AAMAC | Aplastic Anemia & Myelodysplasia Association of Canada
ACAAM | Association canadienne de l'anémie aplasique et de la myélodysplasie

Newsletter - Spring 2023

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

Message from the Executive Director

I trust everyone has had a good start to 2023. I am delighted that we are able to hold in-person meetings again this year. Please see information on these meetings in the newsletter along with some suggestions to keep everyone safe while attending these meetings.

Awareness of AAMAC is key to patients and caregivers who are affected by MDS, AA and PNH. The next time you are at your clinic for an appointment, please look for opportunities to share information about our meetings and organization. Is there a bulletin board where you could put up a poster? A spot where AAMAC brochures could be displayed? If you find this is a possibility, please contact us at *info@aamac.ca* to let us know. We will be happy to supply posters and/or brochures. We are always looking for AAMAC ambassadors.

We are delighted to welcome two new board members to AAMAC and you can read more about them in this newsletter. The Board will be participating in a Strategic Planning session in April to plan for the future of AAMAC as we look to support patients and caregivers across Canada.

Thank you to Fiona Lewis and Robyn Hodes for the writing and production of this newsletter. I hope you enjoy it.

Cindy Anthony

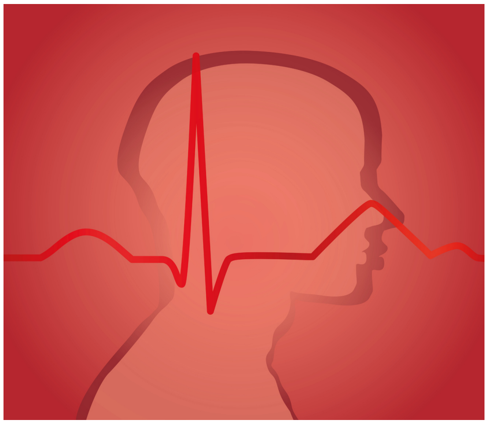
IN THIS ISSUE

COPING WITH BRAIN FOG OR CHEMO BRAIN

By Fiona Lewis

Brain fog does not have a single definition or medical diagnosis. It's often a cluster of cognitive symptoms that people experience. Brain fog can be many different things to different people but can include any or all of the following:

- Trouble focusing
- Difficulty staying attentive
- Trouble remembering familiar details like names, places, or words
- Slow reaction times and information processing
- General fatigue or lethargy
- Cloudiness in judgement
- Frequent loss of train of thought



There is no definitive answer to what causes brain fog. It may be caused by chronic stress, hormonal changes, or an exaggerated immune response to illness such as Covid or to chemotherapy.

There are no known medications or treatments that correct brain fog directly. However, there are strategies you can use to minimize its impact. These include:

- Tell your healthcare team about any fatigue or brain fog, so that they can rule out other conditions that can mimic certain side effects from chemotherapy
- Tell family and friends about any fatigue or brain fog, so that they can understand any limitations you have and provide support
- Focus on improving your sleep (often easier said than done!)
- Ensure you have a nutritious diet with a focus on fruits and vegetables
- Exercise daily, taking small steps to improve your stamina
- Engage in stress-reducing activities that activate all your senses, such as walking outside, listening to music, or learning a new skill.

While brain fog can be frustrating and concerning, the good news is that it can improve over time, through lifestyle changes and therapeutic interventions.

Sources

Harvard Medical School: *https://www.health.harvard.edu/blog/suffering-from-chemo-brain-theres-hope-and-many-things-you-can-do-2019112018403*

Cleveland Clinic: *https://health.clevelandclinic.org/brain-fog/*
Leukemia and Lymphoma Society of Canada:
https://www.bloodcancers.ca/i-have-blood-cancer/how-we-can-help/self-care-and-wellness/managing-fatigue-and-cognitive

ONTARIO TO FOLLOW BC AND ALBERTA'S LEAD ON BIOSIMILARS

Biosimilars were in the news last month as the *Globe and Mail** announced that Ontario is introducing a new policy requiring cheaper versions of biologic drugs (known as biosimilars) to be offered to most patients who need them. A similar Biosimilars Initiative has been in place in B.C. since May 2019 and launched in Alberta last year. What does this mean for people with bone marrow failure?

Biologics are a type of medication therapy made of complex molecules that are engineered from living organisms such as live yeast and bacteria. The first version of a biologic developed is known as an originator drug. Biosimilar drugs are molecules that are based on biologic medications that, though not entirely identical to the originator drug, are assumed to have the same therapeutic characteristics of the originator. One example of a biologic is Eculizumab, used to treat PNH. Biologics can be expensive: the originator biologic drugs Remicade, Humira and Enbrel are 3 of the top 4 drivers of drug spending in Alberta. In general, the use of biologics in bone marrow failure disease is in the early stages.

Patients and patient groups, such as AAMAC, are closely watching these initiatives to see what impact they have. Optimistically, the use of biosimilars can reduce costs for provincial drug plans which could potentially result in improved access to other drugs. However, there are concerns about how much choice patients will have in the switch from an originator drug to a biosimilar. While a biosimilar may work well for one patient, it may be less effective or poorly tolerated for another. Some patient advocates are concerned that the originator drug may be dropped from the Ontario drug formulary, as it was in B.C., reducing access to it for patients who cannot use the biosimilar. At this point, there is not enough transparency about how these initiatives will work to give patients and patient advocates peace of mind.

AAMAC will continue to follow this issue and will, as always, advocate that patient choice be a key feature of provincial drug plans.

**https://www.theglobeandmail.com/canada/article-ontario-mandatory-drug-swap-generic/*

UPDATE FROM THE PATENTED MEDICINE PRICES REVIEW BOARD (*PMPRB*)

The PMPRB has announced a delay in the implementation of their revised draft guidelines, scheduled to come into force January 1, 2023 (*https://www.canada.ca/en/patented-medicine-prices-review/services/consultations/2022-proposed-updates-guidelines.html*). Innovative Medicines Canada (***IMC***) welcomed the delay as a renewed opportunity for the PMPRB to consult with stakeholders and conduct a thorough impact analysis. IMC has expressed concern that the revised draft Guidelines will have significant negative impact on access and will undermine the success of other government priorities such as the National Strategy for Drugs for Rare Disease and the Biomanufacturing and Life Sciences Strategy. Innovative Medicines Canada (*https://innovativemedicines.ca/*) is the national association representing the voice of Canada’s innovative pharmaceutical industry

ADDRESSING PNH UNMET MEDICAL NEEDS: A POLICY ROADMAP TO ASPIRE FOR CHANGE

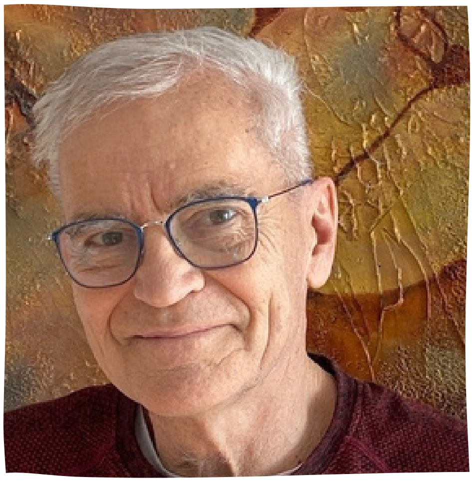
Partnering4PNH is a multistakeholder policy initiative that aims to highlight the gaps and challenges faced by people living with paroxysmal nocturnal hemoglobinuria (PNH) when accessing care and adequate treatments. It aims to examine national and international policies accompanying the patient journey, from presentation of symptoms to diagnosis, to access to treatment and care, as well the impact on mental health and quality of life. On December 7, 2022, Partnering4PNH held an online conference including Cindy Anthony, AAMAC's Executive Director as one of the speakers. She highlighted the importance of patient organizations in improving the quality of life of PNH patients and put forward the following policy recommendations. In her view it is crucial to:

- Improve PNH understanding, namely by capturing the different dimensions of the symptoms (physical, psychological, functional, and social)
- Empower patients and their caregivers in the decision-making process, namely by including patient representatives in health technology assessment (HTA) procedures, and by stimulating collaboration between different patient groups/organizations.

Watch a recording of the event on our website at *https://aamac.ca/addressing-pnh-unmet-medical-needs-a-policy-roadmap-to-aspire-for-change/*.

MEET OUR NEW BOARD MEMBERS

Philip Veness



Philip is a retiree having had a fulfilling career as a social worker. He was a case manager responsible for the assessment and arrangement of provincial services for children with disabilities and their families as well as for providing support counselling to families.

He has been president of the Autism Society of Manitoba as well as a volunteer running weekly "conversation" groups for level 4-6 EAL students.

Since retirement he has continued to volunteer as a tour guide for a local history museum (Dalnavert), for the Winnipeg Art Gallery, and for his seniors' club. He has started volunteering again as an EAL "teacher" and conversation facilitator.

He was diagnosed with Severe Aplastic Anemia in April of 2020. He has had ATG therapy twice and, with the assistance of medication, continues to experience good health.

Philip lives in Winnipeg with his partner of twenty-five years. He has five daughters.

Philip Eappen

Dr. Philip Eappen is an Assistant Professor at Cape Breton University and a Manager of Clinical Services at the Breton Ability Centre. Prior to teaching at Cape Breton University, he taught at the University of Toronto, Southern Alberta Institute of Technology, and Fanshawe College. Before moving to Canada, he worked as the Director of Health Services and Chief Administrator of the Health Center and was an adjunct faculty member at the American University.

Philip's educational background includes a Bachelor of Science in Nursing and a Master of Business Administration in Healthcare Management, after which he completed his Ph.D. in Healthcare Administration and an International Health graduate program at the Central Michigan University in the USA.

He is a native of Kerala, India and is very well-travelled: forty-five countries in the past decade as well as teaching on three different continents – Asia, Africa and North America.

Philip lives in Sydney, NS with his wife Figgi and son Evan.

We are looking forward to working with both Philips who each bring a wealth of knowledge and experience to our team. We are excited to have them join the Board.

MESSAGE FROM CANADIAN BLOOD SERVICES

They need your help to keep the blood supply strong

Winter is always a challenging time for blood and plasma collection. Holiday travel, weather impacts and illness are inevitable, so patients are counting on donors to keep their appointments whenever possible.

CBS are currently experiencing cancellation rates that are much higher than typical, and so the national inventory of several blood types is **far below optimal**. Respiratory illnesses including RSV, flu and COVID have made it more difficult to staff donor centres and donation events, and for donors to keep their appointments.

They're asking for your help to meet patient needs at this critical time…

i. **Encourage blood donation:** Please encourage your families, your networks, your friends, and supporters (if they are able) to book an appointment to give blood or plasma. It's easy at https://www.blood.ca or on their mobile app.
ii. **Spread the word on social media:** Consider following Canadian Blood Services social media accounts on Twitter, Instagram, TikTok, or LinkedIn, and help amplify and spread the messaging about the need for blood and plasma donations.

Your donations matter. They help people be there for their families, give back to their communities and improve the lives of others. When you donate, you help ensure Canada's Lifeline is strong, and you shape someone's tomorrow.

Thank you for your help!

RARE DISEASE DAY 2023

#LightUpForRare this #RareDiseaseDay

Everyone can participate in the Global Chain of Lights and Share Your Colours!

In an effort of global solidarity, you are invited to **light or decorate your home** with the Rare Disease Day colours (blue, green, pink and purple) at **7 PM your local time on 28 February 2023.**

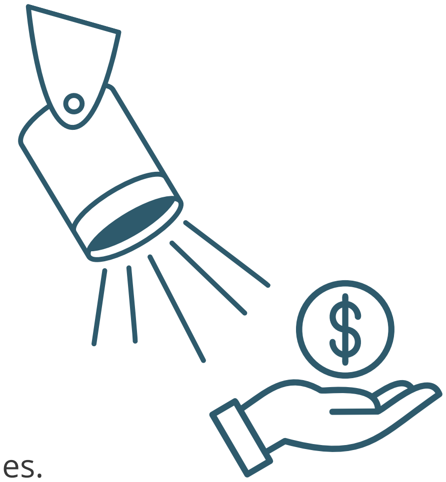
You can use garlands, social media filters, candles, disco lamps, colourful decorations... Let your creativity shine!

Take a picture of yourself with the illuminations or decorations you chose and publish it on your social media using **#rarediseaseday** and **#lightupforrare**. Download a whole hosts of campaign materials - from social media graphics, posters and banners.

RareDiseaseDay.org has everything you need to help raise awareness at *https://www.rarediseaseday.org/downloads/*.

Be part of the change this Rare Disease Day!

DONOR SPOTLIGHT



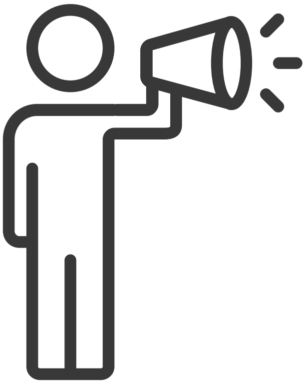
Providing support for bone marrow failure patients and their families is a team effort, and we have you to thank - our donors, pharmaceutical and professional health care partners and committed volunteers - for enabling us to be there for patients and their families.

We want to thank Roderique and Suzanne Lefort for their generous donation through Gift Funds Canada*. The grant is for the highest priority needs of AAMAC which we have allocated to restarting our in-person meetings in the spring.

**Gift Funds Canada is a registered public charitable foundation that holds and manages endowed Charitable Gift Funds for individuals and organizations across Canada.*

BONE MARROW FAILURE AWARENESS WEEK

March 1 - 6, 2023



Bone marrow failure disorders affect hundreds of thousands of people throughout the world. National Aplastic Anemia and MDS Awareness Week takes place in the US in March to raise awareness about these diseases. President Reagan officially established the holiday in 1986 and the Aplastic Anemia & MDS International Foundation has helped to promote awareness and aid for those who have suffered from these diseases for many years. AAMAC is eager to spread the word about aplastic anemia, myelodysplastic syndrome and paroxysmal nocturnal hemoglobinuria in Canada. It's also an opportunity to shed some light on the role cord blood stem cells can play in the treatment of these life-threatening diseases.

What You Can Do for Awareness Week

1. Educate others on bone marrow failure disease. Here are some easy things you can do to teach others about bone marrow failure disease.
    - Educate yourself about each specific disease (*Aplastic Anemia, Myelodysplastic Syndromes (MDS), Paroxysmal Nocturnal Hemoglobinuria (PNH)*) on our website so you learn more about what you can tell others.
    - Tell at least one new person each day about your disease and what it is.
    - Tell people about AAMAC
        - Tell them about our support group meetings and webinars.
        - Direct them to our website for newsletters and brochures (which are available to order).
    - Use social media to educate others by posting facts and information on Facebook, Twitter, Instagram or blogs. Follow AAMAC on social media and share/like our posts.
2. Participate in a bone marrow/blood drive. Donate blood and platelets for transfusions. If you are able, register to donate stem cells through Canadian Blood Services or Héma-Québec.
3. Celebrate your or your loved one's survival story. We are always looking for stories to include in our newsletter. If you would like to share your story, we would love to hear from you.
4. Commemorate and remember loved ones lost. Honour their memory by telling their story.
5. Make a donation in your or your loved one's honour or memory or purchase a leaf for the AAMAC Tree of Life. To purchase a leaf, please contact the National office at 1 (888) 840-0039 or email *info@aamac.ca*.

IN - PERSON MEETINGS

Visit ***AAMAC.CA*** for all meeting and event details and registration

We are kicking off the spring with some in-person meetings featuring speakers from the local medical community. Please visit our website for the details and to register.

We know that Zoom meetings have been useful for allowing people to attend a meeting regardless of where they live. Zoom patient support meetings will be continuing; however, we will be interspersing the monthly meetings with an occasional in-person meeting such as those recently announced.

If you do plan to attend an in-person meeting, please keep the following guidelines in mind for everyone's wellbeing:

- Do not come to the meeting if you are feeling ill or have been told to self-isolate
- Respect physical space by giving and taking as much space as is needed for all to feel comfortable
- Wash your hands frequently or use an alcohol-based hand sanitizer
- Bring a sweater as the meeting room windows and doors may be open to improve ventilation
- Wear a mask if you wish
- Ensure you are fully vaccinated against Covid-19, if advised by your doctor

We look forward to seeing you soon!

VANCOUVER

Saturday April 15, 2023
8:30AM -1PM

Holiday Inn Express Vancouver-Metrotown (Burnaby)
4405 Central Blvd, Burnaby, BC V5H 4M3

Speakers:

- Dr. Heather Leitch – Iron Overload
- Dr. Wendy Davis – Overview of MDS – New Treatment Options
- Dr Tom Nevill – Overview of PNH - New Treatment Options

TORONTO

Saturday April 22, 2023
9AM -1PM

Novotel Toronto — North York
Stage Door Room, 3 Park Home Avenue, Toronto, ON M2N 6L3

Speakers:

- Dr. Karen Yee - Overview of MDS - New Treatment Options
- Dr. Monika Oliver - Overview of PNH and AA - New Treatment Options

HALIFAX

Saturday May 13, 2023
9AM -1PM

Hotel Halifax
MacDonald – MacNab Room
1990 Barrington Street
Halifax NS B3J 3L6

Speakers:

- Dr. Mary-Margaret Keating - Overview of MDS including New Treatments
- Dr. Sue Robinson - Iron Overload

MONTREAL

Saturday May 27, 2023
8:30AM -1PM

Fairmont The Queen Elizabeth - LG Tech
900 René-Lévesque Blvd W,
Montreal, QC H3B 4A5

Speakers:

- Dr. Lea Bernard - Overview of MDS - New Treatment Options
- Dr. Catherine Sperlich - Overview of PNH - New Treatment Options

The presentations will be in French

VIRTUAL MEETINGS & EVENTS

Virtual Patient Support Group Meetings

AAMAC offers monthly virtual patient support group meetings. Join us from the comfort of your home - patients and caregivers welcome!

French Speaking Patient Support Group

Date: Wednesday March 1
Time: 7PM ET
This meeting will be held on the first Wednesday of each month

Central Canada Patient Support Group

Date: Wednesday, March 8
Time: 6pm ET
This meeting will be held on the second Wednesday of each month

Atlantic Patient Support Group

Date: Thursday, March 16
Time: 7pm AT
This meeting is held on the third Thursday of each month

Western Canada Patient Support Group

Date: Monday, March 20
Time: 6PM PT
This meeting is held on the third Monday of each month

NEEDED: AAMAC AMBASSADORS

Time after time we hear from patients that they wish they found AAMAC sooner after their diagnosis of MDS, Aplastic Anemia or PNH. Patients have so many questions after their initial diagnosis and AAMAC is here for all patients and caregivers to navigate those early days and to be a partner in your care.

How can you help? We are looking at the best way to spread the word about AAMAC in health care settings. Would you be willing to speak to your health care team about how best to do this at your hospitals? We have different options available and would be happy to discuss this opportunity with you. Please contact Cindy Anthony at cindyanthony@aamac.ca or call 1-888-840-0039

PATIENT SUPPORT GROUP MEETINGS

Help us to spread the word

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 Now' button on our website

Visit CanadaHelps.org

AAMAC NATIONAL OFFICE

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Western Canada:
bcsupport@aamac.ca

French Speakers:
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