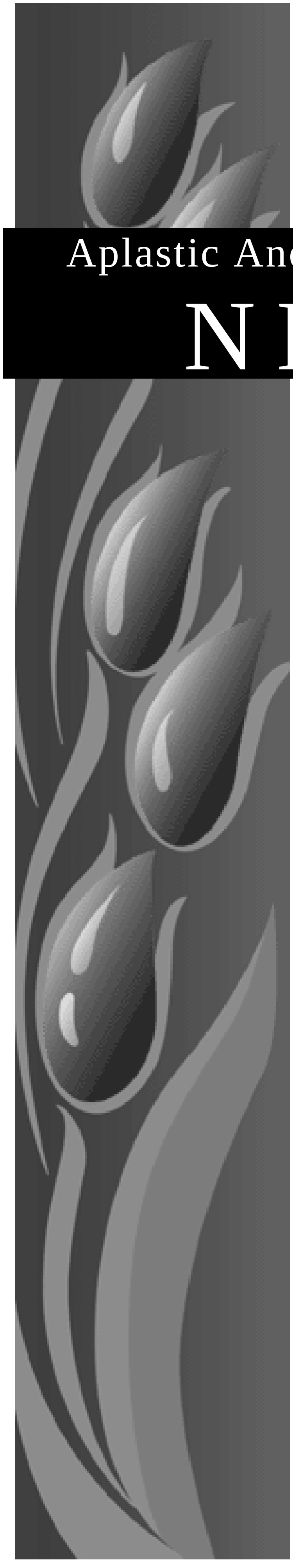

Education
Support
Research

Fall 2017

Aplastic Anemia & Myelodysplasia Association of Canada

NEWSLETTER

Message from the Chair

It's been a beautiful summer so far and I hope you have all been enjoying some relaxing downtime, fun-filled sunny days, and long, warm, breezy evenings with family and friends!

Fall for AAMAC always kicks off with our annual Patient Education Day, this year taking place in Richmond, British Columbia (within 5 minutes of the Vancouver International Airport) on September 30th. This is the first time in 6 years that we are back on the west coast and we are looking forward to connecting with old and new friends during a day of inspired speakers.

The agenda for Patient Education Day is enclosed within this newsletter and you will see that we have a diverse group of expert speakers as well as an inspiring panel of patients and caregivers joining us for the day. There is no fee to attend but we do ask that you pre-register. The registration form is also included with this newsletter.

In addition to patient education sessions, there will also be a Lunch and Learn session for nurses who work with AA, MDS and/or PNH patients.

As always, we will be uploading selected presentations to our website after the event for those of you who are not able to join us and we will keep you informed of other upcoming educational opportunities across the country as we continue through the year. Information on these events can be found on our website (www.aamac.ca) and on our Facebook page (www.facebook.com/AAMACanada/)
Patient Education Day as well as our other support programs would not be possible without the support of our sponsors and donors; I'd like to thank them all for their incredible generosity and support. They make all the things we do possible.

I wish you all the very best for the rest of the summer and into the fall and for those who can make it in September, I look forward to seeing you at Patient Education Day.

All the best,

Ashley Oakes
Chair of the Board
AAMAC

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ASSOCIATION OF CANADA
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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.

The Aplastic Anemia & Myelodysplasia Association of Canada Newsletter is published 4 times a year. The contents are not intended to provide medical advice, which should be obtained from a qualified health professional. No part of this publication may be used or reprinted without written permission. For submissions, inquiries or comments, please contact us at:

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Patient Education Day

Join us on Saturday, September 30, 2017 for our annual national patient education day. This year we'll be at the Sheraton Vancouver Airport Hotel, 7551 Westminister Hwy, Richmond, B.C. Visit aamac.ca or contact the office for more information.

BC Update

By Janice Cook

I'm starting to get excited about Ed Day Eleven. We've got terrific speakers, a patient panel who have "been there," and we've just heard about some surprise guests who will join us. Most people should be able to relate with someone on the panel, and they've all volunteered to try and give some tips on what worked/works for them. That's peer support face to face!

Please get registered and come see us. It's free and worth your time. And if you find yourself explaining your rare bone marrow failure disease to your nurses, invite them to register and join us at the whole conference or the lunchtime learning session about MDS just for them.

Peer support is one of AAMAC's most important jobs. The volunteer Board of Directors and the staff all try our best to provide it or facilitate others by matching patients with others who have had similar experiences. Sometimes people come together by geography rather than similar experience, because coping in isolation can be more difficult.

For some of us, a peer support person became a lifelong friend. For others, it is a limited experience that helps one get through a difficult time, perhaps with more understanding and coping skills. The mechanics of support, whether by phone, email or in person don't matter; it's how the participants feel about the interaction that is important. We just don't want to feel all alone.

Sometimes a single person can make a huge difference. Gerry is one of those people. He came to AAMAC looking for support for himself, and finding no group in Kamloops, where he lives, he started one.

This what one of the group members says: "Gerry's work here in Kamloops to form and nurture a support group has been incredibly selfless. He is to be commended for his time and interest. I would expect every community would benefit from this process and we need to promote this any way we can."

We totally agree, and hope that anyone interested in starting something similar will contact our office to receive written guidelines, advice, answers to questions and anything else we can do to help.

Gerry's group is similar to groups that have operated in the past, or continue to operate in Calgary, Ottawa and Halifax. Sometimes they may have speakers but may meet just as a gathering of like-minded people who can talk about successes or setbacks with each other or a topic of their own interest. Our group in Calgary attended some blood donor clinics to hand out Lifesavers™ to our lifesavers.

Gerry sends out his own bulletin after a meeting so those who could not attend get an update.

Other meetings are arranged by AAMAC staff and are useful in providing speakers and introducing AAMAC to patients and health professionals in areas where we had no regular presence. Darlene is doing a wonderful job of this in the Toronto area, and Sue has recently begun in the Edmonton area.

Now I'm very happy to report that we will be expanding this service to the Vancouver Metro area. Although we have a few committed volunteers in B.C., none of us lives in the area with the greatest population and number of hematologists, so meetings there are a challenge for us.

I hope that by the next newsletter, you will have notice of a support group meeting in Vancouver. In the meantime, come and join us on September 30 in Richmond. You'll be glad you did.

Several members at the "Kamloops BMF (for Bone Marrow Failure) Guys and Gals" June meeting remember Bob who passed away earlier this year. Holding Bob's photo is his wife Peggy. She is surrounded (left to right) by Les, Diane, Peter, group founder Gerry, and Rita (seated).

Atlantic Region Update

By Gwen Barry

At the invitation of Dr. S. Dolan, Conference Convenor, I attended the Annual New Brunswick Hematology Conference at St. Andrews-by-the-Sea, on May 21 and 22 in order to represent AAMAC Atlantic Region.

At this conference, presentations were made on various bone marrow/blood disorders, allowing hematologists and hematology nurses to learn new information and share experiences about these disorders, all in the interest of their patients.

Small sticky note pads advertising AAMAC's support services have been provided to several hematologists in New Brunswick hospitals for them to hand out to newly diagnosed AA, MDS and/or PNH patients. As well, educational materials about AA/MDS/PNH in both official languages have been placed in the main waiting rooms of several New Brunswick hospitals. These are in addition to similar material already available in hematology clinics in Halifax, Nova Scotia and St. John's, Newfoundland.

The next newsletter should have information about a mini-Education Day tentatively planned for May 2018 in Halifax. Those on the Atlantic Region mailing list will be provided with further information concerning this event early in the new year. If you wish to be included on our Atlantic Region mailing list, please contact me.

If you live in the greater Halifax area, and would like to attend any of our local Halifax meetings, please also contact me at (902) 864-8872 or gwenb@eastlink.ca.

Finally, if you live anywhere in Atlantic Canada and would like to take advantage of AAMAC's Peer Support Service, also contact me. This service arranges for newly diagnosed patients to communicate by phone, or by email with another patient who has the same type of AA/MDS/PNH, and some experience with it, and/or with a particular drug treatment.

Dr. Sean Dolan, Conference Convenor of the New Brunswick Hematology Conference held in May 2017.

Ontario Update

By Darlene Edmonds, Regional Support Liaison, Ontario

I hope everyone had a great summer and enjoyed time with family and friends. The fall is almost here so we're ready for the fall series of our patient support group meetings. I hope everyone will try to attend just one – feel free to bring family and friends to any of these meetings.

Please just don't forget to register for all patient support group meetings by calling or emailing the office.

If you have any topics or speakers that you would like us to explore, please share your ideas with the AAMAC team.

We have an exciting fall line up:

- Join our Hamilton Peer to Peer Support Group on Saturday, September 13, 2017 from 6 to 8 p.m. with a light dinner at 5:30 p.m.
- On Saturday, September 30, 2017 at 10:30 a.m. in London, Ontario, Dr. C. Hsia will join us to answer questions about blood results. There will also be Peer to Peer Support component.
- On Saturday, October 21, 2017 from 10 a.m. to noon join us in Kitchener, Ontario for Peer to Peer Support.
- On Saturday, October 28, 2017, Dr. Wells will answer your questions in Toronto, Ontario. This meeting will be held in a new location – The Walmer Centre which is just around the corner from our previous location.
- We meet at a new Oshawa location on Saturday, November 4, 2017 from 10:30 a.m. to 12:30 p.m. Pamela West will discuss "The Quality of Life when Dealing with a Chronic Disease."

Check out our website for all the meeting details and feel free to email me with any ideas at ontariosupport@aamac.ca.

Please also challenge your family and friends to walk or run for AAMAC on Sunday, October 22, 2017 in Toronto. See the article in this newsletter for more information about registering.

Alberta Update

By Sue Miles, Alberta Patient Support Liaison

Save the date for the next Patient Support meeting in Edmonton on Saturday, October 28 from 10 a.m. to noon.

The meeting takes place at the Chateau Lacombe Hotel, 10111 Bellamy Hill.

Watch for details about the speaker and topic on the website.

Quebec Patient Support and Education Update

By Claude Francoeur

View of participants and, from left to right, speakers including Dr. Robert Delage, Chief Haematologist Services, Marianne Émond, Pharmacist, Claude Francoeur, AAMAC Director for the Province of Quebec and Patrice Montreuil, Psychologist.

With good support from Cindy and Carol, a half-day education session took place in Quebec City on April 29, 2017.

Our first speaker was Dr. Robert Delage, M.D. M.Sc. FRCP, Chief of the Haematology Clinic for the Centre Hospitalier de l'Université Laval (CHUL). Dr. Delage was the president and host of the CCMDS held in Quebec City last fall. He is a super communicator, with easy to understand examples to illustrate difficult subjects. He knew most of the patients, if not all of them. His Chief Nurse was very enthusiastic about having the first education session for her patients and she supported this with her team.

Our second speaker was Mrs. Émond, a pharmacist who delivered an excellent presentation on iron overload and the chelator Déférinox (Exjade and Jadenu). When I learned about the presence of the Celgene representative, Ms. Boutet, I asked her to discuss the company's product Vidaza and she did so very well.

In discussions with the psychologist before the meeting, I mentioned that at AAMAC education sessions, we have a patient talking about his or her experience with the disease. He said that this was an excellent idea, so I ended up being the person, talking about my MDS diagnosis period and the evolution to date.

Our third speaker was Mr. Montreuil, the psychologist, and he was also excellent. Everyone was listening to him with great concentration, trying to absorb all the concepts and deeply thinking, I believe.

All speakers received many pertinent questions and we had to try to limit them to follow the time schedule. We finished slightly after noon but for many participants we could have continued much longer.

It went very well with 37 partcipants (14 with MDS, seven family members or friends of someone with MDS, 1PNH patient and spouse, 10 nurses, three speakers and the Celgene rep.

The overall evaluation from the survey sheet rated the morning as excellent and the participants seemed to be very happy with the education session.

On your mark. Get set. Let's Go!

By Janice Cook

Congratulations to everyone who took part as a "Marrow Mover" in the charity five-kilometre walk on June 25!

The $3,450 raised is rather remarkable as no portion of that came from the funds earned by the charity run itself.

Also, it deserves mention that, aside from me, the other participants are all still under treatment for their BMF. I'm so proud of them. It was an incredibly hot day for Vancouver (30 degrees), made bearable by the early start, the breeze off the ocean, and the lovely, partly shaded course along Stanley Park and English Bay.

From left to right are Vancouver participants Marilynne, Ashley, Janice and Guja.

There is still another walk to go, this time on October 22, 2017 in Toronto.

Do you want to join the AAMAC Marrow Movers Team? Toronto registrants can sign-up directly with Scotiabank Marathon at: www.torontowaterfrontmarathon.com/stwm-charities/aamac-aplastic-anemia-myelodysplasia-association-canada/

You don't have to be a runner to join. You can walk or run. Strollers are welcome!

Tax receipts will be issued for donations $25 and over. Raise $100 and your Scotiabank Marathon registration fee will be refunded by AAMAC. Raise over $25 and receive a free Marrow Movers T-shirt.

Your support will help AAMAC help people like Regan, Joe and Jordan.

- Regan was diagnosed with Aplastic Anemia on her 50th birthday. She endured a grueling year (and a bit) of treatment, ending in a life-saving bone marrow transplant. She is thankful for non-profit organizations such as AAMAC. She feels that Canada is blessed to have a such great support organizations and fantastic medical advances.
- Joe was diagnosed with MDS in 2008. He dug deep and found the inner strength to face MDS with a positive attitude and vowed that this disease would not be allowed to live "rent-free" in his head. His motto is, " How shall I live? Not, how shall I die?"
- Jordan was diagnosed with AA and PNH in 2014. He underwent a rigorous treatment regimen. Looking back today, he can honestly say that he is very fortunate for the medical advancements that saved his life. Jesse wants you to know, "there is hope."

Movie Screening

Please join us on Thursday, September 28 at 7 p.m. in Toronto for a screening of Mixed Match. This event is presented in conjunction with the Japanese Canadian Cultural Centre at 6 Garamond Court in Don Mills, Ontario.

This is a great opportunity to see an informative movie and assist AAMAC with fundraising. Funds raised will go towards assisting patients with bone marrow failure diseases.

Mixed Match is an award winning documentary about mixed race people suffering from cancer reflecting on their multiracial identities and complex genetics as they struggle to find bone marrow donors.

Tickets are $12 and a portion of proceeds will be donated to AAMAC.

Additional details will be posted at aamac.ca when available.

The Aplastic Anemia & Myelodysplasia Association of Canada and the JCCC present a fundraising screening of award-winning Japanese Canadian filmmaker Jeff Chiba Stearns' new documentary. His film explores the crisis in identifying bone marrow and cord blood donors to donate to patients of mixed ethnicity suffering from life threatening blood diseases such as leukemia. Mixed Match tells an important human story from the perspective of youth who are discovering their identities through their deadly illnesses and how their multiethnic backgrounds threaten their chances at survival. This powerful film raises critical awareness about the need for multiethnic donors worldwide.

Thursday September 28, 2017 @ 7pm

$10 JCCC members
$12 non-members
Tickets available at 416.441.2345

6 Garamond Court, Toronto, ON M3C 1Z5 www.jccc.on.ca 416.441.2345

Advocacy Update

By Haydn Liang

AAMAC has been involved in the consultations led by the Patented Medicines Prices Review Board (PMPRB) to ensure that Canadians with AA, MDS, and PNH can have adequate access to treatments they need.

The PMPRB was created 30 years ago to help regulate drug prices in Canada and encourage research and innovation. The Board is responsible for setting the maximum price at which a patented drug can be sold based on

- the price of the drug in Canada,
- the price of other drugs in the same therapeutic class in Canada,
- the price of the drug and other drugs in the same therapeutic class in other countries, and
- changes in the rate of inflation.

Currently, the PMPRB is holding consultations to update the guidelines which it uses to set price ceilings for new medications. Many of our patients with AA, MDS, and/or PNH rely on innovative patented medications. And to ensure that the voices of Canadians living with AA, MDS, and PNH are well represented, AAMAC has been and will continue to be involved throughout the consultation stages.

Ontario Increasing Access to Transplants

Adapted and reprinted from ontario.ca news release.

In July, Ontario announced it is increasing access to stem cell transplants for people who have complex blood cancers, with new state-of-the-art hospital units in Toronto and London. Dr. Eric Hoskins, Minister of Health and Long-Term Care, was at the Princess Margaret Cancer Centre in Toronto today to make the announcement.

The new and modern inpatient units will address an increasing demand for stem cell transplants, and will be located in two major hospitals:

- Princess Margaret Cancer Centre will have 15 new inpatient beds and a new outpatient clinic that will support up to eight new stem cell therapy physicians.
- London Health Sciences Centre will have seven new inpatient beds, a renovated and larger

outpatient treatment clinic, and a new outpatient and chemotherapy pharmacy.

When complete, the provincial government says that patients in Ontario that need stem cell transplants will benefit from 22 new beds, which will allow for a total of 440 stem cell transplants per year.

Ontario is also releasing the year-end report from the Minister's Stem Cell Consultation Group, which includes progress made in expanding capacity and access for stem cell transplants in Ontario. The announcement was informed by the group's advice on improving stem cell delivery and the patient experience.

Ontario is increasing access to care, reducing wait times and improving the patient experience through its Patients First Action Plan for Health Care and OHIP+: Children and Youth Pharmacare.

A stem cell transplant is a procedure that replaces abnormal cells in patients whose normal cells have been affected by lymphoma, leukemia, myeloma and other cancers and disorders affecting the blood.

There are three types of stem cell transplants: those where the cells come from the patient (autologous), those where the cells are taken from a related donor (allogeneic related) and those provided by an unrelated donor (allogenic unrelated).

Six hospitals provide stem cell transplant services in Ontario: Princess Margaret Cancer Centre, Hamilton Health Sciences Centre, Kingston General Hospital, Health Sciences North, London Health Sciences Centre, and the Ottawa Hospital.

The Stem Cell Transplant Consultation Group includes clinical experts, hospital leaders and patient and family representatives. They provide advice to improve capacity and patient access for stem cell transplants.

Ontario is providing a one-time funding to both hospitals to speed up the construction of the new units.

“With this new funding, we are helping hospitals provide life-saving stem cell treatment closer to home. The excellent work and recommendations of the Stem Cell Treatment Consultation Group has enabled the construction of these state-of-the-art facilities in Toronto and London. The government’s investment in the two new units will reduce wait times and improve care for Ontarians who need stem cell transplants,” says Michael Sherar, President and CEO of Cancer Care Ontario. “This investment by the Ontario government to build additional capacity for stem cell transplants in our province is a critical component of our work to ensure that patients with blood cancer have timely access to high-quality care as close to home as possible.”

The announcement “is critical to the future of cancer care and our ability to serve the needs of leukemia patients in the future. Coupled with the government’s investment at Sunnybrook Health Sciences, this will allow Princess Margaret Cancer Centre and Sunnybrook to serve all leukemia patients who need an allogeneic bone marrow transplant. It will also ensure that the Greater Toronto Area has sufficient capacity to make bone marrow transplants available close to home,” said Peter Pisters, President and CEO, University Health Network (which includes Princess Margaret).

The announcement “will enable us to fulfill our vision of expanding current services to become a comprehensive stem cell transplant centre. This funding will allow our staff and physicians to better serve the people of London and region by providing specialized stem cell transplant inpatient and day treatment facilities, dedicated hematology outpatient clinics, as well as support services in plasmapheresis, laboratory services and pharmacy services,” says Murray Glendining, President and CEO of the London Health Science Centre.

CBS Launches New Tool to Engage Young Blood Donors

Adapted and reprinted from blood.ca news release.

Canadian Blood Services, together with EY, announced a world’s first among national blood operators by introducing a chat bot to engage donors on Facebook Messenger. This new tool is an innovative effort to engage younger audiences in a lifetime of blood donation and to promote the constant need for blood.

“The chat bot is a fun and interactive tool that will attract new, young, and lifelong donors, at a time when the blood supply needs a boost to prepare for summer,” said Mark Donnison, vice-president, donor relations.

The chat bot will help users on Facebook Messenger learn more about the donation process and the people who are helped by donations. It will also encourage people to book an appointment online or through the National Contact Centre.

“We are very excited and proud to take this lead in digital engagement,” said Ralph Michaelis, chief information officer. “Developed in partnership with the digital team at EY, the chat bot is one more example of our commitment to embrace new and innovative digital technologies to reach and engage donors, whether they are new or returning.”

Donors can meet the chat bot today by messaging Canadian Blood Services’ Facebook page.

“EY is honored to collaborate with Canadian Blood Services in support of its lifesaving mission, leveraging the power of messaging platforms and conversational interfaces to reach and engage donors in new and innovative ways,” said Keith Strier, Americas AI and digital offerings leader, EY.