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

Newsletter - Winter 2022

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

Message from the Executive Director

Happy Fall Everyone!! I do hope everyone had a most enjoyable summer and are enjoying the beautiful fall days we have been having.

Over the past two years we have certainly seen how important our nurses are to our Health Care System. AAMAC is pleased to offer a scholarship each year through the Canadian Nurses Foundation and you can read about this year's recipient in this issue. The award was renamed in memory of Marilynne Convey, a former Board Member and nurse.

October 22nd AAMAC held the Annual General Meeting and elected our Board Members for the next year. Everyone at AAMAC was saddened to hear of the passing of Pam Wishart, a long serving Board Member who gave so much of her time and talent to AAMAC. Pam's many accomplishments while on the Board are highlighted in this newsletter. Pam will be missed dearly.

How did you first hear about AAMAC? A google search, through a friend, perhaps at your hospital clinic? So many patients and caregivers say they wish they had been told about AAMAC earlier in their diagnosis. You can help spread the word and we would love for you to do so. Please contact me at cindyanthony@aamac.ca, to find out how you may be able to assist is this important work. We have so much to offer patients and caregivers and would love to be able to reach more patients.

AAMAC values the support we receive each year in the way of donations so that we can continue to offer the services to patients and caregivers. The opportunity for a donation is included with this newsletter. Thank you for consideration of a donation to support the ongoing work we do.

I hope you enjoy this issue of our newsletter.

Thank you.

Cindy Anthony

IN THIS ISSUE

2022 MARILYNNE CONVEY AAMAC AWARD RECIPIENT: TORI SUTYLA

I was drawn to the nursing profession after watching many individuals in my family receive care for their cancer diagnoses. The compassion and dedication their nurses displayed was truly inspiring. I had a strong background in science coming out of high school, having participated in an advanced placement program which helped to prepare me for my undergraduate nursing studies.

After finishing my undergraduate nursing degree, I chose to start my career in oncology, with a focus in stem cell transplantation and acute hematological malignancies. Working in this area inspired me to further my education and I am currently enrolled in a Nurse Practitioner Masters program. I hope to graduate and continue working in acute malignant hematology, as this patient population is so important to me, and I could not imagine working with anyone else. I have had the privilege to care for many patients during my career with similar stories to that of Marilynne Convey, and I am honoured to have been chosen to receive this award.

I would like to thank the AAMAC, the Canadian Nurses Foundation, and Marilynne for supporting me in my educational pursuits. I hope to make you all proud and continue this tradition of giving back.

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.

NEEDED: AAMAC AMBASSADORS

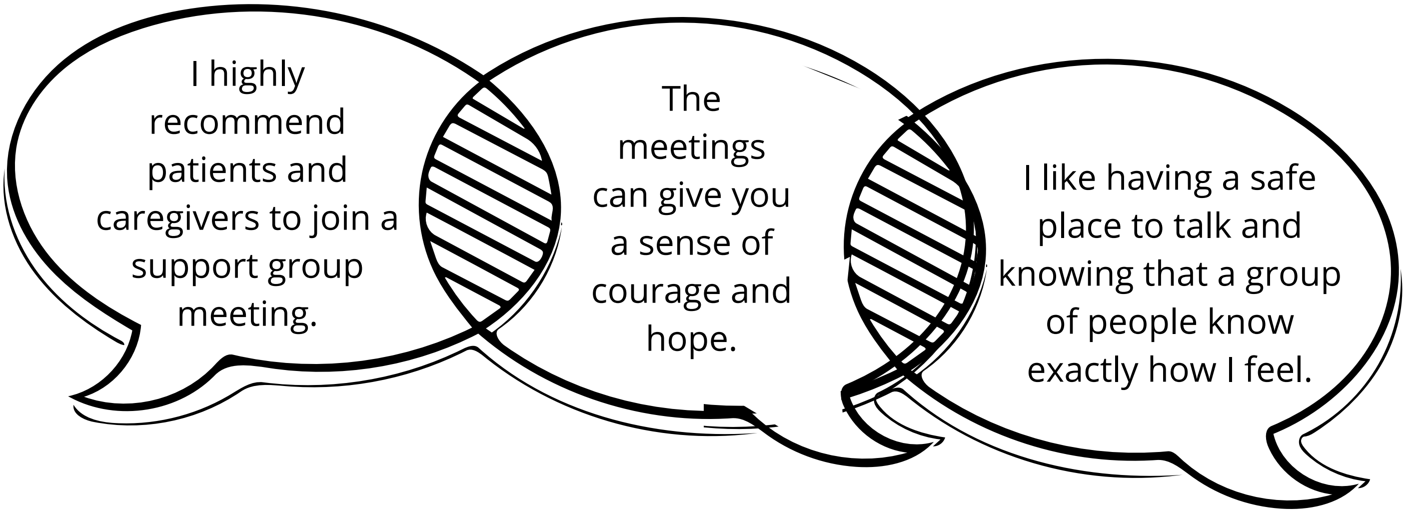
Time after time we hear from patients that they wish they found AAMAC sooner after their diagnosis of MDS, Aplastic Anemia or PNH. Patients have so many questions after their initial diagnosis and AAMAC is here for all patients and caregivers to navigate those early days and to be a partner in your care.

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



I highly recommend patients and caregivers to join a support group meeting.

The meetings can give you a sense of courage and hope.

I like having a safe place to talk and knowing that a group of people know exactly how I feel.

2023 PATIENT TRACKERS

Our popular 2023 trackers are in production and 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/*

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My Progress Tracker

2023

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.

IN MEMORIAM:

Pam Wishart

It is with great sadness that we inform you of the passing of board member, Pam Wishart. After twenty years of service to AAMAC, Pam's passing will leave a gaping hole.

Pam was our longest serving board member. She was diagnosed with MDS in early 2000 after several years of feeling more and more unfit despite exercising regularly. In 2003, she attended an Aplastic Anemia & MDS International Foundation (*AAMDSIF*) patient conference in San Francisco where she met one other Canadian, who was on the Board of AAMAC at the time. Pam remembers the feeling of being with people who completely understood her disease and how important that was. Later that year, Pam was invited to join AAMAC while living in Montreal. She was the main voice on the board trying to extend our support for patients living in Quebec.

She began her support role of others with MDS as a member of a US email-based listserv AA-MDS-Talk. Since then, she had a long history of connecting and supporting patients through the internet, phone chats and face to face visits.

After moving to BC Pam remained on the board and over the years served as Secretary, President, Past President, Chapter Coordinator and Grants Coordinator. She consistently carried out her roles with diligence, objectivity, and thoroughness.

Her scientific background and her interest in bone marrow diseases led her to review multiple journals and research reports which she generously shared with the rest of the board. Often this found its way to our newsletter which meant a wider audience including patients. She easily liaised with AAMAC's Medical and Scientific Advisory Committee (*MSAC*) and other medical practitioners to improve our understanding of AA, MDS and PNH. She was skillful in the composition and editing of letters including our newsletter.

Pam has represented AAMAC on other national organizations such as Canadian Blood Services, Canadian Conference on Myelodysplastic Syndromes (*CCMDS*) and

AAMDSIF. She brought a patient focus to the board which is often a lifeline to patients with bone marrow diseases.

She will very much be missed by both the Board and everyone involved in AAMAC.

Our sympathies go out to Pam's husband, sons and other family members.

FALL PREVENTION MONTH

by Fiona Lewis

November is Fall Prevention Month and, as we know people with bone marrow failure may be at increased risk of falls, we thought we would share a few good resources for fall prevention:

Regular **physical activity** makes you stronger, improves your balance and helps prevent falls. The BC Government has created *this illustrated handout* describing some simple exercises you can do in your kitchen

Certain **medications** can make you more likely to fall. *The Canadian Medication Appropriateness and Deprescribing Network* provides information about which medications increase the risk of falls.

The **home** is the most common place for older adults to fall. There are a few simple and inexpensive changes you can make to your home to reduce the risk of falling. *Finding Balance* has checklists and videos describing how you can make your home safer.

Vision changes can also increase the risk of a fall. Finding Balance Alberta explains what you can do in *this poster*.

Sometimes falls can seem inevitable but **Fall Prevention Month** reminds us that there are many preventative steps we can take.

MDS WORLD AWARENESS DAY

October 25, 2022

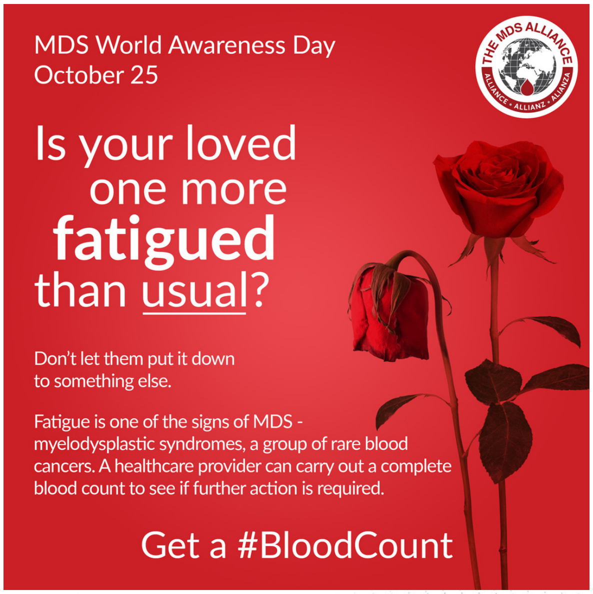
Every year on October 25, the MDS Alliance and their member groups around the world (including AAMAC), come together to raise awareness of MDS. For those who missed it this year, the campaign tried to engage with the loved ones of those experiencing MDS symptoms to encourage them to act and get checked out via a blood test with a full blood count/complete blood count. We may not notice ourselves just how frequently we are feeling tired, or how quickly we get out of breath for activities that used to feel easy. But our loved ones can notice these changes much more easily.

There are a number of types of MDS, some of which stay mild and can be undetected for years, others are more serious and progressive, and symptoms are felt and seen.

This World Awareness Day, the MDS Alliance shared information on the signs and symptoms of MDS, highlighting the need for a blood test, with a full blood count analysis to confirm a diagnosis. As with all cancers, the earlier the diagnosis, the better.

MDS is difficult to diagnose, by raising awareness of MDS and taking action to get a blood test if you are experiencing symptoms - we aim to improve diagnosis.

Please share the signs of MDS.



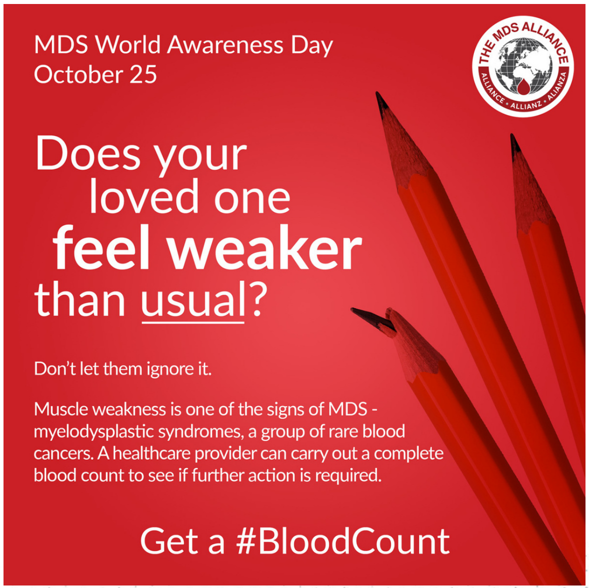
MDS World Awareness Day
October 25

Is your loved one more **fatigued** than usual?

Don't let them put it down to something else.

Fatigue is one of the signs of MDS - myelodysplastic syndromes, a group of rare blood cancers. A healthcare provider can carry out a complete blood count to see if further action is required.

Get a #BloodCount



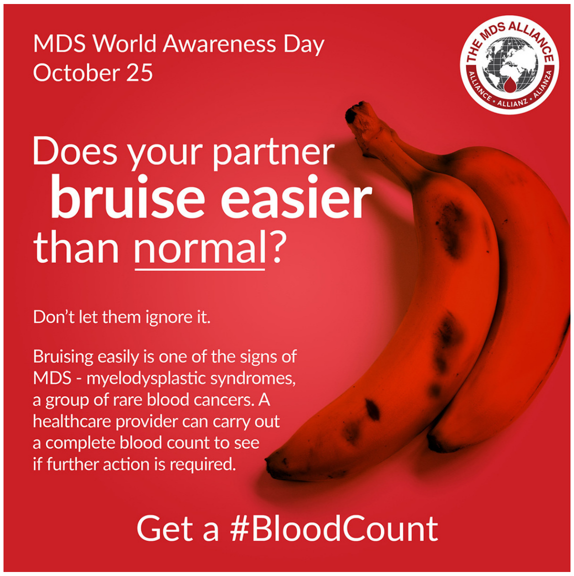
MDS World Awareness Day
October 25

Does your loved one **feel weaker** than usual?

Don't let them ignore it.

Muscle weakness is one of the signs of MDS - myelodysplastic syndromes, a group of rare blood cancers. A healthcare provider can carry out a complete blood count to see if further action is required.

Get a #BloodCount



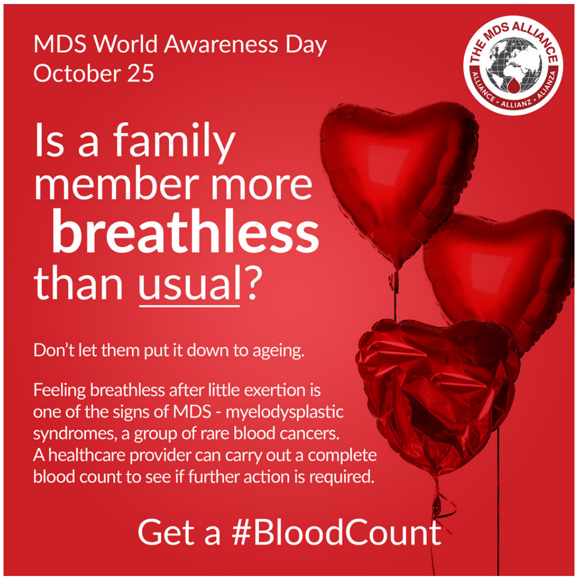
MDS World Awareness Day
October 25

Does your partner **bruise easier** than normal?

Don't let them ignore it.

Bruising easily is one of the signs of MDS - myelodysplastic syndromes, a group of rare blood cancers. A healthcare provider can carry out a complete blood count to see if further action is required.

Get a #BloodCount



MDS World Awareness Day
October 25

Is a family member more **breathless** than usual?

Don't let them put it down to ageing.

Feeling breathless after little exertion is one of the signs of MDS - myelodysplastic syndromes, a group of rare blood cancers. A healthcare provider can carry out a complete blood count to see if further action is required.

Get a #BloodCount

You can follow the MDS Alliance on social media at:

@MDS Alliance @MDSAlliance @mdsalliance @MDS Alliance

In recognition of MDS World Awareness Day, we teamed up with Macleans to share Bob, Ann and Candace Markovich's touching story. Thanks to innovative therapies and the expansion of telehealth services, Bob has been able to receive much of his treatment from the comfort of his own home. Also featured is Bob's hematologist at Hamilton, ON's Juravinski Cancer Centre, Dr. Dina Khalaf.

Read "*Reflections on a rich and remarkable life: Bob's story*" via Macleans.ca.

THE STUDY OF SUPPORTIVE CARE TREATMENTS AMONG PATIENTS WITH MYELODYSPLASTIC SYNDROME

Dr Brett Houston and Nora Choi at CancerCare Manitoba are designing studies with the goal of reducing infection and bleeding among patients with MDS. Your input is really valuable in helping them to design and carry out these studies.

Please help by completing the survey found at:
https://www.surveymonkey.com/r/XG7ZFX7

Your participation on this survey is completely voluntary. If you would like more information about this survey or for any questions, please contact Nora Choi at nchoi@hsc.mb.ca.

GIVINGTUESDAY

November 29, 2022

GivingTuesday is a global generosity movement, taking place each year after Black Friday. It harnesses the potential of social media and the generosity of people providing a platform for them to encourage the donation of time, resources and talents to address local challenges. It also encourages acts of kindness.

It was created in 2012 as a simple idea: a day that encourages people to do good: make someone smile, help a neighbour or stranger, show up for an issue you care about, or give some of what you have to those in need. Over the past nine years it has since grown into a global movement, unleashing the power of people and organizations to transform their communities and the world.

GivingTuesday is a time when Canadians, charities, and businesses come together to celebrate giving and participate in activities that support charities and non-profits; to thank, help, give, show kindness, and share what they have with those in need.

Every act of generosity counts. Everybody has something to give. You can get involved in many ways, from sharing our posts on social media, telling your friends and family about our work and donating to AAMAC via our ***website*** or ***CanadaHelps***.

Your generous donations help us to provide programming and patient support meetings to every Canadian patient, family member, friend and concerned healthcare provider dealing with aplastic anemia, MDS or PNH.

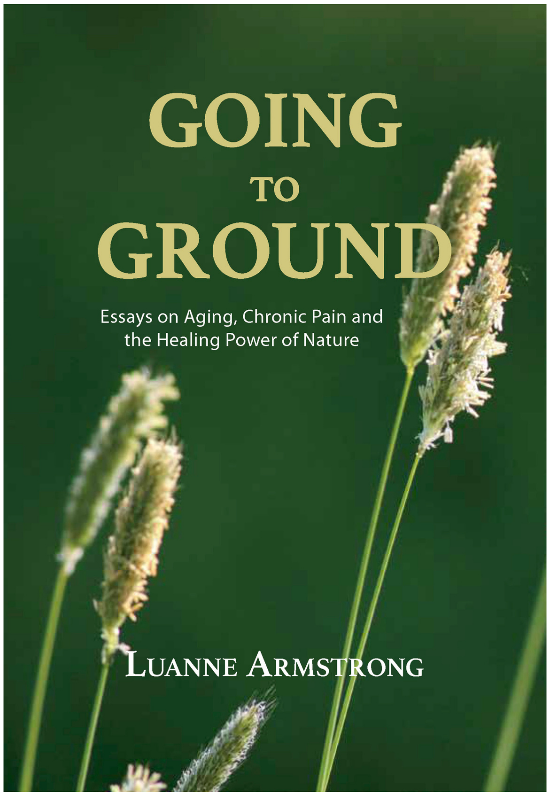
Every little bit helps, and we are so grateful for your support. Thank you for helping us make a difference this GivingTuesday!

GIVING
TUESDAY

Nov
29

BOOK REVIEW

by Fiona Lewis



In her latest book, Going to Ground: Essays on Aging, Chronic Pain and the Healing Power of Nature, Luann Armstrong explores issues that are likely very familiar to those living with bone marrow failure. Armstrong, an older adult living alone on a rural property in the Kootenays, was injured in two separate car accidents during the past decade. She now lives with the aftereffects which she describes as a pain in her head that "….feels as if someone has wrapped a rope around it inside, pulled as tightly as possible and then set it on fire. "Along with the pain comes fatigue, insomnia, and the challenges of aging.

Armstrong is candid and reflective in these short essays which explore pain, insomnia, loss, depression, childhood memories and rural life. In describing her battles with fatigue, she says, "I push myself hard, hard, knowing the fatigue will get me back, knowing that I can stretch my energy like a rubber band until it snaps back hard." This description will no doubt resonate with readers who experience severe fatigue.

Armstrong also brings a wry humour to her essays as when she states, "Nothing is more ridiculous than trying too hard to sleep." Her love/hate relationship with sleeping pills will be very familiar to those who have experienced regular insomnia. As for old age, she says, "People head into old age as naively as teenagers heading into puberty." Her reflections on the aging process ("I hate old age") will have many readers thinking, yes, it's exactly like that.

Armstrong's honesty with herself and others is most evident in discussing the reactions of family and friends to her conditions of both chronic pain and aging. While her children are focused on keeping her safe (albeit less independent), some friends are unable to understand the impact of her injuries, which are mostly invisible. One friend tactlessly states, "Well, I have aches and pains too, but I don't let them ruin my day", leaving Armstrong to make some tough decisions about ending the friendship.

While some readers may find Armstrong's essays to be too despairing or melancholy, others may by heartened by the spaces in which Armstrong herself finds hope. These include finding connection with others, walking outside, writing, and noticing – noticing birds, leaves, animals, the light, clouds, and that she is alive. Armstrong's book, while challenging in some ways, will also help readers in similar circumstances feel that they are not alone.

You can order your copy at *https://caitlin-press.com/our-books/going-to-ground/*.

OTHER NEWS

Thank you Christine

Christine Pappas has resigned from the AAMAC Board. It was a difficult decision to make, but Christine has decided she wants to keep travelling for as long as her health will allow.

Thank you Christine for all of your hard work and dedication in supporting the Board over the past 4 years.

New Board Elected

On October 22 the AAMAC's 2022-2023 Board was elected at the annual general meeting. They are - Ashley Oakes, Gwen Barry (Secretary), Haydn Liang, Jennifer Garvey, Jesse Prager (Chair), Rohail Badami and Vivian Do (Treasurer).

Office move

We will be moving to a smaller unit in our current building. Our mailing address and phone number will not change.

The smaller unit will mean a reduced rent, resulting in lower running costs. Even as Canada experiences an increase in inflation that has not been seen in decades, the value of any donations will not be diminished and donations will continue to be used to achieve our mission.

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!

French Speaking Patient Support Group

Date: Wednesday, December 7th
Time: 7PM ET
This meeting will be held on the first Wednesday of each month.

Central Canada Patient Support Group

Date: Wednesday, December 14th
Time: 6pm ET
This meeting will be held on the second Wednesday of each month

Atlantic Patient Support Group

Date: Thursday, December 15th
Time: 7pm AT
This meeting is held on the third Thursday of each month

Western Canada Patient Support Group

Date: Monday, December 19th
Time: 6PM PT
This meeting is held on the third Monday of each month

Webinars

Self-Compassion for Caregivers

Date: November 22, 2022
Time: 2 pm (Eastern Time (ET))
Speaker: Patricia Williams

Iron Overload Management

Date: November 26, 2022
Time: 11 AM (ET)
Speaker: Cyrus Hsia

Sexual Health and Intimacy in the Context of Serious Illness

Date: January 24, 2023
Time: 7PM (ET)
Speaker: Reanne Booker

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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