

*Education
Support
Research*

Spring 2017

Aplastic Anemia & Myelodysplasia Association of Canada

NEWSLETTER

Message from the Chair

Happy New Year and I hope that 2017 has gotten off to a good start!

In the coming year, AAMAC will be holding patient support group meetings across the country! These meetings ensure we are working vigorously towards our mission to provide a seamless support network for every Canadian patient, family member, friend, and concerned healthcare provider dealing with aplastic anemia, myelodysplasia (myelodysplastic syndrome or MDS) and paroxysmal nocturnal hemoglobinuria (PNH).

In addition to holding patient support group meetings and our annual patient education day, held in the fall, AAMAC board members and our Executive Director represent our patients, families and caregivers through our involvement with Canadian Blood Services (CBS) National Liaison Committee, the Network of Rare Blood Disorder Organizations, and the Canadian Organization for Rare Disorders. This work ensures we stay on top of the latest developments that impact our patient population and ensure we are advocating for patients, families and caregivers from coast to coast to coast.

AAMAC's annual patient education day will be held at the Sheraton Vancouver Airport Hotel on Saturday, September 30, so please mark your calendars. We look forward to distributing more details in the coming months!

As always, please contact our office – by emailing info@aamac.ca or by calling 1 (888) 840-0039 – if you would like to volunteer, if you are in need of support, or if you would like us to mail you educational and support material. All material and support services are available in English and French.

Ashley Oakes
Chair of the Board
AAMAC



Aplastic Anemia & Myelodysplasia
ASSOCIATION OF CANADA
ASSOCIATION CANADIENNE
de l'anémie aplasique et de la myélodysplasie

The Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC) provides information about aplastic anemia (AA), myelodysplasia (also called myelodysplastic syndrome or MDS) and paroxysmal nocturnal hemoglobinuria (PNH) to the public; operates a nationwide support network for patients, families and medical professionals; supports Canadian Blood Services blood programs and OneMatch Stem Cell and Marrow Network; and raises funds for medical research.

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BC Update

By Janice Cook

Is it spring yet? As I write this at the end of January, we still have snow and ice in sheltered places where I live, and the winter sessions of soccer have been all but abandoned since November's end.

It has been a hard winter for anyone to get outside and walk, and especially troublesome to those with limited mobility, cold intolerance, or just debilitating fatigue. So take advantage of the sun and warmth and dry sidewalks to go for a walk; it's usually good for both physical and mental health.

Another thing that might be good for your spirits is taking care to look your best. A patient just reminded me of that recently. She finds doing her normal social activities as much as possible to be a great help, and included suggestions such as the hair dresser and makeup.

It reminded me of the summer I was completely transfusion dependant for blood and platelets. My daughter was getting married and I looked and felt so awful I couldn't even think about shopping for a dress. But my sister convinced the people at the BC Cancer Agency's Look Good Feel Better program that I should be accepted into its workshop even though I didn't have cancer.

Of course aplastic anemia is rare enough that they had never heard of it, but I was being treated in the outpatient unit with the leukemia patients and I had a PICC line, so I was accepted.

One look at my stark white face and weakened, drained appearance and I had makeup and hair people advising me for two hours, and left with a big goodie bag of products that participants receive. It was a great lift for my spirits. I even attended a work party that week instead of avoiding everyone.

I hated looking sick. It doesn't matter what activities you do, just push yourself a bit to actually get out there. Pick something that you enjoy doing, adjust for fatigue, plan on a day when you can rest before and after, and if you are transfusion dependent, take advantage of your latest boost of hemoglobin to help you participate.

A small group of men from the Kamloops region are planning another support group meeting. These BMF (bone marrow failure) guys are making an effort to learn from each other about coping with their chronic illness as well as finding out all of the things they have in common. A meeting is being planned for mid-March and others are welcome to attend. If you'd like to join the group, you can contact Gerry at (250) 851-1155 or hghartley@shaw.ca.

Please look at the information in this newsletter about the Thanks Mom Give Life Campaign to be held in Vancouver on May 13. As a community partner of the event, AAMAC will help spread the word about blood products, stem cells, umbilical cords for transplants, and other tissues and organs needed for transplants. The need is greatest for multiethnic donors, and young men are the prime donor candidates for transplantation of stem cells.

We are currently making plans for Education Day in September and hope you will mark your calendars and plan to join us. Later we'll be calling for volunteers to take posters around to clinics and hospitals in the lower mainland, so please consider helping.

Take care.



Thanks Mom Give Life 2017 Campaign

By Paul and Eileen Sue

“Mothers have given us life and we, in turn can give life to others.” This is the premise of Thanks Mom campaigns which ran in 2006, 2011 and 2012 and now return for 2017! The 100% volunteer grassroots Thanks Mom Committee partners with CBS to raise public awareness about the need to help others through donation of blood, adult stem cells, cord blood stem cells or organ/tissues.

The event works with CBS’ OneMatch to register people for the unrelated stem cell and bone marrow registry in Canada (especially those of multi-ethnic backgrounds). There will also be other community partners present including the BC Transplant Society, Leukemia & Lymphoma Society, various student groups from schools – including the University of British Columbia, British Columbia Institute of Technology, Simon Fraser University and Langara College – to raise awareness of other ways to donate!

WHAT: Thanks Mom Give Life 2017 Campaign

WHEN: Saturday, May 13, 2017 (the day before Mother’s Day) 10 a.m. to 9 p.m. (mall hours)

WHERE: Metropolis at Metrotown Mall, Burnaby BC
Grand Court

WHY: Mothers have given us life – let’s give life to others through blood donation or potential stem cell donation. Do it in honour of Mom!

WHO:

- age 17 to 35 especially male, ethnic background (optimum donor) for OneMatch (swab) – willing to help anyone anywhere anytime when asked IF a match;
- age 17+ for blood donation (book appointment with CBS);
- age 18+ and pregnant for cord blood

donation (arrange through BC Women’s Hospital); and
- age 18+ for organ/tissue donation (sign up through BC Transplant).

HOW: Register with OneMatch as a POTENTIAL stem cell donor (questionnaire and cheek swab) and/or obtain information about other ways to give life!

COMMUNITY PARTNERS: BC Transplant, Leukemia & Lymphoma Society, AAMAC, Metropolis at Metrotown, Explorasian.

For more information, contact info@thanksmom.org, or visit www.thanksmom.org, facebook.com/thanks.mom.drive or twitter.com/thxmomstemcell.

Hope to see you there! AAMAC has been a great supporting community partner and continues to be!

Atlantic Region Update

By Gwen Barry



The Halifax area support group enjoys its 2016 Christmas luncheon.

The Halifax Area Support Group held its annual Christmas Pot Luck Luncheon at the home of Delores d’Entremont on November 30, 2016. The food and camaraderie were great, as were the Christmas carols led by Jennifer Garvey, with her wonderful voice.

The Halifax Support Group collected sufficient funds to purchase a Leaf on AAMAC’s Tree of Life in memory of the late Marian Peters (MDS), who passed away in 2015.

In January 2017, an email was sent to all patient/family contacts in the four Atlantic provinces to determine interest in being listed on AAMAC’s peer-to-peer support list.

Small sticky note pads advertising AAMAC’s support services have been placed in the 14 waiting rooms at the Halifax Hematology Clinic, and in the St John’s, Newfoundland Hematology Clinics.

In both cases, the hematologists and/or the hematology registered nurses (RNs) have agreed to hand out a sticky note to newly diagnosed AA, MDS, and PNH patients, making

them aware of the support services available through AAMAC.

If you live in the greater Halifax area, and would like to attend any of our local events, please contact Gwen Barry at (902) 864-8872 or gwenb@eastlink.ca. If you live anywhere in Atlantic Canada and would like to take advantage of AAMAC's peer-to-peer support service, please also contact Gwen.

Ontario Chapter Update

By Darlene Edmonds, Regional Support Liaison, Ontario

Happy New Year! Spring flowers are just around the corner!

I've been busy booking meeting space for the upcoming Spring round of patient support group meetings in Hamilton, Toronto and London.

Please save the dates:

- Saturday, March 25 in London, Ontario;
- Saturday, April 1 in Hamilton, Ontario; and
- Saturday, May 6 in Toronto.

The Toronto meeting will feature a presentation about aplastic anemia and children by Dr. Vicky Breakey, a pediatric hematologist/oncologist at McMaster Children's Hospital.

Check the events section of this newsletter for details.

If you have a topic suggestion for a future meeting, or if you've heard someone present that you were really impressed with, please share the details with the AAMAC office. We are always looking for speaker suggestions.

If you live in the Sarnia/Windsor area and would like to help me arrange a meeting in the Chatham area this fall, please contact the office.

Marrow Movers on the Move Again

If you live in or plan to visit Vancouver or Toronto and would like to be a part of the Marrow Movers Team to raise funds for AAMAC, please mark these dates on your calendar: June 25, 2017 (Vancouver) and October 22, 2017 (Toronto).

Those are the dates for Scotiabank-sponsored events where you can run or walk in support of a charity of your choice – like AAMAC!

In past years, AAMAC set up a team called the Marrow Movers. Patients and family members alike came together with most walking or even rolling the five-kilometre option. Some ambitious members even took part in the half marathon.

More details regarding registration and pledge form instructions will be available on the website soon.

Celebrate Canada's 150th Anniversary By Volunteering

Adapted from volunteer150for150.ca



The Canada 150 for 150 Volunteer Challenge is a nation-wide movement led by Volunteer Ottawa in partnership with Volunteer Canada

and Volunteer Centres across the country.

The goal is to have Canadians give 150 hours of volunteer time in 2017 in celebration of Canada's 150th anniversary. The Canada 150 for 150 Volunteer Challenge will engage tens of thousands in making a difference in the lives of Canadians.

Volunteerism is a movement to benefit community and serve the common good without financial gain. Volunteerism can be formal or informal.

Formal volunteering takes place as part of a non-profit organization's activities like canvassing for funds; providing advice, counselling or mentoring; visiting seniors; preparing and delivering food; serving as volunteer drivers; advocating for social causes; coaching children or serving on boards and committees.

Informal volunteering are those actions that benefit people outside the family or household.

Canadians are known for helping our neighbours, random acts of kindness like shovelling a sidewalk or buying someone's coffee in the line up behind us. We organize community activities, like BBQs or litter clean-ups.

Canadians find out how to register for the Challenge, track volunteer hours, tell your volunteer stories and create a volunteer profile at volunteer150for150.ca

Those who have contributed the most hours in each province and territory will be invited to Ottawa to be recognized in a ceremony in early 2018. Special recognition will be awarded to "New Canadian 150 for 150 Volunteer", "Aboriginal 150 for 150 Volunteer", "Youth 150 for 150 Volunteer" and "Senior 150 for 150 Volunteer".

Volunteers are at the heart of Canadian communities. Volunteering creates a positive ripple effect

transforming the lives of the people who volunteer and the people who benefit. To celebrate the 150th Anniversary of Canada, all Canadians are invited to give 150 hours of their time during 2017 and give back to their community and their country.

Editor's note: If you don't already, please also consider volunteering for AAMAC this year! There are many ways to help. Just contact the office or your local chapter representative.

Thank You AAMAC Volunteers!

April 23 to 29 is National Volunteer Week and it's an important annual time to mark the contributions of people in our community.

People with bone marrow failure disorders and family members who turn to AAMAC benefit greatly from the generous contributions of volunteers across the country.

We thank each and every volunteer for all that they do whether it's helping to organize a support group, running a fundraiser, lending an understanding ear as part of our peer-to-peer support list or serving on a Board or Committee.

Given how the lives of many people with bone marrow depend on blood and platelet donors, we also send a special shout out to those who literally donate of themselves or encourage others to give the gift of life.

Thank you volunteers!

Mixed Match Continues to Spread Marrow Message

In November, representatives from AAMAC had the opportunity to

attend one of the Canadian screenings of the documentary *Mixed Match* at the Toronto Reel Asian Film Festival where it received the Audience Choice Award.

The film is about the need for bone marrow and stem cell donors for patients with "mixed" ancestry. AAMAC contributed funding to the film early in its development to help bring attention to the need for donors from diverse backgrounds.

A stem cell drive was held at the screening for attendees who would like to sign up for the bone marrow and stem cell registry, OneMatch. Visit blood.ca for more information about signing up online.

Earlier last year, the film premiered at the Vancouver International Film Festival where it won the People's



Canadian Blood Services registers audience members for OneMatch at the screening.



AAMAC Executive Director and Mixed Match film-maker Jeff Chiba Stearns pose for a "cellfie" with promotional stuffed stem cells at the screening.

Choice Award – appropriate given that Jeff is from B.C. and based in Vancouver.

It has since been seen at film festivals across North America including the San Diego Asian Film Festival, the Hawaiian International Film Festival, the Philadelphia Asian American Film Festival, Victoria Film Festival, Seattle Asian American Film Festival and the Spokane International Film Festival. A community screening was also held in Kelowna, B.C.

According to the film's website, "Mixed Match is an important human story told from the perspective of mixed race blood cancer patients who are forced to reflect on their multiracial identities and complex genetics as they struggle with a seemingly impossible search to find bone marrow donors, all while exploring what role race plays in medicine. With the multiracial community becoming one of the fastest growing demographics in North America, being mixed race is no longer just about an identity, it can be a matter of life and death."

Visit mixedmatchproject.com for more information including upcoming screenings.

Mark Your Calendars

Please also check local provincial updates for regional support group meetings and education events.

For further information about events, call the office toll-free at 1 (888) 840-0039 or contact info@aamac.ca.

Southern Ontario, Patient Support Group Meetings

Join us at a free patient support meeting near you.

What to expect at a support group meeting? A guest speaker, time for Q&As and time for patients to share some of their experiences. In these meetings, patients and caregivers come together in a safe environment to share and learn from one another and access various resources through AAMAC.

London: Please hold Saturday, March 25 from 10:30 a.m. to 12:30 p.m. at the Wellspring Cancer Support Centre, 382 Waterloo Street in London. Refreshments will be served. Please note that the Centre is in the YMCA building.

Hamilton: Saturday, April 1, 2017 from 10:30 a.m. to 12:30 p.m. at Wellwood, 501 Sanatorium Road in Hamilton. Refreshments will be served.

The London and Hamilton meetings will include time to share successes and challenges with one another and a round table discussion.

Toronto: Join us on Saturday, May 6, 2017 from 10:30 a.m. to 12 p.m. at the Bloor Street United Church, 300 Bloor Street West in Toronto. Our guest speaker Dr. Vicky Breakey, a Pediatric Hematologist/Oncologist at McMaster Children's Hospital will discuss "Aplastic Anemia in Children: the Challenges of Diagnosis and Treatment." At this meeting we will also hear from a youth and his mother

who will share their experiences. Refreshments will be served.

Edmonton Patient Meeting

Please join us Saturday, April 29, 2017 from 10:30 a.m. to 12:30 p.m. for "New Treatments for MDS" with Nancy Zhu, MD, FRCPC, from the Division of Clinical Hematology at the University of Alberta. Following the speaker we will discuss future meetings of a patient group in Edmonton. The meeting will be at the Chateau Lacombe Hotel, 10111 Bellamy Hill in the Lacombe Room. A light continental breakfast will be served.

Walk or Run for AAMAC

Join our Marrow Movers Team in Vancouver on June 25 or Toronto on October 22 to raise funds for AAMAC. See the article in this issue for more information and watch our website for registration details.

Annual Patient Education Day & AAMAC Annual General Meeting

Mark your calendar! AAMAC's next annual Education Day is headed west and will take place in Metro Vancouver on September 30, 2017 at the Sheraton Vancouver Airport Hotel, 7551 Westminster Highway in Richmond. Registration and speaker information will be available on the website soon.

AAMDSIF and MDS Foundation Plan 2017 Patient Conferences

Two U.S.-based organizations are planning events for patients and their families, including many near the border with Canada.

The Aplastic Anemia and MDS International Foundation (AAMDSIF) is offering six national "Living with Aplastic Anemia, MDS, PNH" patient and family conferences in six cities around the United States. Each free conference offers learning opportunities from leading American medical experts and opportunities to connect with other patients and caregivers.

This year's national conferences take place in:

- Las Vegas – April 22
- Nashville – June 24*
- Minneapolis – July 22
- Newark (New York City Metro Area) – September 16
- Kansas City – October 14*
- Orlando – November 4

**Conferences end after lunch*

The organization also posts information about webinars on its website. For information visit aamads.org or email conference@aamds.org.

The MDS Foundation also plans a number of events focused on MDS:

- Chicago – April 22
- Seattle – April 29
- Buffalo – September 9
- Charleston – September 9
- San Francisco – October 28
- Atlanta – October 28
- San Antonio – November 18
- Iowa City – November 18

Visit mds-foundation.org for details.

If attending a conference outside Canada, please keep in mind that there may be some differences in treatment options available. Always check with your health care team about what's best for you.

News of Note

Bilingual Logo/logo bilingue

AAMAC has a new logo which incorporates the Association's name in French. AAMAC already has a number of materials in both French and English including patient education materials and the newsletter and is keen to reach patients across the country whether they speak French or English.



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