

Aplastic Anemia & Myelodysplasia Association of Canada NEWSLETTER

Message from the Chair

AAMAC has had a busy and productive start this winter and with spring now here we are excitedly planning the annual Patient Education Day which will be held in Ottawa on October 13! Our annual patient education day is shaping up to be an excellent and informative schedule for patients, practitioners and caregivers. Registration for this event is enclosed in the newsletter. Please don't hesitate to contact us if you have any questions.

I would like to take this opportunity to introduce AAMAC's newest board member, Marilynne Convey. Marilynne brings to the Board a wealth of experience in health care with her background as a nurse leading a team of over 100 people. Based out of Victoria, Marilynne will be assisting AAMAC in the continued development of our Nurse Education Program. Additionally, Marilynne is passionate about patient advocacy and we are thrilled to have her as part of the team!

Additionally, AAMAC has hired Fiona Lewis to join our staff team as the BC Patient Support Coordinator. Fiona is a dynamic and experienced planner and project manager and is already busy at work planning for her first patient support meeting in Vancouver on June 9, 2018 at the Champlain Heights branch of the Vancouver Public Library.

The annual Thanks Mom Campaign and donor drive took place on May 5 and 6 at the Quilford Town Centre in Surrey, BC. "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, 2012 and 2017 and is back again for 2018! The 100% volunteer grassroots Thanks Mom Committee partners with Canadian Blood Services (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.

We are excited to have created a new planned giving brochure which is now available on request! Planned giving allows you to plan charitable giving into your estate and AAMAC is pleased to discuss with you how your charitable estate donations could support the long-term work of our organization. Please contact the AAMAC office at info@aamac.ca if you would like to learn more.

Thank you for your support of AAMAC and we hope to see you soon.

Sincerely,
Ashley Oakes
Chair of the Board
AAMAC



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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Claude Francoeur 1940-2018

It was with regret that the AAMAC Board of Directors and staff learned of the death of Claude Francoeur on March 20, 2018 of complications from MDS.

Claude became a Director on AAMAC's Board in October 2014. With his wealth of experience with Bombardier and his membership on the Board of Quebec Provincial Engineers, Claude was instrumental in introducing AAMAC's Board to several best practices.

He was also AAMAC's Coordinator for the Province of Quebec, which resulted in several AA/MDS/PNH Patient and Caregiver Education Days in Montreal and Quebec City.

The funeral, in his home town of St-Felix-de-Kingsey, Quebec, was attended by Gwen Barry, on behalf of AAMAC's Board.

He will very much be missed.

Our sympathies go out to his wife Toshimi Tsuji, his children Edith, Patrick, Motohiko Tsuji, brothers and sisters Aurele, Jacques, Huguette, and other family members.

Atlantic Region Update

By Cindy Anthony

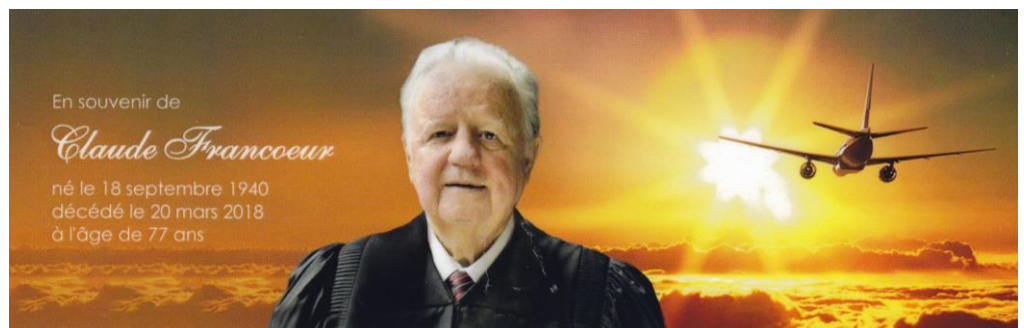
On Saturday, May 5, a patient education meeting was held in Halifax with two speakers from the QE II Health Sciences Centre.

Dr. Mary Margaret Keating gave an interesting talk that gave an overview of MDS, Aplastic Anemia and PNH including new treatments that are currently in clinical trial stages. The participants gained a great deal of knowledge from the presentation and Dr. Keating answered questions after her talk.

Dr. Nick Forward, from the same hospital, delivered a very interesting talk about iron overload which is very important to our patients, many of whom rely on ongoing blood transfusions. Dr. Forward also answered a number of questions from patients and is also in our group photo on the following page.

The Atlantic patient group is a very active, caring group and was pleased to welcome a number of new patients at this meeting.

We were sorry that Gwen Barry was unable to attend due to a cold, but thank Gwen and other volunteers who helped to make this meeting a success.





Members attend the Halifax Patient Education Meeting.

Hamilton: For our last Spring meeting in Hamilton, the sun was out and we had a wonderful turnout. We had 11 people in attendance. Nurse practitioner Tammy de Gelder helped facilitate our conversation on MDS. We also heard from Erin Jamula, MSc, a research coordinator working with Dr. Brian Leber. Erin shared a bit about some of the studies that are happening at Juravinski Hospital.

I want to thank everyone who came out to the patient support group meetings during the Spring. I hope many of you will join us in Ottawa for the Patient Education Day on Saturday, October 13, 2018. This day will be filled with speakers and panel discussions and is a great opportunity to hear from experts in various fields. It's very worthwhile to attend if you can. Watch our website for more details.

I wish everyone a very happy summer. Enjoy the sunshine, but use your sunscreen!

Ontario Update

By Darlene Edmonds, Ontario Support Coordinator

Spring has finally arrived here in Southern Ontario and I know how much happiness this must bring to all of you. I know I'm pretty pumped now that the good weather has arrived.

Please feel free to drop me a line for suggestions on Patient Support Group Meetings and topics and let us know how we're doing. I'd love to hear from you at ontariosupport@aamac.ca.

2018 has been a busy time around the province. Overall we had some good turnouts, with the exception for the Oshawa meeting.

Kitchener: We had three people in attendance and had two great speakers... nurse coordinators with a focus on the basics of MDS.

Toronto: The Marrow Failure & Myelodysplasia Patient and Family Conference at the Hospital for Sick Children was well attended. We had approximately 10 children take part and a great number of attendees. The information was of such value and it was great to hear the knowledgeable

speakers, but the best part was listening to young people speak about the challenges, hurdles, and coping techniques for living life while living with MDS.

Oshawa: This was our second attempt at hosting a meeting in the Oshawa area, this time with speaker Pamela West, a nurse practitioner in oncology and supportive care. Unfortunately, no one attended. So for now, we will not be hosting any meetings in this area. However, Heart Place Cancer Support Centre will be hosting evening patient support meetings every second Thursday and fourth Wednesday of the month. More information can be found at www.heartplace.org. The facilitator of these meetings is Pamela West, the speaker we had arranged. Our AAMAC information will be available at these meetings.

We invite you to visit aamac.ca and check out the power point presentation that was created by Pamela West. It's called Quality of Life When Dealing with a Chronic Disease.

London: We had a peer-to-peer support group and touched on some quality of life indicators, had a new member join us, and everyone enjoyed the time to share their experiences.

Alberta Update

Patients, family and friends are invited to join our Edmonton Patient Support Meeting on Saturday, November 17, 2018 from 1 to 3 p.m.

The meeting will take place at the Edmonton Clinic Health Academy at the University of Alberta.

Please register for this free meeting by contacting us at info@aamac.ca or 1(888) 840-0039.

BC Update

Please join us on Saturday, June 9 from 10:30 a.m. to noon for our next Patient Support Group meeting.

The meeting takes place at the Vancouver Public Library, Champlain Heights Branch, 7110 Kerr St., Vancouver (behind the shopping centre).

The meeting includes registered nurse Michelle Forman who will speak about “Living well with your disease... strategies to manage your disease and side effects.”

After the talk, there will be time for information sharing. Refreshments and AAMAC resources will also be available.

Please register by contacting info@aamac.ca or 1 (888) 840-0039.

A Life-Changing Wish Comes True

By Make-A-Wish®

Garcia is a five-year-old boy from Southwestern Ontario who lives with aplastic anemia; but that hasn't stopped his social and adventurous spirit.

Due to his illness, Garcia suffered a

spleen infection, underwent chemotherapy, had more than 50 blood transfusions, a bone marrow transplant and was isolated for 18 months to avoid being hospitalized. He spent his fourth birthday at SickKids as a result of complications after his transplant, but according to his mom, he never complained, made friends with his caregivers and asked many questions to understand his condition better.

Garcia's medical condition qualified him to have his wish granted by Make-A-Wish®. Despite such an ordeal, Garcia is excited about everyday life, such as grocery shopping, where he enjoys being around people and greets them all cheerfully. He especially looks forward to spending quality time with his family and taking a bath – something he was not able to do because of his central line.

“Being with family makes everything fun!” – Garcia

Garcia's wish combined all these things, making up for his family New Year's vacation they had missed because he had been sick: *A pirate adventure.*

He and his family stayed at Pirate

Island after flying with WestJet to Turks and Caicos, where their only worry was deciding between the beach or the pool. The flight crew welcomed Garcia with a special announcement and made sure he was well stocked with his favourite treats.

With the help of Make-A-Wish® Southwestern Ontario, Garcia experienced playgrounds, water slides, swimming and spending time with his loved ones.

“It was a great way to celebrate the miracle of Garcia's new life and spend some magical, worry-free days together.” – Garcia's parents

When a wish is granted, it does much more than bring joy to a child and their family. For kids like Garcia, who live with critical illnesses, a wish-come-true provides them with the strength to battle through those difficult days and gives them hope for healthier, happier days ahead.

Refer a child with aplastic anemia for a transformational wish today. Visit makeawish.ca to learn more.

Prednisone Arms

By Pam Wishart

One of things we hear all the time from patients is how much they enjoy the chance to meet and talk to others with the same condition they have, be it MDS, AA or PNH.

Given the size of our country and the rarity of our diseases it just isn't easy to meet others face-to-face. So, I'm wondering, how about one or two patient stories in the Newsletter?

We tend to think stories have to be uplifting but, the truth is, not all our stories are. In fact, if you think about it, it's not at all uplifting to have one of these diseases!

So how do we manage? That is what is





moved there in 2008 when I looked her up again. Since then we've met for lunch several times a year.

I don't know why Anne's hematologist prescribed prednisone several years ago but I do know that shortly after her transfusion needs decreased until she no longer needed them for about three years. She now needs them again but is still taking the prednisone.

interesting to us, how do we manage the fatigue from low red cells, the risk of bleeding from low platelets and/or the risk of infection from low white cells? How do PNH patients manage their risks and adjust their lives?

And what about the decision to have a transplant? Sometimes that's an easy decision because the choice is the risk of the transplant and perhaps a cure or a rapid progression of the disease. Sometimes the decision isn't nearly as clear-cut.

I have an "MDS" friend in Germany who right now is agonising about the choice. One expert says "You need it", another "You're doing well on regular transfusions and chelation, so why take the risk?" This person is fifty something, so, many years ahead if cured but how do you make the decision? Talking to others who have been there or reading their stories certainly helps.

How about sharing your stories, letting our readers know how you manage and we'll publish one or two of them a quarter in this newsletter? We'd really love to hear from you.

And to start you off, here's a small part of two MDS patients' stories which happen to be similar in one respect: prednisone skin! And, yes, other drugs and age can have a similar effect.

I was diagnosed with MDS in 2000 and Anne in 2001. Anne also has chronic myelomonocytic leukemia (CMML). We first met at an AAMAC event in Victoria several years before I

My haematologist in Montreal tried me on prednisone when he realised how difficult it was going to be supporting me with transfusions when they couldn't find red blood cells my body would accept. It has definitely helped but is a drug with many side-effects and certainly not the first choice for MDS!

One side effect is thinning of the skin, especially noticeable on the forearms and lower legs. The slightest graze results in red/purple blotches under the skin if it doesn't tear the skin. And if it does tear the skin, then bleeding and a bandage – another problem. Forget ripping the bandage off

quickly, no, it has to be removed very carefully, millimetre by millimetre. Too quickly and you repeat the tearing/blotching. The blotches and scabs are replaced by blue/brown discolorations as they heal. These don't go away.

Still, a small price to pay for a drug which has helped to keep both of us alive. Anne will be 83 and I 75 this summer. When I was diagnosed at the age of 56 my prognosis was two to eight years so I'm not complaining and I bet Anne isn't either given she was diagnosed in 2001. Unfortunately, Anne is again transfusion-dependent and my "usual" haemoglobin concentration has decreased. Still, prednisone helped, and is still helping, us both for many years.

In 2000, the International Prognostic Scoring System (IPSS) had, in the upper right corner the median time for progression to Acute Myeloid Leukemia (AML). It was 9+ years. From time to time I would look at it longingly although I wasn't in the group to whom it applied. But, guess what? It did apply to me and there will



BC Chapter Coordinator Fiona X (left) and long-time AAMAC volunteer Eileen Sue (right) were among the volunteers at the Mom Give Life event in BC to spread awareness about the vital importance of Canadian Blood Services and the need for more stem cell donor registrants on OneMatch Stem Cell and Marrow Network (onematch.ca).

be many of you like me to whom it applies (although it's no longer there in the revised IPSS-R). Our understanding of MDS and the many subgroups of the disease has increased exponentially in the past decade. Although there haven't been many new treatments, surely that is going to change in the near future.

News of Note

A Way to Say "Thank You"

Have you, a family member or a friend benefitted from a blood donation, blood products or a stem cell transplant? Have you ever wanted a way to say thank you? Are you comfortable telling your story at a blood donor clinic or at a Canadian Blood Services (CBS) event? CBS is often looking for people who have a story to share with those who donate or to recruit new donors, so, if you answered yes to all three questions, please contact CBS at 1 (888) 2-DONATE – that's 1 (888) 236-6283.

SAFE Project Survey

We have been asked to inform our readers of a study funded by Canadian Blood Services about attitudes towards blood donation and especially policies about obtaining blood donations from men-who-have-sex-with-men. The researchers are particularly interested in gaining insight on how people would react to possible changes in policy that might loosen restrictions on receiving blood from men who have sex with men. As a recipient or potential donor you may be interested in participating.

If you click on the link below or paste it into your browser, you will see an "Informed Consent Form" with a description of the survey, guarantees of privacy, etc. After reading the information you have a choice of agreeing or not agreeing to participate. If you agree you then start the survey.

The survey can be found at the following link:
www.surveymonkey.com/r/563MHZD

New office

AAMAC recently moved into a new office space not far from our previous Richmond Hill location. The new office in nearby King City, Ontario has more room for volunteers to come and help.

Pictured in the office from top to bottom are AAMAC's administrative assistant Carol Fazari and office

volunteer Robyn Hodes.

The office also includes a new space for AAMAC's Tree of Life to be displayed. "Leaves" on the hand-made tree in honour or memory of a special person can be purchased. Funds raised support the association's work.

To find out more about the Tree of Life, visit www.aamac.ca.

