



AAMAC
ACAAM

Aplastic Anemia & Myelodysplasia
Association of Canada

Association canadienne de l'anémie
aplasique et de la myélodysplasie

Newsletter - Spring 2021

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

Important Message from AAMAC's Medical Advisory Committee for Adult Patients

Please go ahead and get the COVID vaccine provided you do not have other contraindications from the point of view of your other doctors. Please be aware that we do not know whether the vaccine is fully effective in patients with blood disorders or receiving immunosuppressive medications (e.g. cyclosporine). Therefore, even after vaccinated, you and the people in your bubble should continue to follow COVID precautions as outlined by the Public Health authorities. Anyone in your bubble who is eligible for vaccination should be vaccinated if possible, provided they have no contraindications of their own. This advice applies to the Pfizer and Moderna vaccines. Any newer vaccines will need to be discussed once they become available. Please check the Covid-19 section on [AAMAC's website](#) for more information.

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GET TO KNOW AAMAC'S NEWEST BOARD MEMBER: NICOLE SABA

How did you hear about AAMAC?

Everyone once in a while, I look into what is new in MDS, after accompanying my mom in her fight a few years ago. I stumbled on a posting for a new board member for AAMAC. It was the first I had heard about the organization and I thought how helpful AAMAC would have been for my mom and I back then. I wish I had known about it earlier.

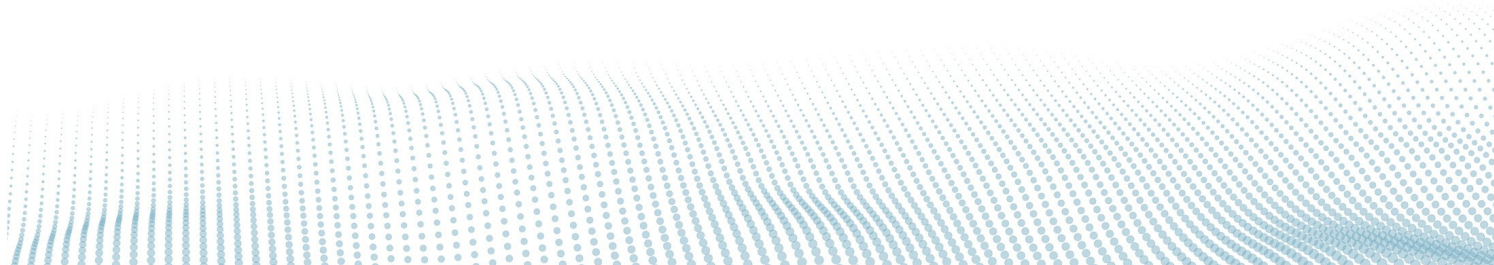


Why did you decide to become a board member?

I contemplated applying for a while. I appreciated how patient centric AAMAC's mandate is because I felt resources for patients were certainly lacking for my mother here in the Quebec region. I wanted to contribute my time and my experience to help bridge the gap between patients and the health-care system. My family had trouble accessing support and information related to Mom's illness so I would like to assist with that. I recognize that each experience is unique and so I join the board with a lot of humility and eagerness to learn how best to contribute.

What would you like to achieve as a board member?

I really want to build on all the successes from across the country and ensure they are adapted and implemented within the Quebec community, ensuring accessibility in both languages. I want to work in partnership with the medical community, mobilizing them to share our vision in patient-centered care and support. I want to help move things forward in the Quebec region and amplify the good work going on. I also hope to be innovative in adapting to patients' changing needs, related to the pandemic and leveraging emerging technologies to improve access to comprehensive resources. Essentially, I want to help others avoid the headache and heartache my mom experienced with respect to lack of resources.



***Any surprises since joining AAMAC?***

Still a bit early to tell. I just joined in December. Everyone has been great in providing me with background information. I'm more impressed than surprised, with the dedication of the team. The AAMAC community is proactive, inquisitive and incredibly knowledgeable. It's very comprehensive in pulling information together and bringing it to patients, in ways that recognize and respond to their unique needs.

Anything else you'd like to share?

I am married with two young girls, in their tweens and an adorable little dog. We live on the south shore of Montreal and I am a public servant with the federal government. I love learning about others so do not hesitate to reach out and share your story or your suggestions. You can contact me at saba.nicole@gmail.com

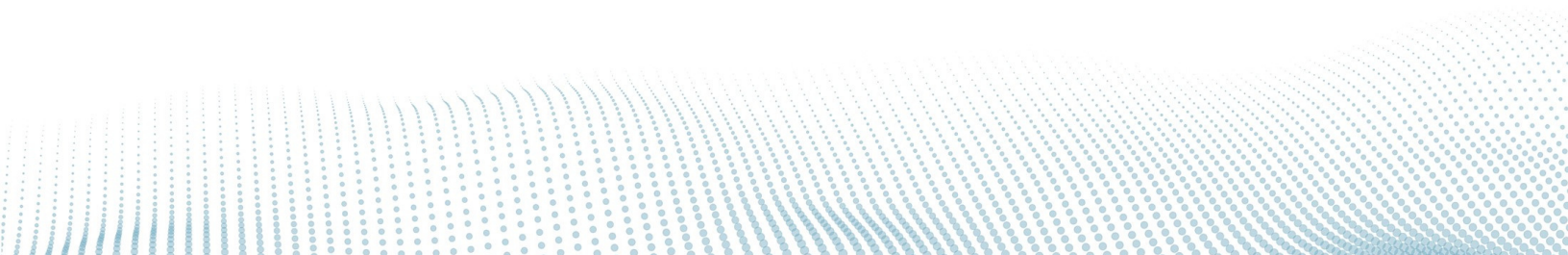


National Volunteer Week



In advance of [National Volunteer Week](#) in April, AAMAC would like to extend its sincere thanks to all our volunteers for their generous support throughout the year.

AAMAC volunteers serve on our board, provide peer support and run some of our patient support programs. We truly could not operate without them, including our newest volunteer, Nicole Saba.





LET'S TALK ABOUT THE BURDEN OF BLOOD TRANSFUSIONS AND MDS

REPRINT FROM ZOOMER MAGAZINE, DECEMBER 2020

For those living with myelodysplastic syndromes (MDS), a group of blood cancers, blood transfusions are burdensome; even more so with the pandemic. Here, we shed light on what it's like to rely on transfusions to survive and why gaps in treatment options need to be addressed to improve patients' quality of life.

MDS occurs in the blood and bone marrow in which the DNA of stem cells is damaged and prevents the development of healthy, mature red blood cells (RBCs). It usually develops in older people and is more common in men. Approximately 86% of patients with MDS are aged 60+ when diagnosed.

MDS is a serious health concern — 50% of patients succumb to the disease within six years of diagnosis. “The usual clinical problem for patients with MDS is anemia, a condition caused by low red blood cells, or low hemoglobin,” explains Dr. Heather Leitch, hematologist at Providence Hematology and Clinical Professor at the University of British Columbia. Hemoglobin is the part of RBCs that carries oxygen. When someone has low hemoglobin levels, their tissue doesn't get enough oxygen and can't function properly.

Gwen was diagnosed with MDS in 2007 at age 65 when a routine blood test showed her hemoglobin was below normal (for women, normal is 120-160 g/L). Over the next year, with a wait-and-watch approach, her hemoglobin dropped below 80. Gwen had another therapy to help boost her hemoglobin. It worked until 2018, when her hemoglobin dropped again. She required several transfusions over the course of two months, and her dosage was increased to the maximum. If the medication stops working, Gwen has no other options. “Plan B is blood transfusions forever — until a treatment comes along that will reduce the blood transfusion burden,” Gwen says.



This article features an interview with Gwen, AAMAC Board Member



More than 90% of those with MDS report ongoing fatigue, a persistent exhaustion that interferes with their ability to carry on with everyday activities.

Gwen has become used to it. “I really don’t feel any fatigue. They tell me that’s my new normal and I’ve adjusted to it.” She has other symptoms of anemia, including night sweats and a pale complexion. An avid swimmer for many years, she now has to use a mask and snorkel due to shortness of breath caused by her anemia.

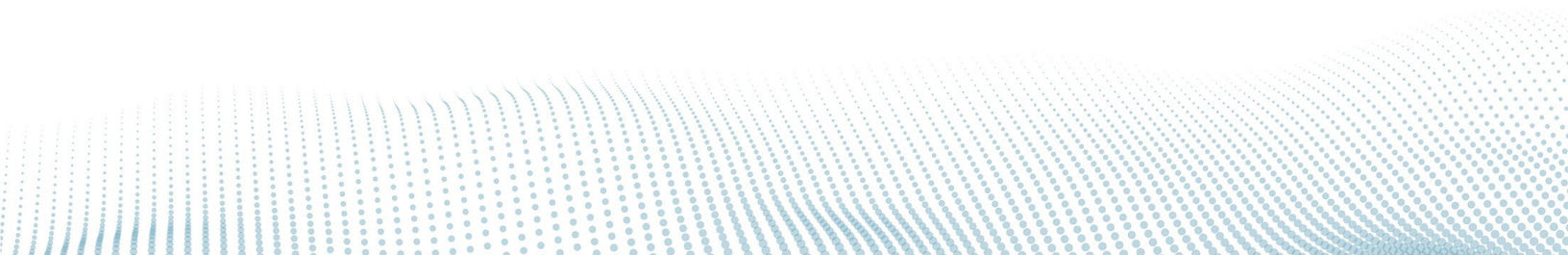
“Anemia can result in symptoms such as weakness and shortness of breath, and it can exacerbate pre-existing conditions. For example, if a patient has coronary artery disease or congestive heart failure, it can put a strain on the lungs and heart and make those conditions worse. That’s why patients become transfusion-dependent or need other means to support their hemoglobin,” says Dr. Leitch.

Transfusions can help to relieve symptoms.

“After having a blood transfusion, I know what normal feels like. You definitely notice the difference,” says Gwen. According to Dr. Leitch, how long the improvement lasts varies from person to person and depends on their degree of bone marrow failure. “Some people require transfusions every four weeks or eight weeks, and others are there on a bi-weekly or even weekly basis.” Often, the time between transfusions gradually gets shorter.

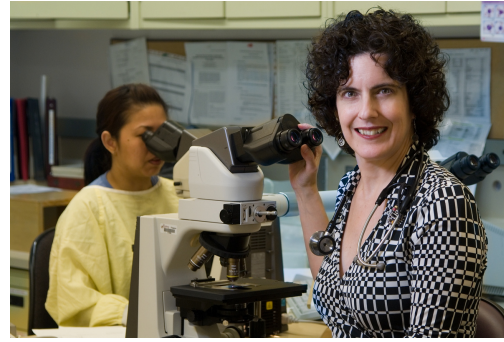
At this point, Gwen doesn’t require regular transfusions. She needed several when she got a bacterial infection from a small nick in her elbow. It took four months for her hemoglobin to come back over 80. She considers herself one of the lucky ones who do not need blood transfusions weekly or bi-weekly to stay alive. “But for people where the hemoglobin booster doesn’t work for them, their only recourse is repeated blood transfusions.”

For those who are transfusion-dependent, therapy is demanding, especially in this COVID-19 era.





"Transfusions are quite a burden," explains Dr. Leitch. Some patients travel a long distance. They're not feeling well. They have to come in the day before to be crossmatched for compatibility with the donor blood. "All these things add up. It's quite an impact on their quality of life."



Dr. Heather Leitch

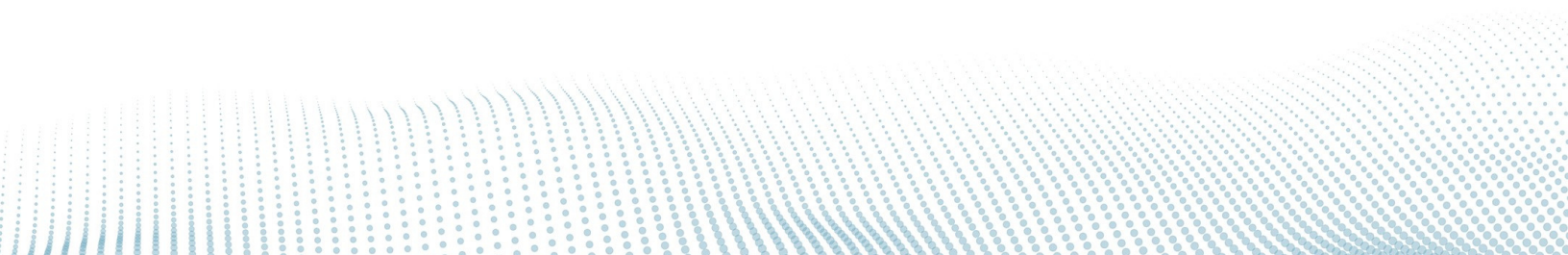
A transfusion takes up to four hours and typically involves a trip to a hospital. "No one wants to go in a hospital with this pandemic," says Gwen. MDS patients have compromised immune systems, are typically older and at greater risk of serious consequences if infected with COVID-19. More transfusions mean more potential exposure to the virus.

In Dr. Leitch's centre, COVID-19 hasn't had a major impact on their ability to deliver care to patients with MDS who require transfusions. She's dealing with patients primarily by telehealth rather than in person. "But we all worry about what's going to happen if and when the healthcare system becomes overwhelmed."

"While many MDS patients depend on regular transfusions to survive, the transfusions themselves can have complications."

Ongoing RBC transfusions put patients at risk of iron overload. RBCs contain iron, and as the donated blood cells wear out, that iron stays in the body. Too much can significantly damage the heart, liver and other organs if not treated with medications to take away excess iron.

Other risks associated with transfusions are fevers, allergic reactions and blood-borne infections. The body's immune system can attack the donated blood, and people can have acute reactions such as sudden respiratory distress. "These are all kinds of reasons, including quality life, that we'd like to use other means to support the hemoglobin and induce transfusion independence," says Dr. Leitch.





New approaches are needed to ease burdensome symptoms and reduce the need for frequent transfusions.

MDS often becomes hard to treat over time, and in about one-third of cases, the disease deteriorates into acute myeloid leukemia. Luckily, Gwen's MDS is low risk to turn into leukemia. As board member and Atlantic region coordinator of the Aplastic Anemia & Myelodysplasia Association of Canada, her advice is to keep fit and be careful about infections. "Until something comes along that treats this disorder, there's not much else anyone can do. Everybody's wish is to keep off blood transfusions and hope for a new treatment."

As Dr. Leitch describes, "Unfortunately, our treatment options to boost hemoglobin are relatively limited right now, although there are new treatments under development that look promising for lower-risk MDS."

Find more information about MDS, treatment and patient support at www.aamac.ca

Visit *Everything Zoomer* to read this article



Rare Disease Day - February 28, 2021

Rare Disease Day takes place on the last day of February each year. The main objective of Rare Disease Day is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives.

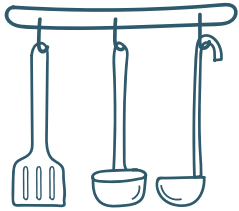




COPING WITH COVID-19:

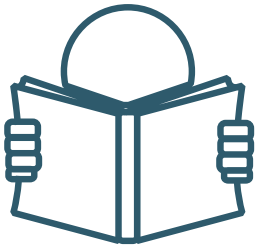
We asked AAMAC staff and board members to share their tips on coping with Covid-19 restrictions.

Here's what they offered:



Cindy, Executive Director

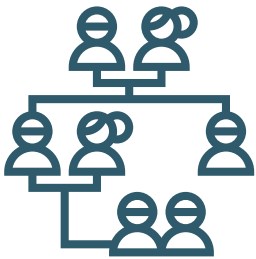
I have found it very helpful to cook meals and deliver to our family. We have 2 sons on the front line, an ER nurse and firefighter. While we aren't able to visit them, it made me feel closer to them by providing them a home cooked meal after their long shifts.



Nicole, Board Member

To deal with the boredom, I sometimes find myself reading 2-3 books at a time. I also love to shamelessly binge TV series after I put the kids to bed. But when I really need that personal connection, I hop on zoom for cocktail hour with close friends. Works like a charm.

Nicole



Gwen, Board Member

My suggestion: Start a family tree, by calling all your oldest relatives to get information. Then subscribe to [ancestry.com](https://www.ancestry.com) where there are millions of records. It will give you a chance to catch up with relatives you may have lost touch with, and keep you busy searching and writing.

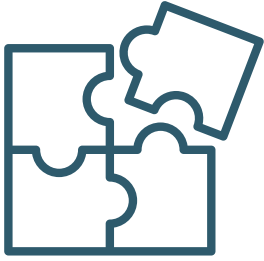


Jennifer, Board Member

You could put together a chat group of people you know to have group chats (neighbour chat, work chat, book club chat, hobby chat). The more groups you set up, the more messages you'll get. And the input you get from other people may give you inspiration for new activities.



COPING WITH COVID-19:



Fiona, BC/Alberta Patient Liaison

When the weather is bad, I like to do jigsaw puzzles and when it is good, walks outside make a huge difference to my mood. With the help of a book about walks in Metro Vancouver, we have discovered all sorts of parks and trails we have never visited before.



Ashley, Board Member

My number #1 is physical exercise. For me that is trail running, or hopping on the spin bike we have at home. For those who are experiencing low counts (and when I was experiencing low counts) it might be a walk in the neighbourhood or light yoga. For me, really, it's all about my physical and emotional health and taking this time to make improvements to my long term well-being. Instead of gaining weight in the pandemic, I have lost 40 pounds!

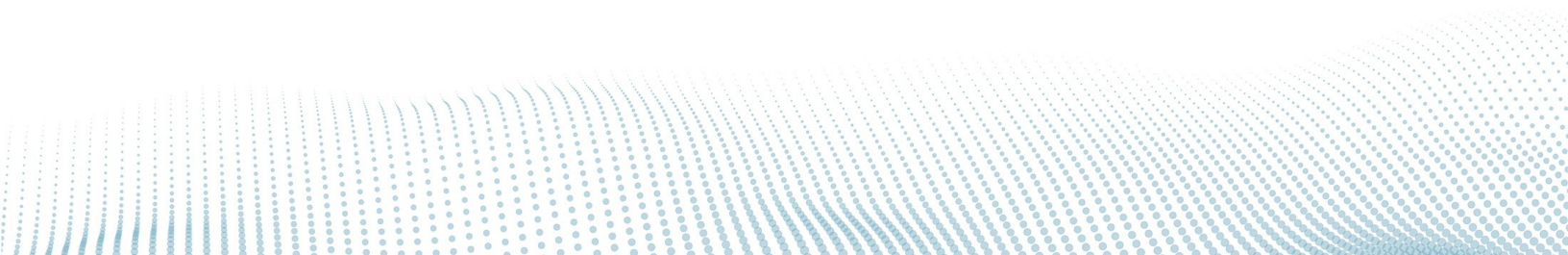


Robyn, Executive Assistant

To deal with boredom, I usually go out for a walk or run. I have also become obsessed with crossword puzzles and download a number of them in the evening. Like many people we succumbed to getting a puppy!

For resources on staying mentally healthy
during Covid-19, please visit

<https://cmha.ca/news/covid-19-and-mental-health>





BEWARE AND BE AWARE

by Pamela Wishart

I'm a patient diagnosed with MDS in 2000 at the age of 56. I'm now 77 and have some age-related issues such as balance to complicate things. What I'm writing is based solely on my experience and my opinion.

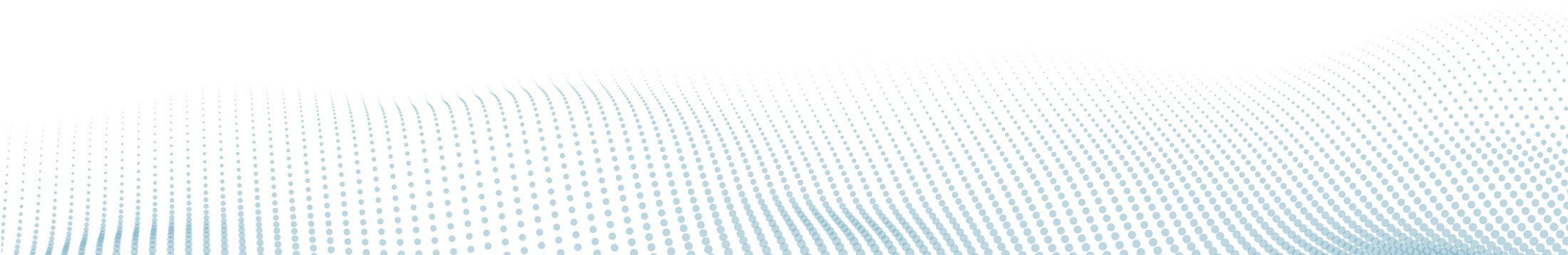


I don't know about you, but I've always been the sort of person who does things in a hurry; for example, why make three trips from the car to the house when maybe you could do it in one? Problem is, as we age our balance and agility reduces, sometimes drastically. And as our reflexes become worse so does our ability to heal, sometimes with deadly results.

A quick look on the Internet showed me many ways in which to reduce the risk of falls and other accidents. Don't have loose carpets, make sure there are clear and wide passages between pieces of furniture. And keep yourself as fit as you can. What I didn't see, but which may be out there, is beware of your own stupidity!

We have two dogs who sleep in the bedroom. We also had a bed with a 3" wooden ledge around the outside. One evening, now over 2 years ago, I brought some dog bedding into the room and dumped it on the floor. Later that evening I had to walk past the bedding, no problem, right? Except I slipped and in falling caught my inner right leg on the corner of the bed. I also bruised a couple of ribs and a hip but they were minor compared to the large triangular flap starting about 3" above my ankle. A visit to the ER and 12 stitches closed it up and I had instructions to have the stitches removed 10 to 14 days later.

So, two weeks later my GP started to remove stitches, only a few as he was worried the flap would reopen. Two days later another few were removed and I was given a prescription for antibiotics, then an appointment for the infections clinic at a local hospital. After days of both IV and oral antibiotics, the wound remained infection-free but wasn't healing so I was referred to the wound clinic.





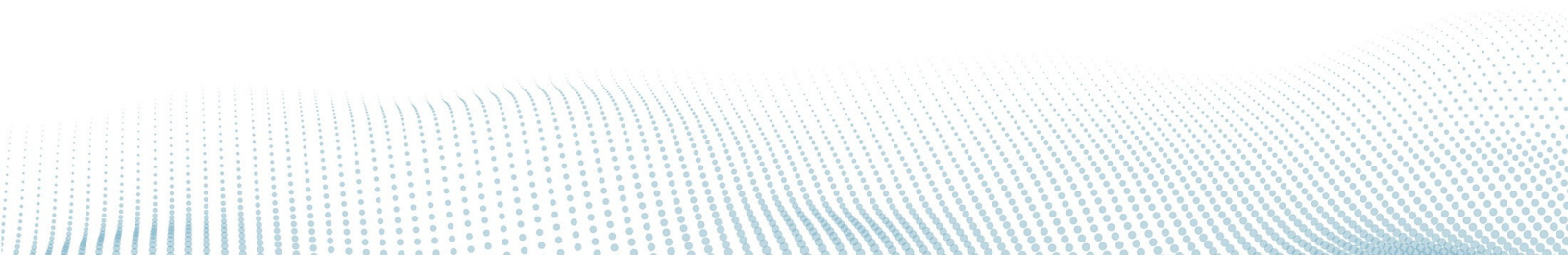
This was now 6 weeks after the fall! After several weeks of visits to the wound clinic with no improvement, I was asked if I would consider trying maggots! Funnily enough, my younger son had said “maggots” to me shortly after I injured myself so the idea was already in the back of my mind. I said “Yes, I’m ready to try anything!” So, on went the maggots for 48 hours. I had been warned that most people don’t notice them for the first 24 hours but then feel them a bit. What I wasn’t prepared for was the intense pain, especially at night. The second night I was up every hour walking for 10 to 20 minutes as they quietened down if I was active. I was a wreck when I showed up at the clinic 48 hours later to have them removed!

It was a relief to see what a great job they’d done. All the slough which was preventing healing had gone and they had revealed a 1 cm. deep puncture wound which we hadn’t known about. Different dressings were tried but weren’t working and then a silver dressing did the trick. A few weeks later the wound had healed and I was discharged from the wound clinic, 5 months to the day after I injured myself. Good, old-fashioned medicine!

So, 5 months of many, many weeks of visits to doctors and nurses all of whom were wonderful, I am no longer paying the price of my mistake, other than the scar! I’m not alone in having this type of accident happen: a number of my friends have suffered from cuts and broken bones.

What do we have in common? We’re all well over 70 and assume we can just do things we could always do without thinking about it. It’s so important that we don’t make these assumptions. Don’t leave things lying on the floor where you might slip on them, sit down or hold on to something when putting on your pants, take care in the shower, don’t make one trip to carry things in when two or three would be better. And pay attention to the sidewalk surface. All things which don’t come naturally given we’ve spent much of our life not even having to think about them.

And despite what I’ve just written, I was putting on my jeans one morning, got my foot caught and had to hop across the floor and sit down on the bed – more stupidity! Think about what issues you have, what silly things you do and how they might have a negative impact on you and modify your behaviour – beware and be aware!





REMEMBERING MARILYNNE CONVEY

Sadly, AAMAC board member, Marilynne Convey passed away on November 13, 2020. Marilynne was diagnosed with Aplastic Anemia five years ago but it did not slow her down. She became an avid spokesperson for AAMAC and volunteered much of her time to lead the nurse education program and attend the Haematology conferences. As she depended on donated blood, she became a big proponent for others to give blood. She is survived by her husband Paul, her children Cindy (Frank), Shawna (Martin) and Krista (Donovan), her grandchildren Emma, Aiden, Matthew and Grace, and her faithful 4-legged companion Sadie.

AAMAC colleagues shared the following memories of Marilynne:

Marilynne was so passionate and dedicated to AAMAC and to growing the Nurse Education program. She was an incredibly kind and compassionate women and she will be deeply missed by all of us who were lucky enough to know her.

Ashley



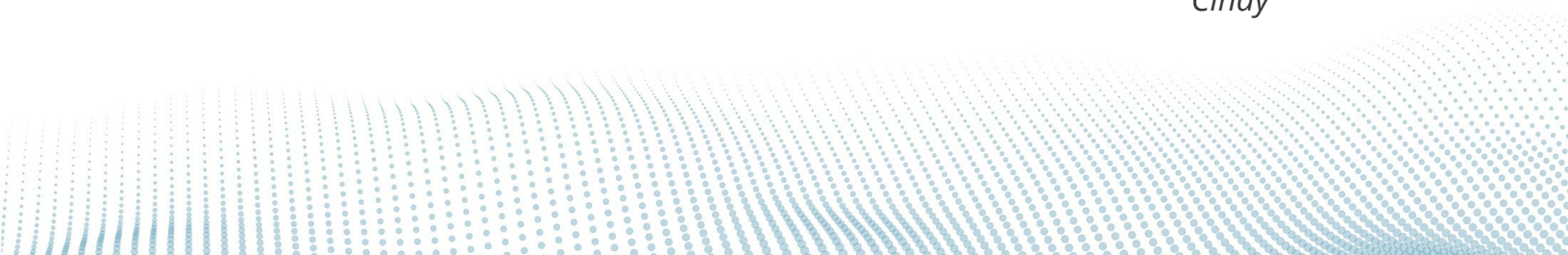
Over the years I've had a handful of discussions with Marilynne about our histories, often "comparing notes" and what always stood out was how passionate, positive and hopeful Marilynne was with everything that she did. Whether it was her role with AAMAC as a board member or spearheading our nurse education program, Marilynne always gave 110% and kept such a positive outlook on life even as she was going through her own journey. Her knowledge, passion and charisma will be missed dearly by those who knew her.

Jesse



Marilynne had a passion for AAMAC and it was evident in everything she did. No matter where she was, AAMAC was on her mind and always sought opportunities to promote our organization to ensure patients and caregivers received support. Her work on our Nurse Education Program advanced the program ahead and I will miss working with her.

Cindy





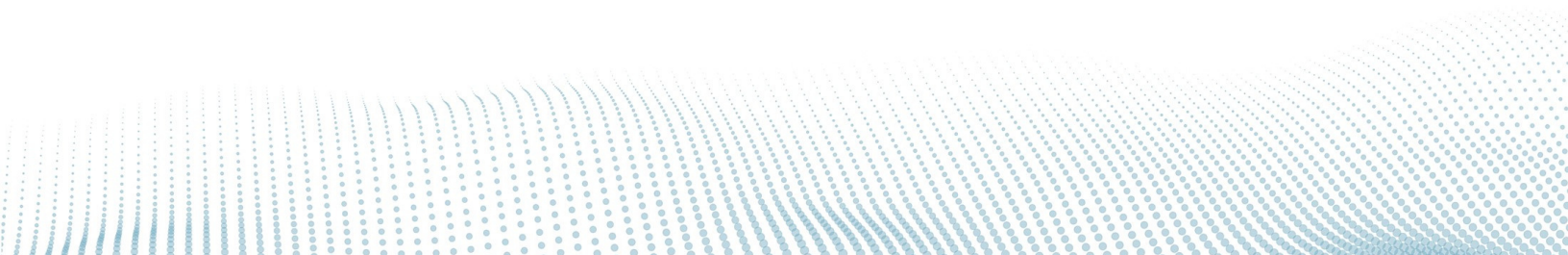
Looking back, I was surprised to see Marilynne only joined the Board in the spring of 2018 which means I first met her in 2017. An AAMAC colleague sent me an email suggesting I contact Marilynne as we both lived in Victoria and she might be a possible Board member. We met for coffee, in the summer of 2017. Marilynne told me she had Aplastic Anemia, had undergone ATG, and was more or less, but not quite, in remission. She also told me she curled, volunteered with several groups and she and Paul, her husband, were planning a trip to the Maritimes that fall.

I was amazed at how busy she was, where on earth did she get the energy? She delighted in a trip to Montreal to watch a grand-daughter compete in a synchronized-swimming competition. She had a trip to Europe in 2019 planned with a grand-daughter, and had managed to contact doctors there who were willing to arrange platelet transfusions for her, if needed. Sadly, her need for transfusions was too great for her to make the trip.

Marilynne was an excellent story-teller and had me in stitches on many an occasion. It might have been this story-telling ability that added to our travel time as we made so many wrong turns! Yes, I have GPS in my car but it's only for use as a last resort. I have a terrible sense of direction; Marilynne's may have been better but not when travelling with me! First time was to Education Day in Vancouver. Sailing past the exit for her hotel, we crossed a bridge we shouldn't have and found ourselves in a maze of one-way streets trying to double back, missed that exit twice. Second time, Marilynne told me to turn left away from VGH when we should have turned right. Realizing our error, we doubled back again. Third and worst, as we had a ferry deadline, in the dark and pouring rain, I took an exit I shouldn't have and it was several miles before we could double back. Once done, I pulled over and decided a look at the GPS might be a good idea! We always managed to laugh at all these wrong turns; she was very relaxed about it all.

Once Marilynne joined the Board, she wasted no time in greatly expanding the Nurse Education Program. AAMAC will be hard-pressed to find a successor with the passion that Marilynne had. In that, and many other ways, she was a great addition to the Board. And I miss her already. We didn't meet in 2020 thanks to Covid, but it was good to know she was there.

Pam





MARILYNNE CONVEY NURSING SCHOLARSHIP

I'm a Jazzercise instructor with Move & Flow in Kelowna and Sara, the owner, agreed to offer a virtual Facebook dancemix class as a fundraiser. We raised over \$500 dollars for the newly-named Marilynne Convey Nursing Scholarship, awarded annually by AAMAC.

I have been a customer and an instructor with Jazzercise for about 30 years. It truly is my second family so it just seemed right that a celebration to support such a wonderful and amazing woman, my mom, was fitting.

Also, I donated 100% of my Arbonne commissions to the scholarship which was just over \$500.

I couldn't be more proud of our fundraising efforts in support of the scholarship fund. I will miss my mom dearly but the scholarship gives me some comfort that her legacy will live on.

Shawna Gibb

We have received many generous donations in Marilynne's memory. Should you wish to donate, please visit aamac.ca/donate



Marilynne & daughter Shawna



MEETINGS & EVENTS

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

Webinars

Questions & Answers:

Covid-19 Vaccines

Date: Saturday, February 20

Time: 1pm ET

Speaker: Nicole Saba

AAMAC Board Member

Treatments for MDS:

Present & Future

Date: Saturday, March 13

Time: 3pm ET

Speaker: Dr. Mary-Margaret Keating,
Hematologist and Assistant Professor
of Medicine at Dalhousie University

Bone Marrow Transplants

Date: Saturday, April 10

Time: 12pm ET

Speaker: Dr. Michelle Geddes, Clinical
Associate, Division of Hematology
and Haematologic Malignancies
Foothills Medical Centre

Sick Kids Marrow Failure and Myelodysplasia Patient & Family Conference

This virtual conference is for patients and families with bone marrow failure disorders and myelodysplastic syndrome, physicians, other health-care workers, fellows, residents and all others who are interested in the field. Adult patients are also invited. The conference will take place on Saturday, April 17th, 2021.

Patient Support Group Meetings

AAMAC is now offering a monthly virtual patient support group meeting. Join us from the comfort of your home - patients and caregivers welcome!

Atlantic Patient Support Group

Date: Thursday, February 18th

Time: 7pm AT

This meeting will be held on the third Thursday of each month

Ottawa Patient Support Group

Date: Wednesday, March 10th

Time: 6pm ET

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

Western Canada Patient Support Group

Date: Saturday, March 6th

Time: 11am PT

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

Interested in joining a support group?

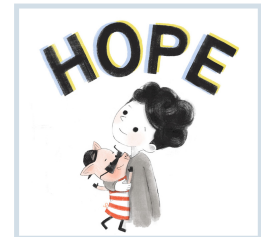
Contact us at
info@aamac.ca to
register for a group



Author, Loretta Garbutt

Book Launch

AAMAC is thrilled to announce the release of a new children's book written by author, Loretta Garbutt called "It's in Me to Win". This is a story about a child's journey from diagnosis of Aplastic Anemia through treatment and recovery. AAMAC will introduce the book at the Pediatric Conference on April 17th with a special reading and it will be available free through the AAMAC office.



Provincial Support Groups & Regional Support Liaisons

British Columbia

Fiona Lewis - bcsupport@aamac.ca

Alberta

Fiona Lewis - albertasupport@aamac.ca

Ontario

Kim Brunelle - ontariosupport@aamac.ca

Atlantic

Kim Brunelle - atlanticsupport@aamac.ca

Other Provinces

Cindy Anthony - info@aamac.ca

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