



AAMAC
ACAAM

Aplastic Anemia & Myelodysplasia
Association of Canada

Association canadienne de l'anémie
aplasique et de la myélodysplasie

Newsletter - Fall 2024

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

Message from the Executive Director

I hope everyone has enjoyed a good summer. We have been busy over the summer planning for the fall meetings.

If you live in or near Edmonton, Montreal or Winnipeg, please check out the details for the upcoming Patient Education Meetings being held in those cities. We will be offering travel subsidies, please check for details on the website. We have excellent speakers and patient panels to provide education for all those who attend.

We sent surveys out after the spring meetings to get ideas on topics of interest to patients and caregivers. We have planned a webinar addressing nutrition for patients and another one on understanding your blood test results. Both of these topics were mentioned in the feedback. Details for registration are on the website as well.

We continue to offer our monthly support groups and welcome new members. Many patients have found these to be very helpful. This is a comment received after a recent meeting by one of our newer participants. ***"I'm grateful for the existence of AAMAC, for the opportunity to participate in fellowship, support, and information sharing with others across the country who are managing a serious medical condition [similar] to mine."***

In order to provide support to other patients and their caregivers it is so important that information about AAMAC is available in as many hospitals across the country as possible. Please check the newsletter to find out how you can become an ambassador for AAMAC. We would really appreciate your assistance with this.

Hoping to see many of you at meetings or online this fall.

Cindy Anthony

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HEALTH AND WELLNESS PODCASTS

Many of us are used to accessing health and wellness information through newspapers, the internet, and possibly social media. Podcasts are a relatively new and popular source of health and wellness information. A podcast is a series of spoken-word audio episodes focused on a particular topic or theme. They often involve a host interviewing an expert or celebrity.



If you're not sure what a podcast is or how to access one, have a quick read of this article: <https://www.thepodcasthost.com/listening/what-is-a-podcast/>

Podcasts can be a great way to access information if:

- You have trouble concentrating on written information
- You have poor vision that makes reading difficult
- You spend a lot of time driving or walking and would welcome some entertainment while doing so
- You would like spoken guidance with an activity like meditation

There are a few downsides to podcasts also:

- When listening, you may need to get past a series of ads or host promotions at the beginning (and sometimes, in the middle). It can take patience to get the gems of information that the podcast may contain.
- Some podcasts offer transcripts but, if not, you may need to take notes of important information you want to retain.
- They require a time investment – most podcasts run between 45 and 90 minutes.

Ready to try a podcast? We've listed below a few health and wellness podcasts that have been recommended to us. You can type any of these podcast titles into your computer browser or your podcast app to get more information about its focus and a list of episodes. For each episode you will see a brief synopsis, names of featured guests, as well as the length and publishing date of the episode.



A Slight Change of Plans with Maya Shankar

Maya Shankar blends compassionate storytelling with the science of human behavior to help us understand who we are and who we become in the face of a big change.

Ten Percent Happier with Dan Harris

Dan Harris is a fidgety, skeptical journalist who had a panic attack on live national television, which led him to make changes in his life. Dan's approach is that happiness is a skill you can train, just like working your bicep in the gym.

Tara Brach

Tara Brach is a clinical psychologist and leading western teacher of Buddhist (mindfulness) meditation, emotional healing and spiritual awakening. Tara's podcast themes reveal the possibility of emotional healing and spiritual awakening through mindful, loving awareness.

Mel Robbins

A New York Times bestselling author and self-publishing phenom, Mel's work includes *The High 5 Habit* and *The 5 Second Rule*. Most importantly, her science-backed tools and relatable advice have changed the lives of millions of people worldwide.

We Can Do Hard Things

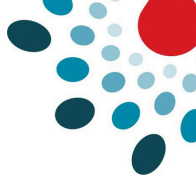
Glennon Doyle, her wife Abby Wambach, and her sister Amanda Doyle do the only thing they've found that has ever made life easier: Drop the fake and talk honestly about the hard things including sex, gender, parenting, blended families, bodies, anxiety, addiction, justice, boundaries, fun, quitting, overwhelm . . . all of it.

Feel Better, Live More with Dr Rangan Chatterjee

Hear stories from leading health experts and personalities who offer easy health life-hacks, expert advice and debunk common health myths giving you the tools to revolutionize how you eat, sleep, move and relax. Hosted by Dr Chatterjee - one of the most influential GPs in the U.K. - *Feel Better, Live More* aims to inspire, empower and transform the way we feel.

We'd be interested to hear what you think of these podcasts or of any others that you listen to regularly. Feel free to email us your thoughts and recommendations at info@aamac.ca





CALLING FOR A BOARD MEMBER WITH A FINANCIAL BACKGROUND

AAMAC has an opening for a Board Member to join us to execute on our goals of providing an integrated support network for every patient, family member, friend and health care professional affected by aplastic anemia, myelodysplasia or paroxysmal nocturnal hemoglobinuria.

If you or someone you know has an interest and time they would like to share with us, please reach out (or have them reach out) to adminoffice@aamac.ca. We are currently looking for individuals with a background in bookkeeping, accounting, finance, or similar fields. Bilingualism would be a great asset but is not required. Previous experience in governance not required.



THE LEGACY OF DR. ROBERT (BOB) MACDONALD

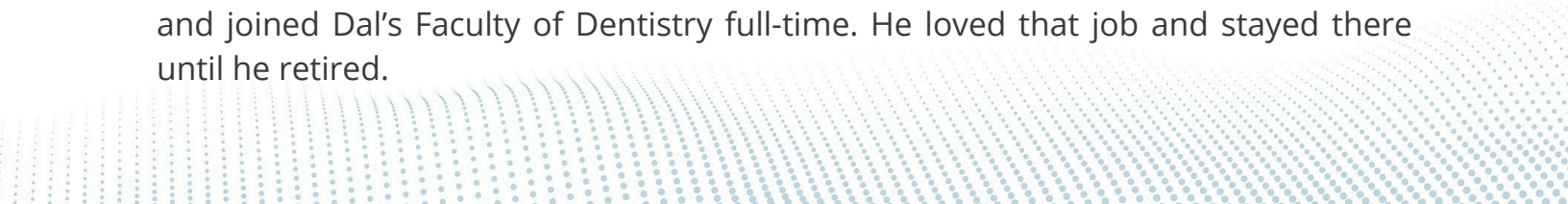
AAMAC was pleased to learn that past board member, the late Dr. Robert (Bob) MacDonald, will be inducted into St. Francis Xavier University's (St. FX) Wall of Honour this October. We spoke with his wife, Jackie MacDonald, to learn more about his legacy.

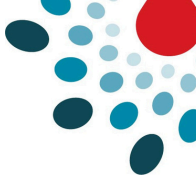
Please tell us more about your late husband's award.

The St. FX Wall of Honour was set up to recognize alumni of the university who have carried out the Xavierian tradition of helping others. The induction ceremony will take place during Homecoming Weekend this October. We have also established a bursary through St. FX in Robert's name that will be awarded for the first time this fall to a 4th year student going into medical or dental studies. All of this coincides with Robert's 65th anniversary of graduating from St. FX, so the timing is pretty special.

Can you tell us about his career?

Robert was a dentist. He went to dental school through a military sponsorship. He served for 12 years as a member of the Royal Canadian Dental Corps. and provided dentistry services in places like Cypress, Germany, Belgium, Sardinia, and London, England. Although we are both from the same small town in Nova Scotia, we got together in 1966 when I met him in Germany. We came home to Canada and got married. After the military, he went into private practice in Halifax but taught part-time at Dalhousie University's School of Dentistry. He eventually left his practice and joined Dal's Faculty of Dentistry full-time. He loved that job and stayed there until he retired.





Can you tell us about his journey with MDS?

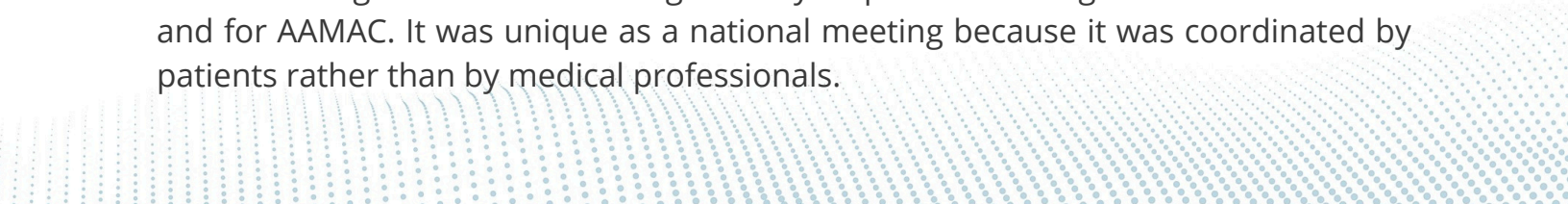
Robert got MDS in his final year of work in 2002. He was tired all the time and got diagnosed in August of that year. He had never been sick in his life and was totally shocked by the news. The hematologist told Robert he would have to have a transplant, but we decided to “watch and wait” for a few months as he finished his last year at Dal. Right after graduation, he got news that his condition had developed into Acute Myelogenous Leukemia (AML). He went into hospital for treatment, spending five weeks there due to various infections from the chemo, which was very tough. As soon as he recovered, he received a stem cell transplant – at that time, he was only the seventh person to receive a stem cell transplant in Nova Scotia. Robert is a twin and his twin sister, Roberta, was able to donate stem cells. His recovery went quite well until Graft-versus-Host Disease (GvHD) hit – it attacked his eyes. He was in pain and couldn’t tolerate any light as the epithelium was gone from his corneas. After trying various drops, ointments, and treatments, they eventually sewed his eyes closed. We were not happy with this outcome, so I asked what else could be done. I was referred to a clinic in Seattle who told me about the Boston Foundation for Sight (BFS). He had four corneal transplants, and thanks to the care he received in both Halifax and Boston, they were able to restore his sight. He continued to have trouble reading but at least he was more comfortable and able to see. It was a tough journey – Robert always preferred to call it a journey not a battle.

How did he get involved with AAMAC?

Robert got involved with AAMAC through another person, Gai Thomas, who was a nurse-educator with MDS. She wanted Robert’s help to start an Atlantic chapter, which happened in 2005. He was reluctant at first as he was not well and his sight was still poor, but he realized how important AAMAC would be to Atlantic Canadian patients. He was appointed chairman of the Atlantic chapter in 2006 and served on the National board from 2006 to 2012. He was very good with other MDS patients – he would talk for hours on the phone with people who wanted more information about the illness and treatment options. Three days before he passed away, he told me he needed to retire from AAMAC and asked me to invite Gwen Barry to take over the Atlantic chapter. Robert wanted the work to continue. We met many wonderful people through AAMAC.

What do you think is his most important accomplishment with AAMAC?

I think the most important was bringing the National Education Day here in 2008. Robert dug in his feet and pushed for the meeting to be here. He and I coordinated a lot of the logistics for the meeting. It really helped build recognition for the disease and for AAMAC. It was unique as a national meeting because it was coordinated by patients rather than by medical professionals.



What motivated him to work so hard with AAMAC while being ill himself?

For both of us, we wanted to be of assistance to others. Robert was always known for taking the time to talk to his students and patients, no matter how busy he was.

How have you stayed involved with AAMAC since Robert's passing in 2012?

I continue to attend the Atlantic patient support group meetings since Robert passed away. I've also helped with fundraising for the Atlantic Chapter and I was the treasurer for a while. There's a core group of us that keeps it going.

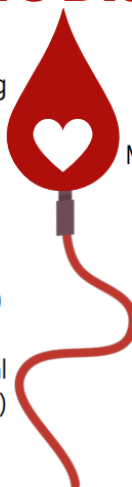
BE AN AAMAC PROMOTER!

Many of you have told us that you wished you had heard about AAMAC when you were first diagnosed. You can help us raise awareness about AAMAC and the support and information we can offer to patients and their caregivers by putting up posters in hospitals and cancer centers across Canada. AAMAC strives to provide a support network to Canadians with bone marrow failure disorders, which relies on increasing awareness about our organization. If you are interested in distributing AAMAC awareness posters to hospitals and cancer centers in your city, please email is at info@aamac.ca to have copies of the posters sent to you!

SUPPORTING CANADIANS WITH **Bone Marrow Failure Disorders**


If You or Someone You Love Are Living With:

- Myelodysplastic Syndromes (MDS)
- Aplastic Anemia (AA)
- Paroxysmal Nocturnal Hemoglobinuria (PNH)





We Offer Support Through:


- Monthly Virtual Patient Support Meetings
- In-Person Educational Days
- Educational Materials
- Connecting Patients Across Canada



**AAMAC
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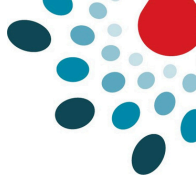
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UPDATE ON PNH TREATMENTS

Dr. Marc Bienz is a hematologist and the Medical Director of Transfusion Medicine in the Division of Hematology at Jewish General Hospital in Montreal. He is also an Assistant Professor in the Department of Medicine at McGill. He is an active member of the Canadian PNH Network. We spoke with him about new and upcoming treatments for Paroxysmal Nocturnal Hemoglobinuria (PNH).



What new treatments are currently available for people with PNH?

Eculizumab is the original treatment. It is a C5 complement inhibitor that is given every two weeks by IV. It was a game changer that dramatically altered the natural course of PNH and extended survival rates to be similar as for the general population.

More recently, we gained access to ravulizumab. It is another C5 terminal complement inhibitor. It is given by IV every 8 weeks at a local infusion centre. Ravulizumab is clinically equivalent to eculizumab. Most patients are now on ravulizumab but they don't have to switch from eculizumab if they don't want to. Some patients have a strong attachment to eculizumab as it was such a life saver for them. It is also the only option we have right now for patients who are pregnant.

The third treatment is pegcetacoplan. It is a second line treatment, meaning that it cannot be given at diagnosis. It's a twice weekly subcutaneous injection that people can give themselves. We can give it only if people don't respond to eculizumab or ravulizumab. About a third of patients may need second line therapy.

What are the benefits to patients?

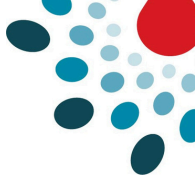
The main benefit of treatment is that it improves survival. It drastically reduces the risk of blood clots. All these drugs improve patients' hemoglobin. Ideally, they won't need transfusions and don't feel as fatigued. Fatigue is one of the most debilitating symptoms of PNH. These drugs can also improve swallowing difficulties and alleviate abdominal cramps, shortness of breath, chest pain, and erectile dysfunction. PNH can also damage other organs such as liver, kidney, and heart. These impacts can be prevented with treatment.

The value of having multiple drug options is the lifestyle benefits that impact quality of life. The newer drugs allow more independence for patients. They can travel and not worry about needing an injection every two weeks.

Are there any access issues for these treatments?

Every province is a bit different but, generally, all three treatments are available across the country. The only issue is that patients must meet the clinical criteria to get the treatment. You need to be sick enough to qualify – clot history or ongoing anemia, for example.





What else do you see coming in the near future?

Three new drugs are under evaluation in Canada and may become available to patients in the near future. Crovalimab is a potentially new first line option under Health Canada that can be given subcutaneously. There are two other drugs that are further along in the approval process: Danicopan is a pill that is a second line treatment to be given as add-on to a first line treatment. It provides a dual inhibition which results in more protection against hemolysis. Iptacopan is also a pill that will be given as a second line, stand-alone treatment.

All these drugs will give people more options to find a treatment that fits with their lifestyle and allows them to be consistent with treatment. Consistency is most important with all these treatments.

The diversity of treatment for this disease requires medical expertise. We recommend that all PNH patients on treatment, particularly if inadequately controlled, be co-followed by a PNH expert, under a shared care model. There is a Canadian network of PNH experts to help other physicians (<https://www.pnhnetwork.ca/>).

The [Canadian Association of PNH Patients](#) is a great resource for patients and care partners.

Dr. Bienz will give a more detailed talk on this topic at our Montreal Patient Education Meeting on Saturday, November 9th. Visit the AAMAC website for more details and to register.



PROFILE OF A PEER SUPPORT VOLUNTEER

Rosemary Pauer has been volunteering with AAMAC's Peer Support Program for over 10 years. The program connects people with bone marrow failure so that those who are newly diagnosed can learn from the experiences of someone who has a similar version of the disease.





Rosemary has had MDS since 2009. She has the version with the 5q deletion, something that is a bit rarer in the MDS community. She heard about the Peer Support Program when she attended an AAMAC Patient Education Day. She says she was motivated to join the program as she could have used it when she was first diagnosed:

“I wanted to give people the help that I didn’t get when I was diagnosed. I want to provide information, comfort and encouragement, so they know it’s not the end of the world.”

Volunteering to provide peer support does not require a large time commitment. Rosemary says some patients only want or need one phone call which can vary from a few minutes to an hour. She also provides support and information via email, when requested.

Common questions or concerns are treatment options, dealing with family and friends, and resources available through AAMAC or elsewhere. However, Rosemary feels that the most beneficial aspect of peer support is often just talking to someone else who understands what you are going through. If someone needs more one-on-one support than Rosemary can provide, she has other resources she can refer them to.

As Rosemary’s physical abilities change, she finds that peer support is a volunteer job that she can continue to do. For her it is a way to give back to AAMAC and help others.

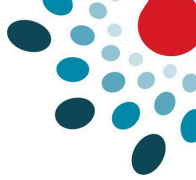
Given the broad range of MDS types and treatments, AAMAC needs more peer support volunteers on our roster. If you are interested in providing peer support, please contact the office (info@aamac.ca).



PATIENT NEWS

The Halifax Support Group was sad to hear of the passing of Vivian Holland, who died on 29 June, 2024 at age 87 at Summerside, PEI. Vivian was the caregiver of her daughter who had Aplastic Anemia. Vivian was one of the earliest active members of the Halifax Support Group, while living in Halifax, and she kept in touch after her move to PEI.





MEETINGS & EVENTS

Visit AAMAC.CA for all meetings, event details, and registration

Upcoming In-Person Patient Support Meetings

EDMONTON

Date: Saturday, October 5, 2024

Time: 8:30 AM - 1 PM

Location: Chateau Nova Kingsway Hotel

Speakers:

- Dr. Monika Oliver - Overview of PNH and AA - New Treatment Options
- Dr. David Page - Overview of MDS - New Treatment Options
- Patient Experience Panel

WINNIPEG

Date: Saturday, November 16, 2024

Time: 8:30 AM - 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
- Patient Experience Panel

MONTREAL

Date: Saturday, November 9, 2024

Time: 8:30 AM - 1 PM

Location: Ruby Foo's Hotel

Speakers:

- Dr. Marc Bienz - PNH Overview - New Treatment Options
- Dr. Chantal Cassis - MDS Overview - New Treatment Options
- Patient Experience Panel

Webinars

Nutrition for Your Energy and Health

Date: Thursday, November 7, 2024

Time: 7 PM ET

Speaker: Anika Dhalla, RD

Understanding Your Lab Results

Date: Friday, November 8, 2024

Time: 1PM ET

Speaker: Dr. Amy Trottier MD, MSc, FRCPC

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 4

Time: 7 PM ET

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

Central Canada Patient Support Group

Date: Wednesday, September 11

Time: 6 PM ET

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

Atlantic Patient Support Group

Date: Thursday, September 19

Time: 7 PM AT

This meeting is held on the third Thursday of each month

Western Canada Patient Support Group

Date: Monday, September 16

Time: 6 PM PT

This meeting is held on the third Monday of each month





AAMAC's 2024 Annual General Meeting will take place virtually on **Saturday, October 19, 2024** at **1:00PM ET.**

Everyone is welcome to join the call!



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

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