



AAMAC
ACAAM

Aplastic Anemia & Myelodysplasia
Association of Canada

Association canadienne de l'anémie
aplasique et de la myélodysplasie

Newsletter - Summer 2024

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

Message from the Executive Director

Happy Summer.

Hoping everyone is enjoying some summer like weather where you live. We have just finished our Spring Patient Meetings and by all accounts they were enjoyed by all who attended. We added a patient panel to the meetings and it was wonderful of patients and caregivers to share their experiences to encourage others. We are looking forward to our fall meetings in Edmonton, Winnipeg and Montreal. The dates and registration information are on the website. The Montreal meeting date will be confirmed soon.

We are excited to launch our new educational books. There is a book to cover each disease and they are available for download on the website or you can order a copy online and we will get one out to you. It is wonderful to have a Canadian based book with the most up to date information to educate patients and caregivers. The French books are in the final stages of review before being sent to print. They should be available by the end of May at the latest.

Anne Anthony will be off until June 1, 2025. Anne and her husband Phillip welcomed a baby boy last week to their family. We are happy to have Maria Dimancheva filling in for Anne for the next year.

Another big change for AAMAC is that we have given up our physical office space and both Maria and I will be working virtually. If you call the AAMAC phone number and leave a message we will respond as soon as possible and you can always reach us by email: info@aamac.ca or cindyanthony@aamac.ca. The new address is on the back page of the newsletter.

Wishing you a wonderful summer. Our online support groups will run all summer, so please join us at any of the meetings that are convenient for you. Details can be found on the website.

Enjoy this issue of the newsletter and thanks as always to Fiona Lewis for her hard work in putting this together.

Cindy Anthony

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TREE OF LIFE

The Tree of Life is a way of recognizing those who have been affected by AA, MDS or PNH.

You may make a tax-deductible donation of \$150 or more to have a special person's name inscribed on the Tree. To purchase a leaf, please contact the National office at: 1-888-840-0039 or info@aamac.ca

In Honour of:

Alan Patt
Barbara Doiron
Beatrice & David Murphy
Bernice Teasdale
Bill Gryba
Bill Hunt
Calogero Ciccarelli
Cameron Root
Caroline Laughlin
Carrie Plotzke Cleghorn
Chris Meyer
Cindy Bell
Don McIntyre
Dr. Melvin Freedman
Gord Sanford
Heather Parsons
Karlee May
Kris Plotzke
Liz Lemire
Lois Henderson
Lori Lockwood
Paul Coad
Pietro Di Ilio
Renee Levine
Rumi Guzder
Ryan Rutherford
Silvia Marchesin
Taylor-Marie Coupland
Trevor Thompson

William Laughlin
Yvette Aloisi

In Memory of:

Albert H. Stahlke
Alexander Bowen
Alexandre Castonguay
Angela M. Poto
Ann Harris
Aristotle John (Telly) Mercury
B. Elaine Pond
Barbara Culbert
Barbara Jean Cronyn
C. Donal Leach
Claude Francoeur
Constantine Deplares
Craig Allen
Daniel Orara
Danny Carrick
David Charles Williams
Deborah Armstrong
Dennis Kadatz
Donald J. Highfield
Dorothy Gregg
Dr. Peter McClure
Dr. Stephen Couban
Earl J. Banford
Ed Glazier
Elinor MacLean
Elizabeth Rose Herman

Elmer Kerbes
Erin Lawless
Gai Thomas
Geof Smith
Giovanni Arcuri
Glenn D. Schwartzendruber
Gord Sanford
Gordon Burgess
Gordon O'Halloran
Harry Alfred Roper
Harvey Buck
Heather McIntyre
Helen Robinson
Herb Sixt
James Novak
Jim Smith
Joan MacDonald
Joe Burleigh
John Maxwell Cameron
John R. Barton
Joseph MacDonald
Judy Bridges
Keith Curry
Kenneth Kwok Shing Mok
Kenny Wentzell
Laurel Burgess
Lauren Renaud
Linda O'Brien
Marcelle Gai Thomas
Marian Elizabeth Peters
Marilynne Convey



In Memory of:

Marko Lyshak
Marnie Douglas
Megan Locke
Nastor W. Bill Gryba
Nicole Wilson
Nicky Renaud
Olive Lilian Sündal
Pam Wishart
Paul Ullrich

Paul van Bolderen
Philip Doiron
Pietro Di Ilio
Robert M. MacDonald
Rodney W. Crocker
Roger Fortin
Sheila Rivest
Sheryl Hylton
Stanley Foch Willis
Stephanie Dawn Temple

Sterling Ruggles
Susan Laughlin
Talsa Coon
Trevor Thompson
Valdemars Jankovskis
Vern Coles
Walter Salamandyk
Wilfred Hinchey
William Slawson
William Terry McEvoy

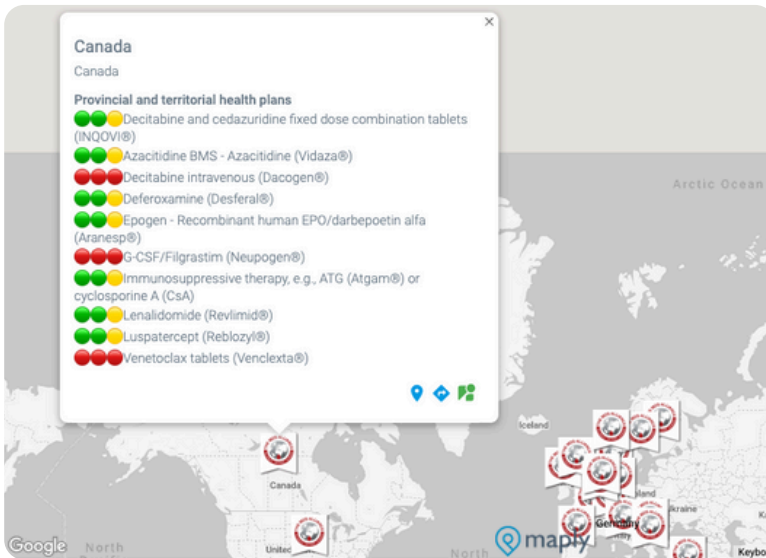


NEW MDS TREATMENT ACCESS PORTAL

The MDS Alliance (MDSA) has released a new web-based MDS Treatment Access Portal. The portal grew out of an identified need to document and report the MDS treatment landscape globally. The insights provided will enable patient groups like AAMAC to advocate for greater access to new therapies in their country.

The main goal was to collect data on the access to 10 different MDS treatments across 24 countries worldwide. Data were acquired through pharmaceutical companies, literature search, as well as general members.

The Treatment Access Map was developed to provide a graphical representation (different colours showing better access), of the varying MDS treatment landscape globally.



The following information is shown on the map:

1. Availability of treatment in a given country, and whether it can be physically obtained in this country or not
2. Approval status of a drug for the treatment of MDS patients, including special forms of approval or conditions attached to the approval.
3. Coverage of treatment costs by the healthcare system in the respective country – does every insured patient have equal access? Additionally, where available, a brief description of the healthcare system and reimbursement is provided on the overview map.

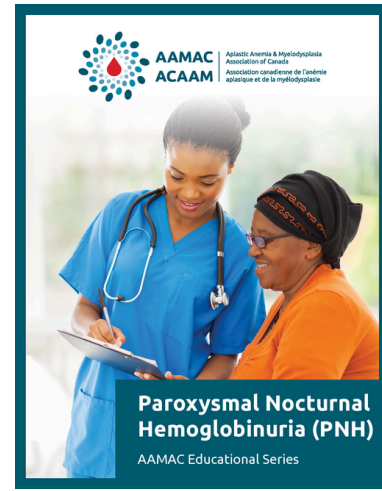
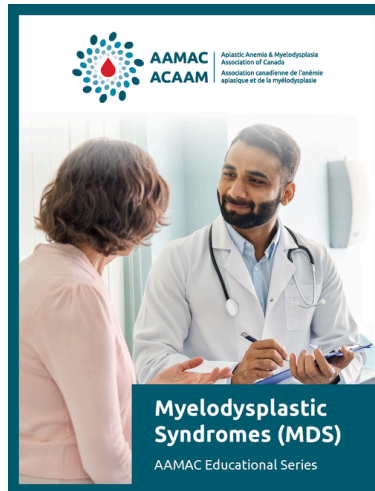
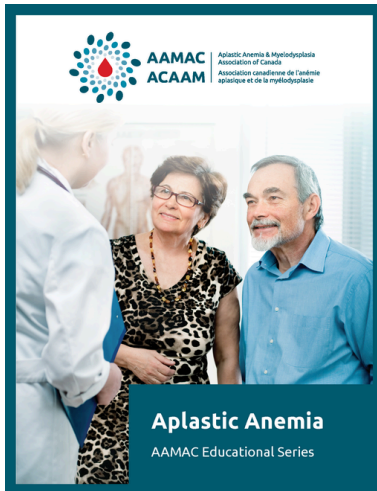
Click [here](#)¹ to access information on treatment availability, approval status and insurance coverage in 24 countries worldwide, including Canada. You can hover your mouse pointer over the coloured dots to get more information.



RELEASE OF NEW BOOKLETS

AAMAC is pleased to announce the publication of a new series of information booklets about bone marrow failure diseases. There are three booklets available: one on **Aplastic Anemia**, one on **Myelodysplastic Syndromes** and one on **Paroxysmal Nocturnal Hemoglobinuria**. These comprehensive booklets were specifically developed for the Canadian context and have been reviewed by Canadian physicians and patients. The booklets are currently available on our website or you can order a copy by contacting the office. Both French and English versions are available.

1 - MDS Access Portal available at <https://www.mds-alliance.org/access-study/>



GETTING TO KNOW AAMAC'S NEWEST BOARD MEMBER - LAURIANE DALPE

Lauriane Dalpe, AAMAC's newest board member, is excited to learn from her fellow board members and contribute some of her skills to AAMAC's work. Lauriane has two motivations for joining AAMAC.

The first is to give back to her community by serving on a board. She says that, coming from the business world, she wants to do something that contributes more to society. Having recently completed her MBA, she believes that this is an ideal time to share some of her skills in project management, financial management, communication, and governance.

Her second motivation for joining the board is much more personal. Her father was diagnosed with MDS in December 2023. While he is still adjusting to the disease, Lauriane is ready to jump in and get more involved. She is also excited to learn from the research and medical expertise of other board members.

Living in Magog, Quebec, Lauriane loves being outside. She is very passionate about skiing, cycling, and hiking. She's also involved in environmental causes and is already starting another degree in Environmental Management at University Sherbrooke. Lauriane has a 17 year-old son and it is important to her to show him her values of protecting the environment and contributing to society. AAMAC staff and volunteers look forward to working with Lauriane.





GETTING TO KNOW AAMAC'S NEWEST BOARD MEMBER - CARRIE A. CHASE

Carrie Chase is passionate about advocating for rare blood disorders as a new board member with AAMAC. Her husband, Clint, was diagnosed with Severe Aplastic Anemia (AA) in 2018 and since then she has used her considerable energy to raise awareness about the disease.



Carrie and Clint first got involved with AAMAC after attending a Patient Education Meeting in Calgary in 2019. Since then, they have been regular attendees at our monthly patient support meetings. Now that Clint's condition has stabilized, they like to offer help and support to other who are struggling.

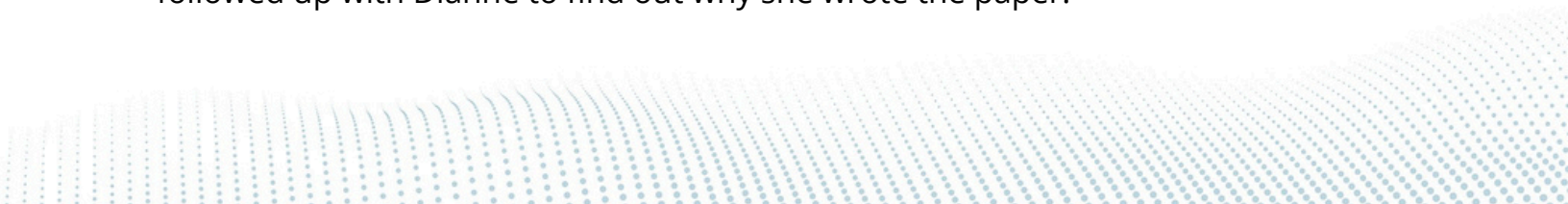
Participating at the board level will give Carrie another opportunity to give back to an organization that was "wonderfully supportive" to her family. As a board member, Carrie looks forward to raising awareness about the disease, promoting bone marrow donation and the registry, and advocating for better funding of drugs and new technologies. She notes that she has a huge passion for Artificial Intelligence and believe it has a lot of potential for speeding up research and evaluation of different treatment options.

Carrie says she's known as an executor – someone who can get things done. She's keen to help with any changes on the horizon for AAMAC. Having worked in the energy and investment environment, she also plans to reach out to her network to increase funding for AAMAC. Carrie is grateful for the opportunity to join the board and AAMAC looks forward to working with her.



DELVING DEEPER INTO APLASTIC ANEMIA

AAMAC member, Dianne McMahon, recently shared with us a scholarly paper she wrote, entitled **Aplastic Anemia, it's not just Anemia**. This paper gives an overview of Aplastic Anemia (AA), shares some history behind the disease, and offers a patient perspective on it as well, all in a very approachable way. We followed up with Dianne to find out why she wrote the paper.





Can you tell me a bit about your journey with AA?

I was diagnosed in the fall of 2018. I had to go to emergency because of a nosebleed. I had experienced other symptoms, like frequent bruising and fatigue, that I had not thought much about. The ER decided to investigate further and found all my blood counts were very low. I was admitted that night and life kind of changed. I was in hospital for 3 weeks and started getting hATG treatment. Later, I went onto cyclosporine and eltrombopag. I improved and went back to work in March. I worked part-time for a year and then COVID happened. I was still on cyclosporine and didn't feel comfortable working where I was, so I left work again. In December of that year, my counts started falling again. By June 2021, I went in for another hATG treatment. I'm no longer on any medication since December 2022. I haven't had transfusions for a couple of years. I still experience fatigue. I'm considering going back to work part-time but want to approach it slowly.

Why did you decide to make AA the subject of an academic paper?

I'm taking some online courses through an American university. I'm working on a degree in Professional Studies which comprises 3 certificates: business administration, graphic design, professional leadership skills. While I was going through my treatment, my brain didn't work well enough to really research the disease. Now that my brain is working better, I thought it would be a good opportunity to learn more while completing an essay assignment.

What did you learn that was new to you, as you did your research?

I learned a lot of big words – I was looking at peer-reviewed technical essays. Certainly, I had to look up some words. I noticed that there were a number of Chinese doctors publishing on this – understandable as there is a higher occurrence rate in the Asian population. I was surprised that, according to my limited research, in the Ottawa General Hospital there was a lot of research on MDS, some on PNH and almost none on AA. I suspect this is due to the interests of the hematologists and the number of their patients affected by each disease. There are lots of new things happening in MDS that makes it exciting to research. This is not so much the case with AA.

What response have you had to your paper?

My professor said, wow, I really didn't understand how serious the disease was. A friend read it and said she had not quite understood the components that made me really sick. Someone else said that I explained very technical stuff in an easy-to-understand manner.





Do you plan to do any more writing about AA?

I might. A friend was encouraging me to be a greater advocate for AA, especially on social media. My essay had a word limit so I could not put everything in that I wanted to.

You are a regular with our patient support group in Ontario? Why is it important to you to participate in this group?

We're a small group but we've all been going through this together for several years. I'm the only regular with AA but it's really nice to talk to someone else who is dealing with bone marrow failure – the treatments, the side effects, the fatigue. Knowing that people care about you makes a difference: they want to know how you are doing.



PATIENT EDUCATION DAYS - A SUCCESS!

AAMAC recently hosted patient education days in Toronto, Halifax, and Vancouver. All three events included treatment updates from medical professionals as well as patient panels where patients and care partners could share their stories.



Dianna McGowan and presenter, Laura Brace, RN, at the Vancouver meeting.



Jackie Foy and Kate He at the Vancouver meeting

Attendees appreciated the opportunity to hear about the latest research while also connecting with others in a supportive atmosphere. Check out our website for upcoming fall meetings!



MEETINGS & EVENTS

Visit [AAMAC.CA](https://www.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

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, June 5

Time: 7 PM ET

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

Central Canada Patient Support Group

Date: Wednesday, June 12

Time: 6 PM ET

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

Atlantic Patient Support Group

Date: Thursday, June 20

Time: 7 PM AT

This meeting is held on the third Thursday of each month

Western Canada Patient Support Group

Date: Monday, June 17

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**



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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