



AAMAC
ACAAM

Aplastic Anemia & Myelodysplasia
Association of Canada

Association canadienne de l'anémie
aplasique et de la myélodysplasie

Newsletter - Spring 2026

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

Message from the Executive Director

Happy New Year! I am not sure how winter is treating you where you live, however, here in Ontario it has been a very snowy, cold winter.

Spring can't come soon enough and we are looking forward to our Spring Meetings, highlighted in this issue. We are looking forward to seeing patients in Vancouver, Calgary and Toronto.

Thank you to all of you who took the time to complete our survey on the Online Patient Support Groups. As a result of this we will be starting up a daytime support group, along with one meeting a month on Monday and Wednesday evening. Plans are being worked on for a group that is specific to caregivers, keep an eye out for information on that as it becomes available.

AAMAC is so grateful to those of you who chose AAMAC in your charitable giving. We could not provide the support we do without these donations and we thank each and every one of you. AAMAC is blessed to have had ongoing support from organizations such as the D.H. Gordon Foundation which is highlighted in this issue. We thank them for 10 years of support.

As always, we have a number of resources available including our 2026 Progress Tracker. Patients use this tracker to keep track of appointments and also other medical information. If you would like to have one sent to you, please email info@aamac.ca and we will get one out to you.

Wishing everyone all the best for 2026 and we hope to see you at a meeting or online this year.

Cindy Anthony

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THE D.H. GORDON FOUNDATION

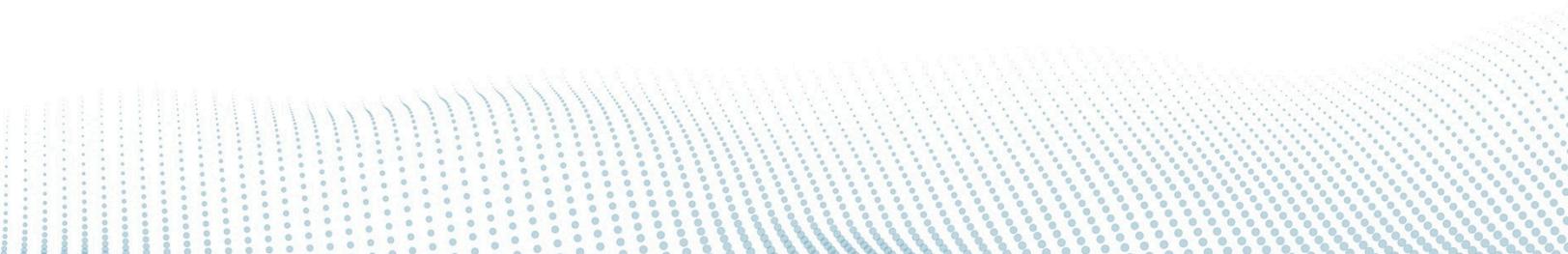
AAMAC is pleased to honour the D.H. Gordon Foundation for its decade of support to our organization. The Foundation was introduced to AAMAC by former board member, Andy May.

Andy and his family became aware of AAMAC in 2007 when his daughter Karlee (4 years old at the time) was diagnosed with Aplastic Anemia. When his daughter stabilized after a bone marrow transplant, Andy got involved with the Ontario Chapter of AAMAC and assisted with fundraising. The Chapter organized large fundraising dinners and dances which brought together families and friends affected by AA and MDS as well as survivors. During one of these events, Jeff Gordon was an invited guest of Andy's family. Jeff later reached out to the family to ask if he could help with D. H. Gordon Foundation. This was the start of a long relationship between the Foundation and AAMAC.

AAMAC Executive Director, Cindy Anthony, states:

"AAMAC values the support of the D.H. Gordon Foundation over the past ten years. Through this generous donation we have been able to offer valuable support programs to patients and caregivers affected with Aplastic Anemia, Myelodysplastic Syndrome and PNH".

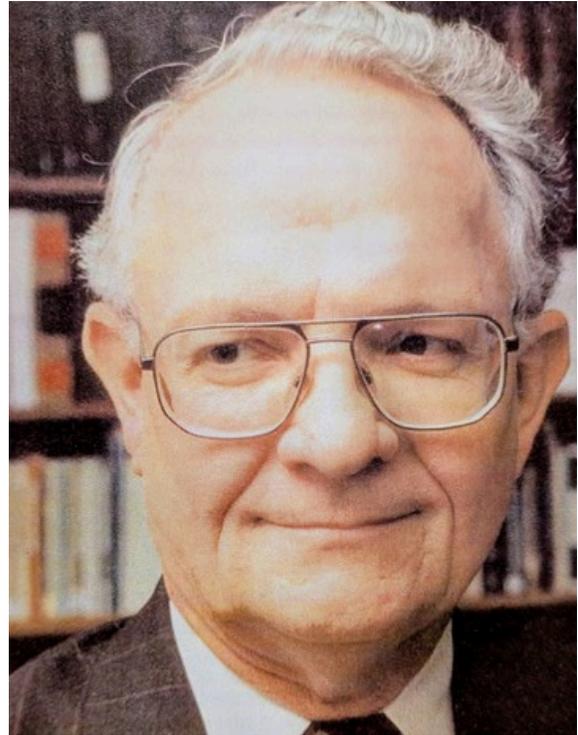
David H. Gordon formed the Foundation near the end of his life. A corporate lawyer, he lived his life with a quiet commitment to helping others and the Foundation became another outlet for his philanthropy, which focused on health care and social services. His focus was smaller charities that don't have the staff and infrastructure to do large fundraising campaigns, those where a donation of \$10,000-20,000 can make a significant difference.





Today, the Foundation is managed by 5 trustees, including David's nieces and nephews. Nephew, Jeff Gordon, described his uncle this way:

"Although David was a senior partner with McCarthy Tetrault, his personality was somewhat casual and understated. Hence, no website or fanfare, just an interest in helping people through difficult times."



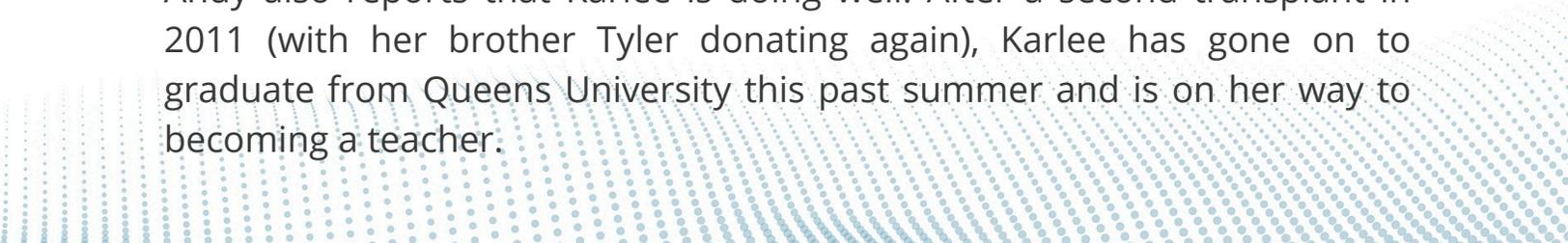
David H. Gordon

Jeff noted that the Foundation's assets are approximately \$18-19 million and it gives away 5% of the total value of the portfolio every year. In addition to AAMAC, the Foundation supports about 35 other Ontario-based charities, including those that focus on food insecurity and children with disabilities. The Foundation will continue in perpetuity as long as the principal continues to earn interest. It is a remarkable legacy for a man who sought to make a difference in a quiet and thoughtful manner.

As Andy noted:

"Jeff's compassion and continued dedication through the D. H. Gordon Foundation to AAMAC has left a positive financial impact for over a decade. Although not currently a member of the AAMAC Board, I am proud to share and acknowledge this partnership and the importance of helping families dealing with these vicious diseases."

Andy also reports that Karlee is doing well. After a second transplant in 2011 (with her brother Tyler donating again), Karlee has gone on to graduate from Queens University this past summer and is on her way to becoming a teacher.





PATIENT SUPPORT GROUP SURVEY RESULTS

In November, we invited patients to respond to a survey about our online patient support groups. We are pleased to share the following results:

25 people responded to the survey. Of those:

- 19 were patients and 6 were care partners or family members
- 18 had attended an online patient support group meeting and 7 had not

Respondents had experience with the following diagnoses:

- Aplastic Anemia – 7
 - Myelodysplasia – 16
 - Paroxysmal Nocturnal Hemoglobinuria – 1
 - Combinations of the above or post transplant – 4
-
- A majority (13) agreed or strongly agreed that the group calls were well-facilitated
 - A majority (12) agreed or strongly agreed that the group calls were informative
 - A majority (10) agreed or strongly agreed that the calls offered emotional support
 - A majority (14) agreed or strongly agreed that they had an opportunity to share their news on the calls
 - A majority (11) agreed or strongly agreed that they had an opportunity to provide support to others on the calls

Respondents were asked to comment on changes they would like to see in the patient support groups. Some of the ideas shared included:

- Use the chat feature in Zoom to allow people to identify their diagnosis





- Have an afternoon meeting
- Provide a way for people to stay in touch outside of the calls

We asked respondents to indicate their interest in different types of support groups. The most popular options were:

- A group that meets in the daytime
- A group that is disease specific (i.e. AA or MDS or PNH)
- A group for newly diagnosed individuals



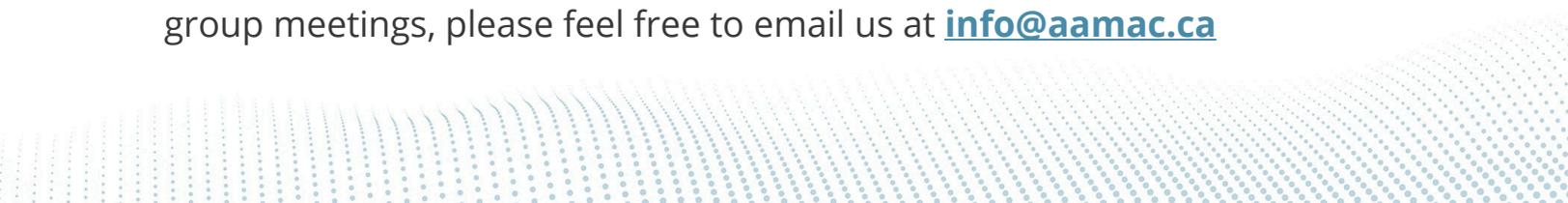
Outcome

Given that the number of respondents was small, we are reluctant to make any changes that would disrupt existing groups where positive relationships have formed.

We have decided to initiate an online group that will meet in the daytime. This group will be held on the second Monday of every month from 3-4 PM Eastern Time. As always, both patients and care partners/family members are welcome to attend. Please register via our website.

For those who would like to stay in touch with other patients between meetings, we invite you to contact the office to indicate your interest and provide your email address, which will then be shared with others from the group who make a similar request.

In the meantime, if you have any feedback about our patient support group meetings, please feel free to email us at info@aamac.ca





CONSIDERING A RETURN TO WORK?

As someone with bone marrow failure, you may be struggling with the decision of whether and when to return to work. You may have left work due to your diagnosis, due to treatment side effects, or due to required isolation related to a stem cell transplant or other treatment. Regardless of the reason you left work, the decision to return can be difficult because of the many issues involved. These include:

Return to work readiness:

- Are you physically able to do the job?
- Have you experienced cognitive changes that may impact your performance?
- How will you handle fatigue at work?
- Can you work full-time?
- Do you need your hours shifted later or earlier in the day?
- Do you need accommodations such as task changes or adaptive equipment?

Communication and teamwork

- Should you tell your colleagues or supervisor about any limitations you have?
- Who can you turn to for support if you have difficulties?
- How do you communicate your plans to your insurance provider?

Legal issues

- What are your rights and obligations regarding disclosing your illness?
- What are your options if your employer will not accommodate you?

Financial issues

- Are there resources available if you must return at reduced hours?
- Will your benefits change if you cannot work full-time?
- How will you manage financially if you do not return to work?





Fortunately, there is a comprehensive, Canadian website available to help patients navigate these questions and more. The website, Cancer and Work, has been developed by McGill University and the BC Cancer Agency. It includes:

- 500 pages of content
- 9 educational videos
- 8 online tools, such as the Return to Work Planner Tool
- Contributions from 27 expert writers

Returning to work is a decision that requires careful consideration. The outcome of a return to work can have a profound impact on your health, your financial well-being and your family. The Cancer and Work website provides the tools and information required to approach this life-changing decision with careful thought and planning. After all, returning to work should be a milestone that you can celebrate in your healthcare journey.

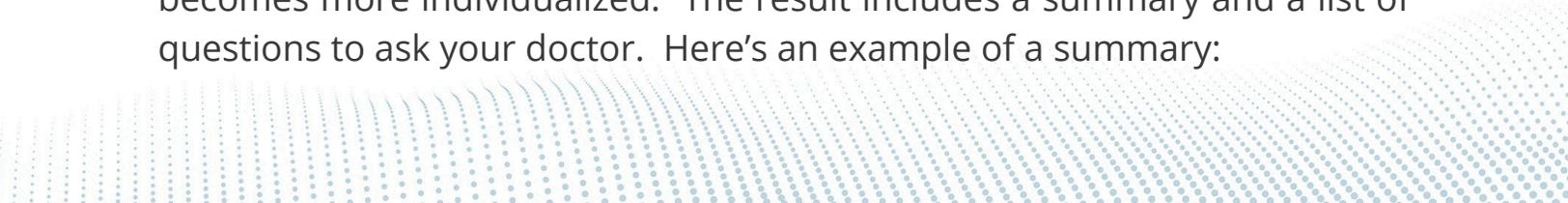


USING AI TO MANAGE YOUR HEALTH

With the growing presence of Artificial Intelligence (AI) in our lives, it is not surprising that patients are looking to AI for information about their condition. While most of us have long used the Internet to search for general information about diseases, symptoms and treatments, we can use AI to obtain customized information based on personalized data that we provide. Before considering the pros and cons of this service, let's look at some examples:

Interpreting test results

Users can enter their test results (such as blood test results) into AI platforms such as Gemini or ChatGPT and get a personalized analysis. If the user then provides additional follow up information, the analysis becomes more individualized. The result includes a summary and a list of questions to ask your doctor. Here's an example of a summary:





What this most likely means

For a 59-year old woman with:

- *Mildly low WBC and neutrophils*
- *Normal red cells and platelets*
- *No medications*

The most common situation is:

- *A benign, mild neutropenia that may be transient or just your baseline.*

Unless you have symptoms like:

- *Recurrent or unusual infections*
- *Persistent fevers, night sweats, unexplained weight loss*
- *Marked fatigue, easy bruising/bleeding, or enlarged lymph nodes*

this usually isn't an emergency, but it is reasonable to follow up.

In addition, some apps will use AI to chart your test results over time and report on trends.

Asking for customized health tips

You can ask AI specific questions related to your health condition. For example, I asked ChatGPT for tips on stimulating my appetite. It gave me a general response but also asked me for more information about my health so that it could tailor the suggestions. AI also powers many apps for health management, which can include medication reminders, sleep monitoring, heart rate monitoring, etc.

Obtaining resources and advice

Visit [My trials.ai](https://mytrials.ai) for an example of a website that uses AI to connect patients with clinical trials that may be relevant to their condition. You can also use AI to summarize a research article related to your disease. AI can even read the article to you if you have trouble reading.



With so many uses, it is clear that AI is a game changer for people managing a chronic health condition. However, let's look at both the pros and cons of using AI for health management.

Pros

- Running your lab results through AI can help calm your anxiety while waiting to hear back from your doctor.
- AI can point out trends in your health that you can then discuss with your doctor.
- AI can save you time by summarizing and customizing information in response to specific health concerns.
- AI can make your appointments with health professionals more productive by highlighting issues, suggesting questions, and explaining medical terminology in advance.

Cons

- Running your lab results through AI may increase your anxiety while waiting to hear back from your doctor.
- Your privacy may be compromised if you enter identifying information into apps or other AI tools.
- The advice AI provides is impacted by how it is prompted. A poorly worded question may produce bad advice.
- AI can produce answers that sound accurate but are actually wrong. When it comes to healthcare, a person with no medical training will likely be unable to recognize a mistake made by an AI assistant.

Like any tool, AI should be used with a good understanding of how it works and what it is capable of. You can enhance your understanding by letting your doctor know that you are using AI and how. This can create an opportunity for discussion about its benefits and limitations.

Full disclosure: I used AI to research and produce this article.





CAMP QUALITY

For children with cancer and blood disorders, Camp Quality provides free summer camps that support the whole family through fun camp adventures. Camps are taking place across Ontario, Alberta, and Manitoba and registrations are now open.



Summer Overnight Kids Camp: Ages 7-17

The 1-week overnight camp welcomes children and their siblings from all over Ontario. At camp they get to experience a week of friendship, fun, and adventure!

Summer Family Camp

The family camp is thoughtfully designed to support the unique experiences of children living with cancer, their siblings, and caregivers. At camp families can relax, connect, and make memories together.

Teen Leadership Camp: Ages 14-17

Camp Quality New Heights is a one-week leadership program for teens that provides opportunities to focus on both personal and group development through team building and leadership.

This program is open to campers across Ontario, Manitoba and Alberta. Camp Quality covers all transportation costs.

Virtual Camp Programs

Open to campers and siblings 5-17 years of age, Camp Quality's virtual camp program brings the magic of camp, the activities, and fun directly to families!

For more information, including specific camp dates, and to register please visit <https://www.campquality.org/>





MEETINGS & EVENTS

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

Upcoming In-Person Patient Education Conferences

VANCOUVER

Date: Saturday, April 25, 2026

Time: 9:00 AM - 1:00 PM

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

TORONTO

Date: Saturday, May 2, 2026

Time: 9:00 AM - 1:00 PM

Location: Novotel Toronto, North York, 3 Park Home Avenue, Toronto

CALGARY

Date: Saturday, May 30, 2026

Time: 9:00 AM - 1:00 PM

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

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, March 9

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, March 11

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

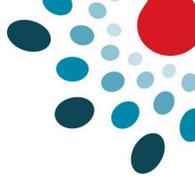
Monday Patient Support Group

Date: Monday, March 16

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

AAMAC NATIONAL OFFICE

390 Beach Drive,
Brighton, ON
K0K 1H0

Phone: 1-888-840-0039

Email: info@aamac.ca

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