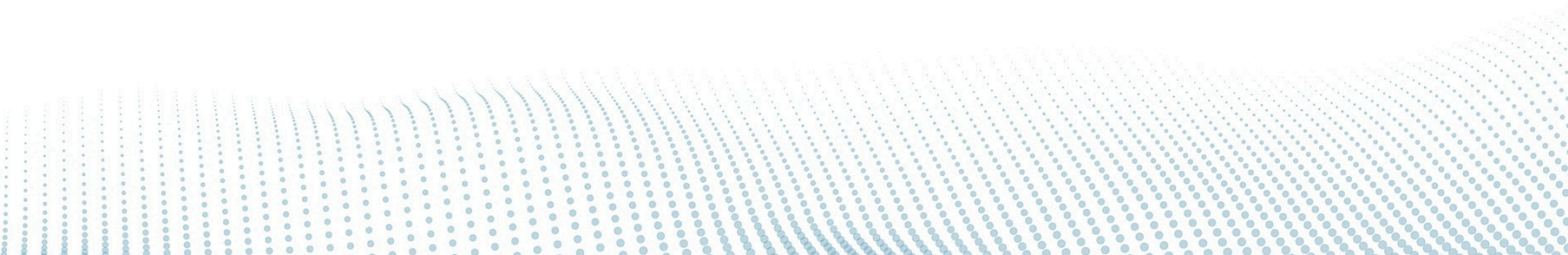
SDM is a collaborative approach in which patients and their families work with health-care providers to make important choices about care, taking treatment options and individual preferences into account. Studies have shown that the use of SDM can result in improved adherence to treatment, less regret from patients about their decisions, reduced demand for health care resources, and improved clinical outcomes.

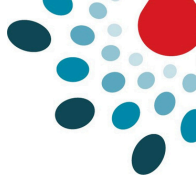
While SDM can include obtaining informed consent to treatment, it goes beyond this first step. It can be used for complex decisions around:

- Medication options
- Treatment pathways
- Clinical trial participation
- Intensity of care
- Plan of care

The SDM process typically includes these steps:

1. Patient and family agreement to participate in the process.
2. Discussion with the health care provider about treatment options, risks and benefits of each option, and evidence-based information about the treatment.



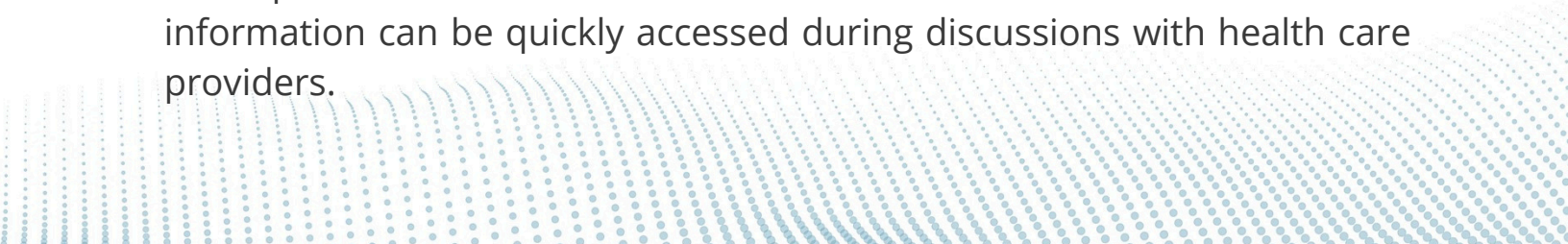


3. Discussion with the health care provider about the patient's values and concerns. This may include discussion about quality vs. quantity of life, the relative importance of each risk and benefit to the patient, the impact of each treatment option on the family and household, spirituality, proximity to treatment location, etc. It may also be important to look at who else is involved in the decision and how important their opinion is.
4. The patient and health care provider come to a joint decision about the treatment.
5. The health care provider checks back with the patient to review the decision after the treatment has started. Together they assess whether treatment goals are being met.



### AAMAC's "My Progress Tracker" 2026

Some health care facilities have specific staff and/or tools to support this process. There may be a staff person assigned to act as a neutral and supportive coach during the process. There may also be tools to assist patients in reviewing and evaluating the information. Some examples of tools that are relevant to AAMAC patients include our Questions Prompt Lists which can assist in gathering information at medical appointments and the Educational Resources on our website. Our Progress Trackers allow patients to chart their test results and medications so that the information can be quickly accessed during discussions with health care providers.



The Ottawa Hospital has developed several resources about SDM including Decision Aids on selected topics. These can be viewed at [www.decisionaid.ohri.ca](http://www.decisionaid.ohri.ca)

If you are struggling with an important decision about your treatment, it may be helpful to ask your specialist if the facility has someone to assist with a Shared Decision Making process. It may be that your own physician or another member of the team such as a social worker or nurse can facilitate the process.

To learn about the use of SDM with PNH patients, please visit the Educational Materials section of the AAMAC website. In the “Videos” section of the website, you can watch a recording of a recent AAMAC webinar, entitled: *Your Health, Your Voice: Making Care Decisions That Fit Your Life*. The presentation slides used by the presenter for this webinar can be accessed under the “Presentations” section of AAMAC’s website.

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## **NUTRITION RESOURCES**

In February, AAMAC hosted a webinar about nutrition with dietician Jenna Swift from Alberta Health Services. We encourage you to view a recording of this webinar on our website. Jenna shared some great advice from her experience working with oncology patients. She also directed us to a wealth of information on nutrition at Alberta Health Services. At <https://ahs.ca/nutritionhandouts>, you can access hundreds of handouts on a wide variety of nutrition topics.

Here are a few titles that caught our eye:

- Adding calories and protein to your diet
- Cooking when you have low energy
- Eating with taste and smell changes
- Making smoothies with more calories and protein
- Safe food handling for immunocompromised individuals
- Nutrition supplements



Here's one of their recipes that will add some extra calories to your morning oatmeal:

### Banana, Peanut Butter, and Maple Oatmeal

Ingredients:

1/3 cup quick oats

2/3 cup water

2 Tbsp peanut butter

1 Tsp maple syrup

1 medium banana, peeled and sliced

1/2 cup fortified soy beverage (or other plant-based beverage such as almond milk)

Directions:

1. Combine oats and water in a bowl and stir.
2. Cook in microwave until oats are soft and thick. Stop to stir every 30 seconds.
3. Stir in peanut butter and maple syrup. Top with banana and soy beverage and serve.

Prepared as above, one serving has:

490 calories

20 g fat

64 g carbohydrates

21g sugar

8g fibre

19g protein





## **GETTING TO KNOW AAMAC'S NEWEST BOARD MEMBER, NINA ARVANTIDIS**

### **How did you hear about AAMAC?**

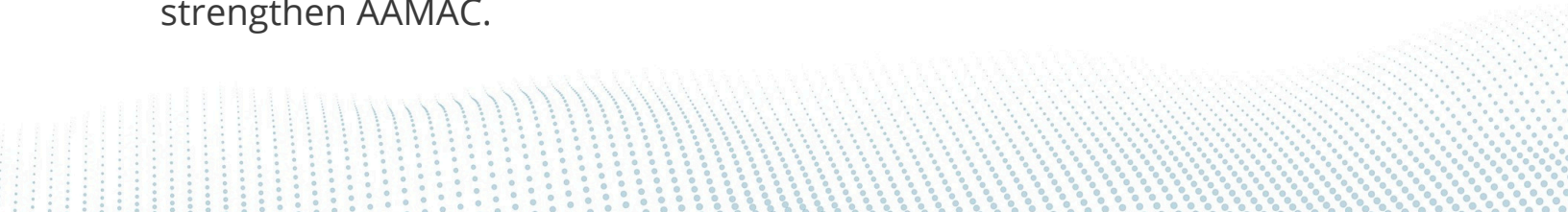
The first time I came across AAMAC was when I saw the posting for a board director position. I had a family member who was affected by MDS and when I read the description, I thought this was a good match for me. My mother-in-law was diagnosed in the fall of 2022 in Ontario and, sadly, we lost her too soon to post stem cell transplant complications. It was a steep learning curve for all of us. Most support came through the cancer care system in Ontario. A support that we were unaware of was the opportunity to connect to other patients with a similar illness.

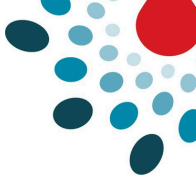
### **Why did you decide to become a board member?**

I have always been passionate about health and patient access to healthcare and support—my early career focused on global HIV/AIDS advocacy. Over time my profession broadened to sustainability, spanning socio-economic, health and environmental impact management for energy sector projects around the world. I'm now at a point of giving back, here at home in Canada, through board service and reconnecting with my passion for health.

### **Are there any special skills you bring to the board?**

I spent about 20 years working in the corporate sector in varied roles, companies and geographies. I'm adept at getting things done. I figure out systems very quickly and am comfortable with complexity. I'm used to a high-performing corporate culture. I am good at strategic, big picture thinking and am comfortable asking questions. I'm also trying to leverage my corporate governance background. I'm now leading the board governance committee, hoping to enhance accountability, efficiency, risk and opportunity management. I believe my corporate background can bring some balance and energy to the board, in turn helping to strengthen AAMAC.





### **Have you experienced any surprises since joining AAMAC?**

I've been surprised by just how small the organization is and how much gets done with so few people. I'm impressed by the ability to deliver such a large mandate with a small organizational structure. I came in with the MDS angle, so I've been deepening my understanding of Aplastic Anemia and PNH. Since joining, I've developed more awareness of how the whole rare blood disorder ecosystem works in Canada, including the important role played by pharmaceutical companies and Canadian Blood Services.

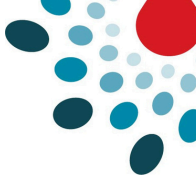


**AAMAC's Newest Board Member, Nina Arvantidis**

### **What would you like to achieve as a board member?**

I want to ensure that the governance processes really work efficiently and effectively by doing some fine turning of these systems. I also want to ensure we have a high performing board with complementary strengths and a diverse mix of individuals—looking at geography, skill set, experience, etc.

Another area where I am keen is helping AAMAC build the network of MDS, AA and PNH patients, practitioners and researchers in each region of the country. These networks need ongoing maintenance over time and I am currently focusing on strengthening awareness of AAMAC in Alberta.



### Anything else you'd like to share with our readers?

I'm looking forward to learning more from the patient perspective. I have a lot of admiration and am deeply humbled by people who are on this journey. I'm also a wife and a mom to 3 kids who are heading into the teen years, which keeps me busy! My family and I are now settled in Calgary after working abroad for many years I bring diverse perspectives and experience from living and working in several different countries. All my children were born outside of Canada and I have also supported multiple family members through their cancer care in Ontario over the years—consequently, I have learned how to navigate many different health care systems!



## PATIENT VOICES

AAMAC was proud to see a Canadian PNH patient, Hannah, featured on the website Patient Voice, a site dedicated to simplifying conversations around health in Canada by elevating patient stories. Hannah describes her journey of discovering she had PNH as she started fertility treatment and then trying different medications as she went through pregnancy and postpartum depression. Hannah's story highlights the importance of advocating for yourself and pushing for the quality of life we all deserve. You can read more about Hannah here: [Hannah's Story](#).





## MEETINGS & EVENTS

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

### Upcoming In-Person Patient Education Conferences

#### HALIFAX

**Date:** Saturday, October 3, 2026

**Time:** 9:00 AM - 1:00 PM

**Venue:** Delta Hotels Halifax Downtown, 1990 Barrington Street, Halifax

**Speakers:**

- Dr. Amy Trottier - MDS
- Speakers for Aplastic Anemia and PNH will be announced soon!

#### SASKATOON

**Date:** Saturday, November 21, 2026

**Time:** 9:00 AM - 1:30 PM

**Venue:** Saskatoon Inn and Conference Centre, 2002 Airport Drive

**Speakers:**

- Dr. Mohamed Elemary - MDS
- Dr. Hadi Goubran-Messiha - PNH
- Dr. Fei Fang - Aplastic Anemia

### 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!

#### Daytime Patient Support Group

Date: Monday, June 8

Time: 4 PM (AT), 3 PM (ET), 1 PM (MT), or 12 PM (PT)

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

#### Wednesday Patient Support Group

Date: Wednesday, June 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

#### Monday Patient Support Group

Date: Monday, June 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



## 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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