



AAMAC
ACAAM

Aplastic Anemia & Myelodysplasia
Association of Canada

Association canadienne de l'anémie
aplasique et de la myélodysplasie

Newsletter - Winter 2021

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

Message from the Executive Director

2021 has been a year of challenges for so many people and AAMAC has worked very hard to ensure our patients and caregivers were supported during this difficult time.

I would like to thank Kim Brunelle and Fiona Lewis for their hard work over the past year planning webinars and creating our 4 online support groups. We are looking at the possibility of in person meetings in the spring and will promote meetings when they are available. AAMAC has developed a vaccination policy. The policy is posted on our website and is also available if you want to email info@aamac.ca. The safety of our patients and caregivers is of the utmost important to us and we will only proceed with in person meetings when safe to do so. We will be continuing our virtual meetings in addition to the in person meetings.

AAMAC values partnerships with other organizations and in this issue you can read about a new partnership with the Schulich School of Medicine & Dentistry, Western University.

Each year AAMAC participates in Giving Tuesday. Without our generous donors we would be unable to offer the programs and resources to support patients and caregivers across Canada. We thank the many people, foundations and companies that support our organization. There are many ways to give to AAMAC that are highlighted in the enclosed letter with this newsletter.

I would like to take this opportunity to wish all of you Happy Holidays and a wonderful 2022.

Cindy Anthony

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2021 MARILYNNE CONVEY AAMAC AWARD RECIPIENT: REANNE BOOKER



I became a nurse after taking a nursing course during my undergraduate science degree program. I wasn't quite sure what I wanted to do with my career and took a few elective courses. After completing just one nursing course, I knew immediately that I wanted to become a nurse. It was one of the best decisions of my life. I've spent most of my nursing career working in the fields of oncology

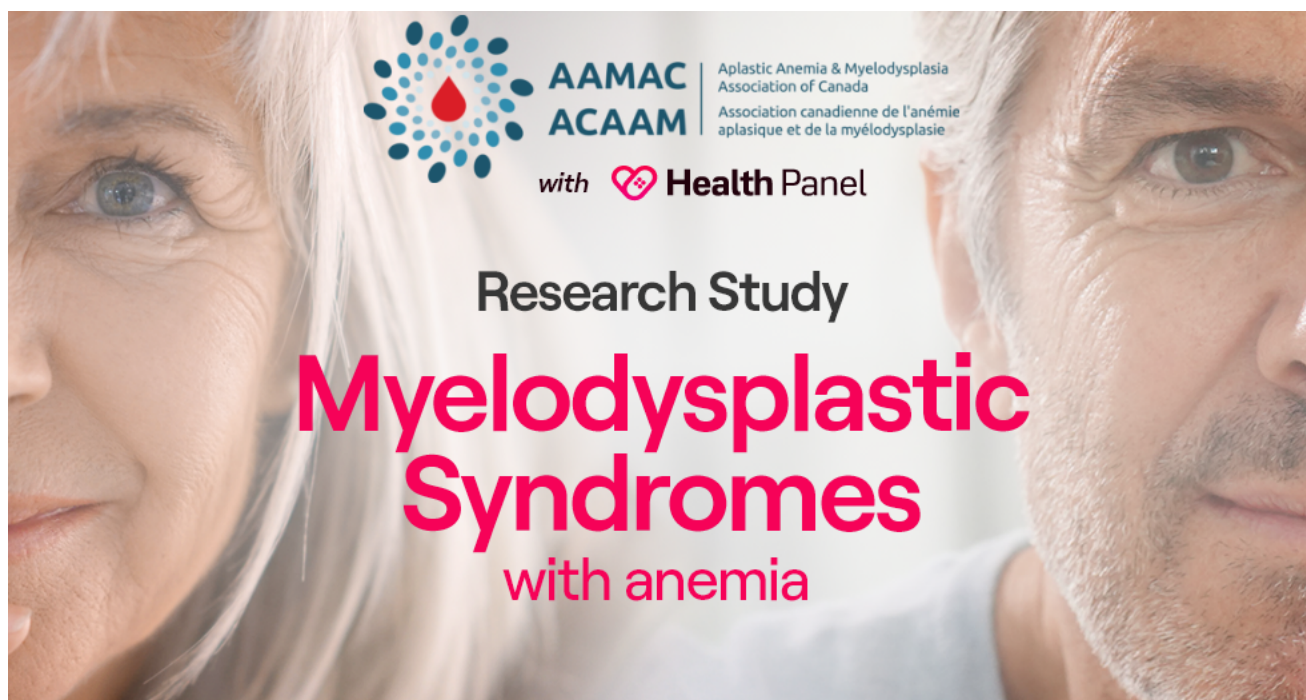
nursing and palliative care. More recently, I've also been helping with the COVID19 vaccination program. I have always felt incredibly fortunate to have a career that affords so many different opportunities and provides so many rewards.

A few recent accomplishments that I am very proud of include: being the President of the Canadian Association of Nurses in Oncology, becoming involved in global oncology initiatives, and completing my PhD candidacy (yay!). However, my proudest moments have always been those quiet times, one-on-one with a patient or their family. Being part of some of the best yet also, some of the most difficult moments in people's lives is a privilege that I don't take lightly. I am very honoured and proud to be a nurse and extremely grateful to the CNF and its donors for this tremendous support.

AAMAC has supported a Canadian Nurses Foundation grant since 2000. The AAMAC Nursing Scholarship has been renamed in honour of Marilynne Convey. Sadly, Marilynne, an AAMAC board member, passed away on November 13, 2020. She was diagnosed with Aplastic Anemia in 2015 and became an avid spokesperson for AAMAC and volunteered much of her time to lead the nurse education program and attend the Haematology conferences.



This is the first year the AAMAC Nursing Scholarship will be awarded in Marilynne's name.



We are local, let our medical team contact you!

Health Panel is a brand, a website and a database, where people with or without chronic diseases can sign up for and participate in research projects. Their mission is to connect people all over the world with research! They operate in the United States, Canada, Australia, United Kingdom, several other countries in Europe, and soon in Asia. On their webpages they strive to provide helpful health articles, disease information as well as new research projects in as many local languages as possible. They exist to improve research, and they can do that with your help!

Currently, they are seeking participants for a research study for adults with anemia due to Myelodysplastic Syndrome (MDS) in Canada.

What is this study about?

People suffering from myelodysplastic syndrome often experience clinical symptoms such as anemia (a decrease in red blood cells and hemoglobin, which may cause fatigue and tiredness) and other abnormal laboratory results (e.g., low white blood cell and/or platelet counts). This often results in the need for blood transfusions, a higher risk for developing infections and an increased risk of developing acute myeloid leukemia (AML). The research study assesses the safety

and efficacy of an investigational medication in the treatment of anemia due to very low, low or intermediate risk myelodysplastic syndromes (MDS). This means that the main purpose of this study is to see if people with your type of anemia due to MDS will experience a lesser need for regular blood transfusions.

We, the Health Panel, are not in charge of the research itself, but are building bridges between research and people. It is the study team, medical professionals, who the participants meet at the study locations.

What are the potential benefits to patients?

Being dependent on blood transfusions is associated with iron overload, and with a negative impact on your quality of life, thus the need for other treatments. Participating in the study can potentially help in leading a more normal life, one that is not so dependent on blood transfusions.

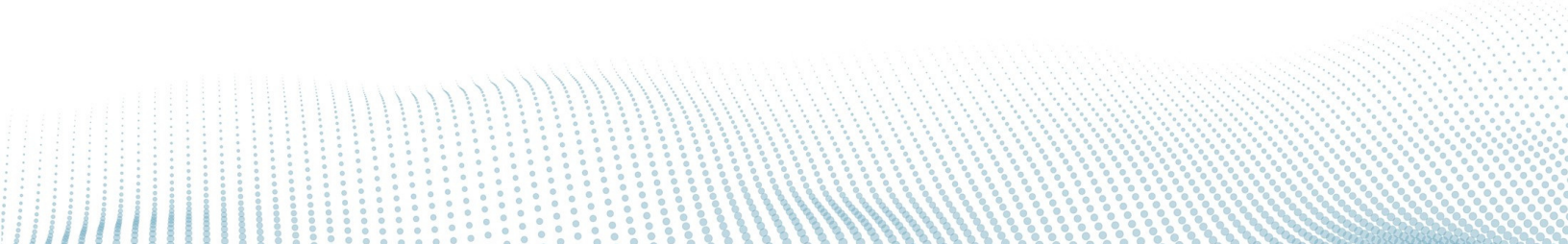
Where does the study take place?

In Canada, eligible participants are referred to the study sites in:

- Ottawa
- Toronto
- Hamilton
- Montréal
- Edmonton
- Calgary

Here, the study team will provide participants with information about study-related procedures and ask additional questions. There will be no additional costs to you if you choose to participate in this research study. The investigational medication and any tests required by the study are provided by the study team, and you will receive reimbursement for travel expenses incurred by taking part in the research study until your participation is complete.

Please note that taxes may need to be paid on travel expense reimbursement; it might also have to be reported to the respective authorities.



Who can participate?

You may participate in this research study if you meet all the following criteria. You must be at least 18 years old, have anemia due to bone marrow failure disorder (Myelodysplastic Syndrome (MDS), and receive red blood cell transfusions. You can withdraw from participation, at any point in time, and you don't have to give any explanations. So, there are no obligations.

How to participate?

Anyone interested in participating can create a health profile and then fill in a digital questionnaire based on study criteria. Health Panel's medically trained pre-screeners will then have a telephone conversation with potential candidates, to verify their questionnaire answers and ask additional questions. If the candidate is deemed eligible, he/she is forwarded to the study site. From there, the study team will take over. They will explain everything about the study and the process.

Apply now →

Do you want to know more about Health Panel?

The primary mission of Health Panel is to raise awareness about research and educate people about the role of research projects in improving old treatments and in discovering new ones.

To register as a potential candidate for a research project, please visit Health Panel's website at <https://www.health-panel.com>.

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My Progress Tracker has been developed to help you be an active partner in your health care. It will help you keep track of your important contact information, appointments, test results and any treatments you receive.

2022 Progress Tracker

Our popular 2022 trackers will be available soon. This booklet helps you keep track of your important contact information, appointments, test results and any treatments you have. To order your copy:

- call 1-888-840-0039;
- email info@aamac.ca; or
- go to <https://aamac.ca/resource-books-available/>



PARTNERSHIP WITH THE SCHULICH SCHOOL OF MEDICINE & DENTISTRY: COMMUNITY ENGAGED LEARNING PROJECT

Community Engaged Learning (CEL) is a form of experiential learning that aims to achieve academic and civic outcomes for students, while making a meaningful contribution to both local and global communities through reciprocal partnerships. The purpose of Community Engaged Learning is to: enrich scholarship, research, and creative activity; enhance curriculum, teaching, and academic learning; prepare students to serve as educated and engaged citizens; strengthen values and civic responsibility; address critical societal issues; and, contribute to the public good.

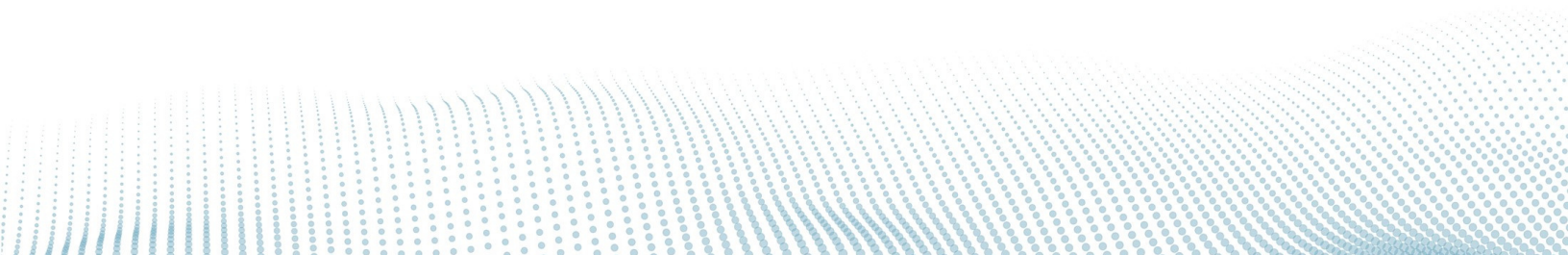


The Master of Science (MSc) in Interdisciplinary Medical Sciences is a one-year (3 terms, beginning in May) course-based Master's program that will augment a students' discipline-specific undergraduate science, biomedical, or health sciences degree with an in-depth, advanced skill set that will enhance the students' research literacy. Graduates of the program will be able to apply their skills and knowledge in a variety of settings, including graduate and professional education, as well as in different roles in government, not-for-profit, and private sectors. As part of their degree requirements, students must complete experiential learning rotations in basic research, clinical, and community-engaged settings.

AAMAC has been funding research projects for many years and we are now in need of a research process to ensure our funding dollars are put to the best use. The project will involve developing a process for proposals, a means to evaluate the proposals and a disbursement and follow-up reporting process.

We look forward to working with the students to create this new process.

Read more about AAMAC's research grants [here](#)





JANICE & IRIS: A TRUE FRIENDSHIP STORY

by Janice Cook

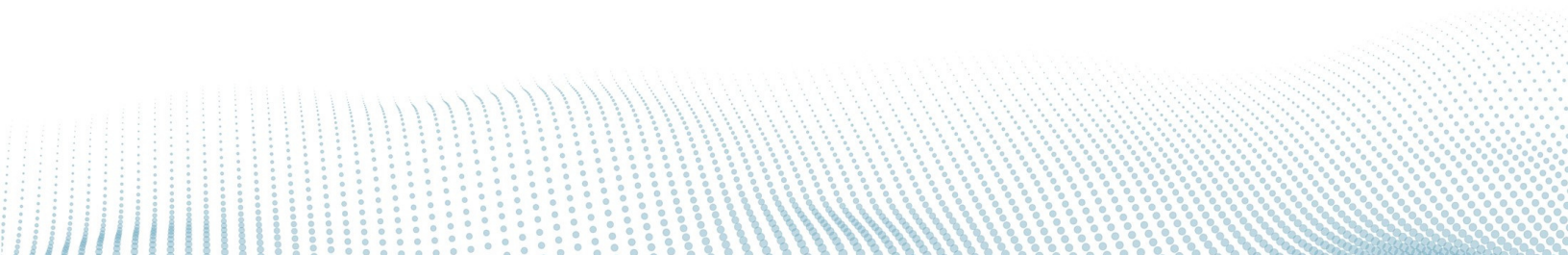
Iris Russell is one of the regular participants in the Western Canada Support Group, which is meeting via zoom due to the pandemic. Since she first found out about AAMAC in 2008, she has attended all the in person support groups and educational events that she could.



I had a diagnosis of SAA in 2004 while living in Calgary. After a year off work and a course of ATG and Cyclosporin, I was in remission and returned to my work as an ER nurse and started as a volunteer Director with AAMAC. In 2008, Iris was living independently in her own condo. She belonged to an RV club and enjoyed driving and travelling with them. She has four daughters and two sons, but although they all live within a days' drive, none live in the same community.

Iris was attending an out of town reunion when she became weak and dizzy, and went to the local hospital where her hemoglobin was found to be 81. She had her first blood transfusion that day, which had her feeling well enough to drive herself home over the Coquihalla highway, which includes a high altitude mountain pass. At home, her GP was concerned by her lab results and referred her to a hematologist. After a bone marrow biopsy she was given the diagnosis of mild MDS and hemolytic anemia. She was on a watch and wait course, with occasional transfusions and her life continued along.

During this time, I moved to BC from Calgary, and took over as BC's chapter coordinator along with Pamela Wishart. It was while updating the chapter list that I found out that Iris and I both lived in the little community of Mission. We also found another MDS patient in the community, and the three of us became friends. Iris assisted with the first BC Patient Education Day in 2011, by filling the participants bags. She brought three of her daughters and a niece along to the conference so they could learn more about her condition.



Since then she has spoken to many people about MDS; people she meets during blood transfusion, friends and neighbours, a student nurse who was doing clinical practice in her seniors' residence, nurses and therapists she has met while hospitalized for a splenectomy, and for rehab after fractures received in falls. She also tries to keep in touch with her MDS contacts.

Iris's MDS course has included immunoglobulin, many transfusions, iron overload, exjade and she also has a number of other medical conditions that impact her life. The latest one was a serious case of heat exhaustion during the severe heat dome in BC in June'21. She, like thousands of others who live in seniors' residences across Canada, has spent many long months of the pandemic in protective isolation with limited contact with family and friends. At 86, she has made some progress in learning to use a tablet for communication with family.

The day I spoke with Iris about this article, she had just received her flu shot and also her covid-19 booster (third dose). As ever she was positive and cheerful and looking forward to the next support group meeting. She enjoys hearing from others about how they are getting along and finds it helpful to hear their experiences. She is one of the most positive people I know, and I admire her very much. Her MDS cannot be cured but she has learned to adapt and live with it, and to live a good life.



MDS. NEW UNDERSTANDING. NEW POSSIBILITIES

The MDS Alliance has collaborated with Novartis on an innovative awareness campaign incorporating the illustrations of internationally renowned artist Noma Bar to help explain MDS and stories from real patients and caregivers to provide examples of the lived experience of MDS. The campaign, MDS. New Understanding. New Possibilities, uses videos that aim to restore hope to those living with MDS, deepen their understanding of the disease and encourage patients to feel empowered in their treatment journey.

These videos will be available in multiple languages to allow patients and caregivers to learn about what could be possible when the body's immune system becomes alert to cancer cell activity and how others living with MDS found positivity and stayed diligent after an MDS diagnosis.

Visit MDSNewUnderstanding.com to learn more.





MEETINGS & EVENTS

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

Patient Support Group Meetings

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

Atlantic Patient Support Group

Date: Thursday, November 18th

Time: 7pm AT

This meeting is held on the third Thursday of each month

Central Canada Patient Support Group

Date: Wednesday, December 8th

Time: 6pm ET

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

Western Canada Patient Support Group

Date: Monday, November 15th

Time: 6PM PT

Future meeting dates to be decided.
Dates will be posted on our website.

French Speaking Patient Support Group

Date: Monday, December 13th

Time: 7PM ET

This meeting will be held on the second Monday of each month.

Webinars

INQOVI®: Everything you want to know about it and other MDS treatments. A talk with Dr. Rena Buckstein

Date: Tuesday, November 16th, 2021

Time: 7:00pm ET


Conferences

Living Well with a Blood Cancer

Presented by the Leukemia & Lymphoma Society of Canada.

Dates: November 22 - 26

Visit llscanada.org to register



Missed a past webinar?

You can find recorded webinars on a variety of topics relevant to both patients and caregivers at our website

www.aamac.ca/videos



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

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