

Aplastic Anemia & Myelodysplasia Association of Canada

NEWSLETTER

Message from the Chair

Dear friends and supporters,

Fall is always our favourite season here at AAMAC. Yes, the fall colours are amazing (though as I write this, Toronto just got its first snow). But more excitingly, we get to meet everyone at our annual Patient Education Day.

For those who are new, we hold our Patient Education Day every Fall in a location rotating from coast to coast so that we can be as inclusive as possible. This free event provides a forum for patients and caregivers from all walks of life to meet and swap notes on our experiences, and meet medical experts specializing in each of our three conditions.

This year, we celebrated our 30th anniversary with a Patient Education Day held in Calgary on October 19. For over 70 patients and caregivers, we hosted talks by hematology specialists Dr. Michelle Geddes and Dr. Loree Larratt, and Dr. Lynn Savoie; tips on living well with a serious chronic condition by psychologist Dr. Sara Beattie; and of course, candid stories from our patients on a panel discussion about their experiences.

Do you have suggestions or comments about our next event? Send us a message via Facebook, Instagram, Twitter, write us an email or call us at 1-888-840-0039.

Our annual general meeting that followed also carried with it a single sombre note. Being an organization that's made up mostly of patients ourselves, I regret to mention that our board member, Sanjeev Parmar, passed away just before the Patient Education Day. We are grateful to Sanjeev for his dedication to helping other people living with rare blood conditions as he was.

Last but not least, I'd like to remind everyone that Giving Tuesday this year is on December 3. For those not familiar, Giving Tuesday is a global day of giving fueled by the power of social media and collaboration – celebrated on the Tuesday following the US Thanksgiving-Black Friday-Cyber Monday weekend. Watch out for an announcement from us and we hope you will give generously in support of everyone living with AA, MDS, and PNH.

As always, thank you for your continued support and we hope to see you at our next patient support event near you.

With warmest regards,

Haydn Liang, PhD
Chair of the Board
AAMAC



Aplastic Anemia & Myelodysplasia
ASSOCIATION OF CANADA

ASSOCIATION CANADIENNE
de l'anémie aplasique et de la myélocytose

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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Ontario Update

By Kimberly Brunelle, Ontario Patient Support Coordinator

Since beginning my role as the Ontario Patient Support Coordinator in April, I have been busy planning our fall meeting and most recently had the opportunity to attend the Patient Education Day in Calgary where I was so happy to be able to meet so many inspiring patients and their families.

It was great to meet AAMAC staff and board members in person. I was so pleased that I was able to attend. I really learned a lot!

I hosted a Patient Support Meeting in Hamilton this fall with Dr. Dina Khalaf from the Juravinski Cancer Centre speaking about MDS. It was wonderful to see so many patients and their family members come out for the meeting. There was a lot of great conversation and many new connections made.

I'm really excited to share that in coordination with my colleague Fiona Lewis in BC, we will be hosting one-hour educational webinars each month from January to March.

Watch the website for details on dates and how you can join! If you have any suggestions for webinar topics, please share them with me. Email me your ideas at ontariosupport@aamac.ca.

Our next in-person support meetings will be held in the spring. I'm working on two meetings – one in London and another in Kitchener.

Stay tuned to the website for dates and registration information.

Atlantic Region Update

By Gwen Barry

On September 14, the Halifax Support Group met for brunch at the Bedford Basin Market and Café, with 10 patients and caregivers in attendance, including one new patient.

From October 19 to 20, 2019 the Atlantic Region was represented by Jennifer Garvey and Gwen Barry at AAMAC's Calgary Patient Education Day and the Annual Board of Directors' Meeting. It was heartening to see so many patients and caregivers in attendance – with about 70 people registered.

We are planning a repeat of last year's highly successful Christmas Pot Luck Lunch at the home of Jennifer Moss and Kirk White in Halifax. This year it will be held on Saturday, December 7, at 11 a.m., again at Jennifer and Kirk's home. All aplastic anemia, MDS and PNH patients and their caregivers, spouses and children are welcome to attend. For further information, please contact me at gwenb@eastlink.ca or (902) 864-8872.

Several members of the Halifax Support Group attended the Annual Bone Marrow Transplant Survivor's Dinner at Dalhousie University in Halifax on October 25. This annual event was spearheaded many years ago by the late Dr. Stephen Couban (Hematologist).

We were pleased to learn that others in the the BMT Transplant Unit of the Victoria General Hospital, and the Hematology Clinic have decided to continue organizing this event.

Atlantic Region patients and caregivers will be pleased to know that the Annual Patient Education Day for 2020 will be held in Halifax on Saturday, October 17 at the Halifax Hotel attached to Scotia Square. It will

be for patients in the four Atlantic provinces and beyond. Travel bursaries will be available. More information will be available next summer, so stay tuned.

BC/Alberta Update

By Fiona Lewis

We are looking forward to our next patient support group meeting in Vancouver on November 2. Mona Walia (RN) will be giving part 2 of her talk on Understanding Blood Counts, a very popular topic.

For 2020, we hope to host a meeting in Surrey in conjunction with the new hematology unit at the Outpatient Care and Surgery Centre there. We are gauging interest in a meeting in Calgary and also hope to bring the Edmonton group together for another meeting in the spring.

We anticipate launching a number of national webinars this winter. We hope these will offer an alternative to patients who are unable to get to our in-person meetings. Please keep an eye for an announcement of dates and speakers for these webinars.

Remembering Sanjeev Singh Parmar

Sanjeev Singh Parmar
December 16, 1979 – September 20, 2019

It was with regret that the AAMAC Board of Directors and staff learned of the death of Sanjeev Parmar, one of our dedicated board members in the Calgary community in September.

Sanjeev became a Director on AAMAC's board in August 2016. He was AAMAC's representative on the Network of Rare Blood Disorders Organization (NRBDO). His kindness and mischievous spirit will be sorely missed.

Sanjeev was born with a rare genetic condition, Fanconi Anemia, and later diagnosed with an aggressive form of cancer in February of 2018.

He was dedicated to helping other people dealing with Fanconi Anemia and other rare blood conditions.

He has served on the boards of AAMAC and Fanconi Canada, and was also an executive committee member of the Leukemia & Lymphoma Society of Canada – “Light the Night” campaign.

Our sympathies go out to his wife Caroline, his daughter Avani and all other family members and friends.

A copy of his obituary can be found at vancouver.sunandprovince.remembering.ca/obituary/sanjeev-parmar-1077293083.

There is a link on the obituary page to plant a tree in Sanjeev's memory.



Sanjeev Singh Parmar

Patient Education Day a Success

“What do you tell your friends when they ask about your illness?” was just one of the questions posed to our patient panel at Patient Education Day in Calgary. Over 70 patients and caregivers attended AAMAC's annual event on October 19. The patient panel was a highlight as patients candidly shared their stories of both struggling and thriving with their illnesses. The topics of mortality, treatment decisions, drug trials and caregiving were explored with both honesty and humour.

Dr. Michelle Geddes started the day by speaking about treatment and new developments for MDS. She reported on some of the quality of life research that is resulting from the National MDS Patient Registry, which now includes over 1,000 patients.

Dr. Loree Larratt followed Dr. Geddes with her talk on new developments in the treatment of Aplastic Anemia and Paroxysmal Nocturnal Hemoglobinuria. She spoke about the amount of time it takes to get a PNH diagnosis and the likelihood that there are hundreds of undiagnosed PNH patients in Canada.

The afternoon began with a talk on Bone Marrow Transplant by Dr. Lynn Savoie. Her talk highlighted the changes in transplant protocols based on successes and failures experienced over the past few decades.

Psychologist Dr. Sara Beattie wrapped up the day sharing research results on living well with a chronic disease. She provided reminders on the importance of listening to your body, pacing yourself, and accessing supportive services.

Feedback from attendees indicated that everyone enjoyed the day and took away useful information. We

hope you will consider joining us at next year's event in Halifax.

Celgene TEAM Award Presentation



Pam Wishart (left) pictured receiving the TEAM Award with Jill Kravinchuk, Senior Manager, Government & External Affairs, Celgene (right)

Established by Celgene Corporation in 2009, The Excellence in Advocacy Medal's purpose is to recognize an individual or group that has contributed significantly to advocacy efforts, improved care, treatment options or improved access to care and treatment options on behalf of bone marrow failure patients.

The TEAM award is a plaque given by Celgene, usually at an AAMAC event, and includes a \$5,000 donation to AAMAC.

In October at AAMAC's Patient Education Day in Calgary, Pam Wishart became the recipient of the 2019 TEAM Award.

Pam is the longest serving board member (2004) of AAMAC. She has had MDS for almost two decades and began her support role of others with MDS as a member of a U.S. email-based listserv AA-MDS-Talk.

Since then she has a long history of connecting and supporting patients through internet, phone chats and face to face visits.

Many years ago she attended an AAMDSIF conference and 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.

After moving to B.C., Pam remained on the Board and over the years has served as Secretary, President, Past President, Chapter Coordinator and Grants Coordinator.

She has consistently carried out her roles with diligence, objectivity and thoroughness.

Her scientific background and her interest in bone marrow diseases leads her to review multiple journals and research which she generously shares with the rest of the Board. Often this finds its way to our newsletter which means a wider audience including patients.

Pam has worked on governance issues and recently the new Terms of Reference for our Medical and Scientific Advisory Committee (MSAC) of AAMAC.

She easily liaises with MSAC and other medical practitioners to improve our understanding of AA, MDS and PNH. She is 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. Pam brings a patient focus to the board which is often a lifeline to patients with bone marrow diseases.

Congratulations Pam!

Liz Lemire Scholarship Recipient

By Reanne Booker

The Elizabeth ("Liz") Lemire Memorial Scholarship was established in 2009 as an enduring way to honour the legacy of Liz Lemire. Liz, a wife, mother, and teacher, was diagnosed with Aplastic Anemia in 2002; she passed away in 2008.

Following her diagnosis, Liz became very involved in educating others about bone marrow failure disorders.

She volunteered with AAMAC and founded the Calgary AAMAC patient support group.

A testament to the profound impact that Liz had on so many, numerous donations were made on her behalf to support initiatives to help improve the lives of those affected by bone marrow failure disorders.

One such initiative was to support nursing education to improve awareness of bone marrow failure disorders, ultimately allowing nurses to provide optimal care for patients and their loved ones.

The Elizabeth Lemire Memorial Scholarship is awarded annually to an Alberta nurse who "reflect[s] Liz' dedication to nursing excellence and patient advocacy" with a preference given to nurses whose clinical and/or research focus is hematology.

(Award information can be found on the Alberta Registered Nurses Educational Trust website, page 2, arnet.ca/wp-content/uploads/2019/04/ARNET-Named-Scholarships-2019.pdf.)

I have been an oncology nurse for more than 18 years; I began my career at the Cross Cancer Institute in Edmonton. In 2005, I moved to

Calgary to join the Alberta Blood and Marrow Transplant Program at the Tom Baker Cancer Centre.

I am currently working at the Tom Baker Cancer Centre as the medical lead for an innovative, multi-disciplinary clinic that addresses patients' sexual health concerns after a cancer diagnosis. I also work with the Palliative and End-of-Life Care Services program in Calgary.

In 2004 and 2005, I was a very appreciative recipient of the Canadian Nurses Foundation AAMAC Nursing Grant in support of my Master's degree studies.

I subsequently joined the AAMAC Board in 2006 and remained on the Board until 2012.

I am now working on my PhD at the University of Victoria; the focus of my research is on the integration of palliative and supportive care in hematopoietic stem cell transplantation.

Words cannot express how grateful I am to be the 2019 recipient of this scholarship. In addition to providing much needed financial support for my studies, receiving this award is profoundly meaningful to me.

I was one of the nurses who was fortunate enough to meet Liz as she was undergoing treatment for leukemia. I can still recall her positive attitude, unfailing wit, and steadfast grace. She was an inspiration then and she continues to be an inspiration now.

Thank you to AAMAC and to the family and friends of Liz Lemire for this incredible honour and support.



Reanne Booker

Aplastic Anemia and Myelodysplasia Nursing Award Recipient 2019-2020

By Danielle Moch



Danielle Moch, University of Alberta

I always knew growing up that I wanted to help people. This stemmed from living in a house hold with a chronically ill father. Shortly after he passed away, I started training to be a medical responder to other people through very challenging and complex situations.

I was accepted into the Bachelor of Science in Nursing program from the University of Alberta in 2010. I

originally thought that I wanted to dedicate my life to emergency and critical care nursing but in 2014, one 12-hour shift completely changed my life. During this shift, I cared for the most wonderful palliative oncology patient and his family in the emergency department.

I am unable to describe how powerful and incredible this day was. I knew after leaving that 12-hour shift that I was meant to be an oncology nurse.

Since 2015, I have been employed in multiple roles at the Central Alberta Cancer Centre, most recently as a Cancer Patient Navigator.

One of my favorite things about cancer care, is that it is constantly changing. The workload is heavy, but the attitude in the cancer world is uplifting and welcoming.

Being able to communicate with my patients and develop relationships with them and their families and truly practice patient-centred care, is a gift.

Since September 2018, I have been attending the Masters of Nursing in Leadership Program at the University of Alberta. I enjoy furthering my education, and want to develop skills in evidence-based research to promote quality improvement and health outcomes in cancer care.

This program is a stepping stone for achieving my professional goals, enhancing my professional knowledge, leadership, and communication skills.

I am very thankful to be a recipient of the AAMAC Award and to be called a 'CNF Scholar.' The support that I have received to complete my master's program, has been overwhelming and I am forever grateful.

*Invest in nurses.
See the difference in healthcare.*



AAMAC at Canadian Association of Nurses in Oncology

By Marilynne Convey

This year's Canadian Association of Nurses in Oncology (CANO) conference was held in Winnipeg from October 20 to 23 and once again AAMAC was an exhibitor.

Four hundred and fifteen nurses from across Canada attended and participated in this event. Each day there were keynote speakers and throughout each day there were multiple smaller presentations by the nurses. While the majority of presentations were focused on oncology there were several that spoke about hematology diseases.

There were four AAMAC Nurse Educators attending and all gave multiple presentations. Also the 2018 (Sam Scime) and 2019 (Dani Moch) recipients of the AAMAC award through the Canadian Nurses Foundation attended and presented.

One of the highlights of this conference was the Winter-peg Gala which was a great celebration of food, friendship and dance.

Two of AAMAC's Nurse Educators will be on the incoming CANO board. Reanne Booker a former AAMAC board member will be president and Sam Scime will be the incoming Director-at-Large, Professional Practice. Barb Hues, another AAMAC Nurse Educator, was on the Scientific Program Committee.

Attending CANO is an excellent opportunity for AAMAC to advance our mission and vision through connecting with nurses who are able to support patients and their families dealing with rare bone marrow failure diseases.

CANO 2020 will be held in Victoria, British Columbia, October 23 to 26.



Pictured above are AAMAC nurse educators and AAMAC Board member Marilynne Convey.



Pictured above are Marilynne Convey, Sam Scime and Lauren Cosolo.

Resources available on our website



AAMAC has various resources on our website, available to download or order. Go to aamac.ca/resources/ and click on the Brochures tab. All the resource books AAMAC has available are listed. You can order directly through the website.

As well as resource books, AAMAC has developed a Prompt List which is a helpful list of questions, which you can use at any point in your AA/MDS/PNH journey.

We appreciate that a rare cancer or bone marrow failure diagnosis can be shocking and understanding the diagnosis can feel a bit like learning a new language.

The Prompt List is intended to be a helpful list of questions. Not every question will apply to you, and you may not want to know the answers to all of them. They are meant to be food for thought when making a list of questions to ask your doctor, either at the initial visit or further along in treatment.

A list for each of AA, MDS and PNH is available to download at aamac.ca/resources/ under the Brochures tab.

Also available are Emergency Room Cards at aamac.ca/emergency-room-cards/.

Please complete the information and you will receive an email with all the details to show in the emergency room (or elsewhere) setting out your disease information.

If you would like a printed copy of the Prompt List or physical emergency card, please email info@aamac.ca or call 1 (888) 840-0039.

