



**AAMAC**  
**ACAAM**

Aplastic Anemia & Myelodysplasia  
Association of Canada

Association canadienne de l'anémie  
aplasique et de la myélodysplasie

## Newsletter - Fall 2023

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

### Message from the Executive Director

I hope everyone is enjoying a good summer, hopefully seeing more family and friends than in previous ones. For many of us we have faced poor air quality due to the fires in many parts of the country. Fiona has written a good article about how best to protect ourselves during the days when there are advisories.

It was wonderful to see many of you at our spring In-Person Patient Meetings. We are very thankful to our speakers and sponsors who make these meetings possible. We are excited to offer meetings in Calgary and Winnipeg this fall and plans are already in place for 2024 meetings. We will be having a psycho-social component to the spring meetings. In speaking to many patients and care partners, I've learned this is so important as you face your day to day lives living with a chronic disease. Plans are in place for breakout sessions with patients and care partners to discuss concerns and learn some strategies to assist.

We will start our webinars again in the fall. November is Care Partner Awareness Month and we will be hosting a webinar for care partners during that month. Please check our website and social media platforms for details as they become available.

If you have not had the opportunity to join one of our online support groups, I encourage you to try one out. Patients and care partners who attend find them very helpful as they connect you to individuals experiencing the same challenges you are facing. It is also a place to celebrate success with treatments. Information on these groups can be found at the end of the newsletter and on our website.

Enjoy the rest of the summer and we look forward to the upcoming events and hope to see many of you.

Cindy

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## AAMAC'S ROLE IN DRUG SUBMISSIONS

As many of you are aware, it can be a long and convoluted journey to approval and funding of a new drug in Canada. As a patient advocacy group, AAMAC plays a small but essential role in that journey. When a pharmaceutical company has a new drug that they would like approved for sale in Canada, they must go through a Health Canada approval process. Once Health Canada approves a drug, Canada's Drug and Health Technology Agency (CADTH) gets involved.

CADTH undertakes reviews of drugs and issues reimbursement recommendations to all federal, provincial, and territorial drug programs and cancer agencies that participate in CADTH's review processes and Canadian Blood Services. Each province and/or program then makes its own reimbursement decisions based on CADTH's

recommendation. CADTH seeks patient perspectives to improve the quality of its assessments of medical procedures, devices, and drugs.

AAMAC learns about opportunities to provide patient input either through pharmaceutical companies or through organizations that serve similar patient groups. Additionally, CADTH sends weekly updates as to drugs being reviewed and the timelines for patient input. Typically, AAMAC will partner with other organizations in preparing a submission to CADTH. These submissions address quality of life issues that may be positively impacted by the new drug. These patient benefits can include:

- Reduced side effects
- More convenient modes of medication administration which can affect ability to work, for example
- Improvement in symptoms such as fatigue

Often AAMAC will initiate a patient survey to gather input prior to preparing the submission. Watch for these on our website.

Visit the [CADTH website](https://www.cadth.ca/)<sup>\*</sup> to find out more about the impact of patient involvement in their review process. You can find out more about the entire drug approval process in

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<sup>\*</sup> <https://www.cadth.ca/>



Canada by checking out a *presentation*\* that the pharmaceutical company, Sobi, did for AAMAC in 2021.

Happily, AAMAC's role in drug submissions has grown in recent years as the number of new treatments for MDS and PNH has increased.

## **“AIR QUALITY ADVISORIES IN EFFECT AS WILDFIRES CONTINUE TO RAGE IN SEVERAL PROVINCES”**

This was the headline in the Globe and Mail on June 25th, leaving many people with health conditions to wonder what it means for them and their daily activities. In this story, we delve a bit deeper into air quality advisories and Canada's Air Quality Health Index (AQHI).

According to the Government of Canada, the AQHI is a scale designed to help you understand what the quality of the air around you means for your health. It is a tool developed by health and environmental professionals to communicate the health risk posed by air pollution. It is designed to help you make decisions to protect your health and the environment by:

- Limiting short-term exposure to air pollution
- Adjusting your activity during episodes of increased air pollution and encouraging physical activity on days when the index is lower
- Reducing your personal contribution to air pollution

The index provides specific advice for people who are especially vulnerable to the effects of air pollution as well as for the general public.

You can assess whether you are at greater risk based on your age, health status and level of outdoor physical activity, and whether or not you are experiencing symptoms such as difficulty breathing. People living with cancer are at a higher risk of health problems when exposed to air pollution.

Negative health effects increase as air pollution worsens. Studies have shown that even modest increases in air pollution can cause small but measurable increases in emergency room visits, hospital admissions and death. Small increases in air pollution over a short period of time can increase symptoms of pre-existing illness among those at risk.

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\* [https://aamac.ca/wp-content/uploads/2021/10/Drug-Approval-Process-in-Canada-AAMAC-presentation-Oct-2021\\_PDF.pdf](https://aamac.ca/wp-content/uploads/2021/10/Drug-Approval-Process-in-Canada-AAMAC-presentation-Oct-2021_PDF.pdf)

The Air Quality Health Index is measured on a scale ranging from 1 to 10+:

- 1-3 = 'Low' health risk
- 4-6 = 'Moderate' health risk
- 7-10 = 'High' health risk
- Above 10 = 'Very high' health risk

The associated health messages for At-Risk Populations are as follows:

- 1-3: Enjoy your usual outdoor activities.
- 4-6: Consider reducing or rescheduling strenuous activities outdoors if you are experiencing symptoms.
- 7-10: Reduce or reschedule strenuous activities outdoors. Children and the elderly should also take it easy.
- Above 10: Avoid strenuous activities outdoors. Children and the elderly should also avoid outdoor physical exertion.

You can find out about the AQHI index for your province and town by clicking [here](#)<sup>\*</sup>. If you click on your nearest town, you can see the risk score for that area currently and for the next 24 hours, which allows you to plan your activities for the day ahead.

## GETTING TO KNOW AAMAC'S NEWEST BOARD MEMBER, KELLY MCKIBBIN

Q. How did you come to get involved with AAMAC?

A. AAMAC was one of the first organizations we saw online when we were looking for support at the time of diagnosis. Now that my daughter, Hillary, is in stable recovery from Aplastic Anemia, I am feeling a sense of responsibility in giving back.

Hillary was 5 years old when we took her for a blood test since she seemed lethargic and had lots of circle bruises on her arms. The lab called that night and told us to take her to the ER immediately for several blood transfusions. It took weeks of genetic testing to arrive at the diagnosis of Idiopathic Aplastic Anemia with PNH clone. Her older sister was only a partial match – a full sibling match is the only known cure for AA.



Kelly and Hillary McKibbin

\* [https://weather.gc.ca/mainmenu/airquality\\_menu\\_e.html](https://weather.gc.ca/mainmenu/airquality_menu_e.html)



After considering treatment options and seeking several opinions across Canada, we proceeded with immunosuppressive therapy (IST) treatment (hATG+cyclosporin). Hillary received a full response but continues with persistent low neutrophils and frequent headaches. We have no idea if she will require a bone marrow transplant from an unrelated donor.

As Hillary continues on the rare disorder path, I feel compelled to keep up with research, conferences, and other opportunities which might help cure my daughter one day.

Q. Can you tell us a bit more about your daughter and how she has handled her diagnosis?

A. Hillary is a catalyst for change. She is now 10 years old. In 2019, we organized a bone marrow donor drive in Ottawa. The city really rallied around Hillary. Our stem cell event broke the record in Canada: 630 people showed up and got swabbed for Hillary. Another 250 were turned away but signed up online when we ran out of kits. We started back up the next day for another 250, and it just grew across Canada, landing us in MacLeans magazine.

Hillary started her own YouTube channel to showcase her doing her twice per day medicine. Even during her worst, when her neutrophils were at 0, she turned on her iPhone camera and got the job done. We have over 1,500 videos we haven't posted yet. In every video she closes with, "Please give blood, get swabbed, and donate to Make-A-Wish."

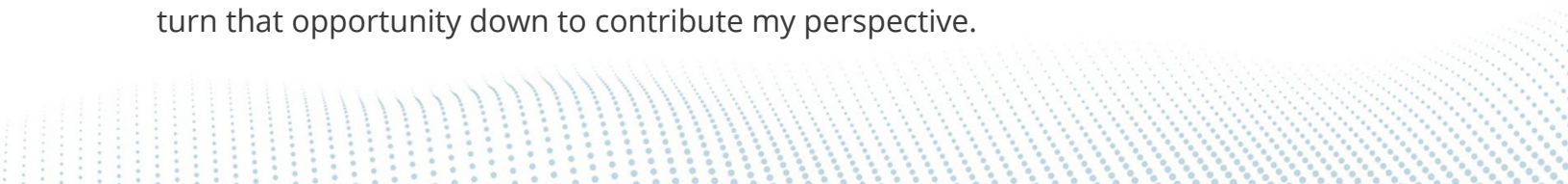
We use social media to inform ourselves and inform others. Hillary is very active on Twitter and is an active part of the Ottawa community. AAMAC is so helpful in that regard. AAMAC helps us feel less alone. They don't ignore our reality.

Q. What kind of response does Hillary get on social media?

A. Hillary gets a 100% positive response on social media. People are decent and kind to children on Twitter, always. We write tweets together and are always careful not to offend others. Hillary shares positive messages only, even on her darkest days. We feel that the only way to raise awareness is to connect people in a positive way.

Q. Why did you decide to become a board member?

A. The Board did not have pediatric representation for Canada and I couldn't possibly turn that opportunity down to contribute my perspective.





Q. What would you like to achieve as a board member?

A. I'd like to use my skills and abilities to achieve more awareness for AA, MDS, and PNH. I think it is key to have resources available at the time of diagnosis, not only for patients, but caregivers and family members. This disorder affects the whole family.

I would also like to explore using social media in a more meaningful way by connecting patients in real time through online support groups. I belong to an international support group and it is so incredibly useful to hear the stories of others. I can see how other countries treat the condition and what new drugs and trials are making their way to Canada. I can read about patients' experiences with these treatments to make my own informed decisions. The real-time nature of social media allows people to get immediate support even as they are being diagnosed or as crises are occurring. I think AAMAC has a wonderful network which helps increase social media engagement. I look forward to being of service.

Links to Hillary's social media and the family's awareness campaign

Website/blog: <http://startwithhillary.ca/>

Twitter: @StartWithHills

YouTube - Hillary McKibbin:  
<https://www.youtube.com/@hillarymckibbin1772>

Students Saving Lives initiative:  
<http://startwithhillary.ca/students-saving-lives/>



## NAVIGATING THE MDS CLEAR PATH

MDS Clear Path is an *online*\* tool designed to help streamline the continuum of care for MDS patients, from diagnosis and staging through to treatment.

It is the outcome of a Canada-wide physician consensus on best practices in MDS management. Although it was designed to support physicians at key decision points in their treatment of MDS, it can also be used by MDS patients.

The tool leads the user through a decision tree which asks questions about the patient's current condition and then recommends next steps in treatment. The tool is technical and geared more to physicians than patients but it contains a lot of information that can be helpful for patients seeking to understand aspects of their care. Most of the decision points are accompanied by an information panel, indicated by an *i* in a circle. Here is a screen shot of the information panel that accompanies the option of "watchful waiting & monitoring".

The screenshot shows a mobile application interface. At the top, a red header bar contains the text 'MDS'. Below this, a grey bar with a red arrow icon on the left and a 'CLOSE INFO PANEL' button on the right contains the title 'WATCHFUL WAITING & MONITORING'. The main content area is white and contains a list of recommendations:

- › Low-risk patient assessment conducted every 3-6 months
- › Should include:
  - › Clinical history, including signs/symptoms of infection, bleeding and anemia
  - › CBC with WBC differential count
  - › Blood smear
  - › LDH
- › May include:
  - › Biochemistry – electrolytes, liver enzymes, bilirubin, creatinine
  - › Ferritin and transferrin saturation (every 6 months)
- › If changes in CBC (progressive cytopenia, development of new cytopenias, appearance of circulating blasts) are observed, and therapy beyond supportive care is contemplated, bone marrow aspirations/biopsies with cytogenetics should be performed

At the bottom of the panel, there is a small text block: 'CBC: complete blood count; LDH: lactate dehydrogenase; WBC: white blood cell; RD: Recommendation of the Steering Committee.' To the left of the main content, there is a vertical sidebar with a red 'R-RISK' button and an information icon (i in a circle) above the text 'ALLO-SCT'. To the right, there is a 'WATCH BACK WIZARD' button and a 'Watchful Waiting for every 3-6 months' button.

Try playing around with the tool and you will quickly learn how to navigate it and find the information you are seeking. We understand that a MDS Clear Path app will be available later this year so information will be even closer to your fingertips.

\* <https://www.mdsclearpath.org/>



## MEETINGS & EVENTS

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

### Upcoming Fall In-person Patient Education Meetings

#### CALGARY

Date: Saturday October 14, 2023

Time: 9AM - 1 PM

Location: Hotel 11 by Sonesta

#### Speakers:

- Dr Michelle Geddes – Overview of MDS – New Treatment Options
- Dr Monika Oliver – Overview of PNH and AA – New Treatment Options

#### WINNIPEG

Date: Saturday November 18, 2023

Time: 830AM - 1 PM

Location: Fairmont Winnipeg

#### Speakers:

- Dr Brett Houston– Overview of MDS – New Treatment Options
- Dr Lin Yang– Overview of PNH and AA – New Treatment Options

### Upcoming Spring In-person Patient Education Meetings

#### TORONTO

Date: Saturday April 20, 2024

Time: 830AM - 1 PM

Location: Novotel Toronto North York

#### Speakers:

- Dr Rena Buckstein – Overview of MDS – New Treatment Options
- Pamela J. West Nurse Practitioner - Living Well with a Chronic Disease - Breakout sessions for Patient and Caregivers

#### HALIFAX

Date: Saturday May 4, 2024

Time: 830AM - 1 PM

Location: Hotel Halifax

#### Speakers:

- To be confirmed

#### VANCOUVER

Date: Saturday May 4, 2024

Time: 830AM - 1 PM

Location: Holiday Inn Express Vancouver-Metrotown

#### Speakers:

- To be confirmed







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### 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 September 6, 2023

Time: 7PM ET

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

#### Central Canada Patient Support Group

Date: Wednesday, September 13, 2023

Time: 6PM ET

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

#### Atlantic Patient Support Group

Date: Thursday, September 21, 2023

Time: 7PM AT

This meeting is held on the third Thursday of each month

#### Western Canada Patient Support Group

Date: Monday, September 18, 2023

Time: 6PM PT

This meeting is held on the third Monday of each month

### Webinars

#### MDS and New Treatment Options

Date: Saturday, November 4, 2023

Time: 11AM ET

#### Caring for Care Partners: Addressing Burnout and Compassion Fatigue

Date: Saturday, November 18, 2023

Time: 1PM ET

#### Speaker:

- Dr Jenny Ho, MD, MSc, FRCPC  
Assistant Professor  
Schulich School of Medicine and  
Dentistry, Western University

#### Speaker:

- Celeigh Barber-Russell, Clinical  
Counsellor, B.Ed, M.Ed, LCT-C, CCC



AAMAC's 2023 Annual General meeting will take place virtually on **Saturday, October 14, 2023** at **1:00PM ET**. To register for the meeting please email [info@aamac.ca](mailto:info@aamac.ca).



## 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)

## AAMAC NATIONAL OFFICE

2201 King Road, Unit #4  
King City, ON  
L7B 1G2  
Phone: 1-888-840-0039  
Email: [info@aamac.ca](mailto:info@aamac.ca)

### Regional Support

Phone: 1-888-840-0039

### Central Canada:

[ontariosupport@aamac.ca](mailto:ontariosupport@aamac.ca)

### Atlantic Canada:

[atlanticsupport@aamac.ca](mailto:atlanticsupport@aamac.ca)

### Western Canada:

[bcsupport@aamac.ca](mailto:bcsupport@aamac.ca)

### French Speakers:

[soutienfrancophone@aamac.ca](mailto:soutienfrancophone@aamac.ca)

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