

Aplastic Anemia & Myelodysplasia Association of Canada

NEWSLETTER

Message from the Chair

Autumn is one of my favourite seasons. The morning air is crisp like newly washed laundry, and those warm evenings inside replaces the summer patios. If only the weather was a tad more predictable.

Luckily, on a sunny Saturday of October 13, we held our annual Patient Education Day in our nation's capital. Thank you, everyone, for taking the time out of your busy schedules to join us at the Ottawa Conference Centre. It was wonderful to catch up with our long-time supporters and welcome a few new friends.

We are grateful to have the support of the medical community: Our experts of the day from the University of Ottawa, Jill Fulcher, MD PhD, and Mitchell Sabloff, MD; the Canadian Blood Services' Sophie Chargé, PhD; our nurse education champion from Sunnybrook Health Sciences Centre, Toronto, Lauren Cosolo, RN, and our clinical social work/therapist speaker from Ottawa, Aimee Anderson, MSW, RSW. We are also grateful for the support of our donors such as yourselves, as well as our sponsors: Achillion, Alexion, Apellis, Celgene, Novartis, and Otsuka. We wouldn't be able to continue our patient-support events without your generosity. For those who couldn't make it to Ottawa, some of the key presentations will be posted online on our website. For any aspiring hematology/oncology nurses, the webcast presented by Lauren Cosolo will also be made available on our website.

Speaking of which, I'm excited to let you know that AAMAC is about to get a brand-new website! The board and our executive director, Cindy Anthony, have been hard at work to make this happen. Stay tuned for our new site launch on November 27, the same day as Giving Tuesday – a global movement for giving and volunteering (but more about that later in this newsletter).

Last but not least, I'd also like to extend a warm welcome from our board of directors to Christine Pappas. Based in Ottawa, Christine brings with her a wealth of knowledge about communications which will no doubt help us raise the awareness of the challenges of living with AA, MDS, and PNH.

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 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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Atlantic Region

By Gwen Barry, Atlantic Region Coordinator

The Halifax Support Group of AAMAC will be having a social Christmas gathering in Halifax from 2 to 4 p.m. on Sunday, November 25, 2018.

All AA/MDS/PNH patients and their caregivers/support persons are welcome to attend. Come and meet others with these disorders. Share your good news and your woes, or just come to forget all about it! For further information, please contact me by phone at (902) 864-8872 or by email at gwenb@eastlink.ca.

BC / Alberta

By Fiona Lewis, BC/Alberta Patient Support Liaison

I hosted a Patient Support Group meeting in Vancouver this fall with Dr. Petraszko from Canadian Blood Services (CBS) speaking about the organization's Rare Blood Program. We learned that CBS is now making a more coordinated effort to recruit and retain donors with rare blood types. These donors are contacted and asked to come in to donate when the inventory of their blood type runs low.

Dr. Petraszko also spoke about the many types of rare blood and the complexities of storing and shipping blood products so that the right product is at the right place when needed.

Last month, with the changing of the seasons bringing Ontario's fall colours into full view, I was pleased to be able to attend the Patient Education Day in Ottawa. I had the opportunity to learn from both patients and health care professionals about bone marrow

failure diseases. It was great to meet AAMAC staff and board members in person! I felt incredibly lucky to be there.

I have recently taken on the task of coordinating patient support group meetings in Alberta, as well as in BC. I am pleased to be hosting meetings in Edmonton, Victoria, and North Vancouver over the next three months. Plans are also in the works for a meeting in Calgary in March. Guests will be speaking about bone marrow failure diseases specifically and also about management of chronic illness more generally. I am confident participants will find something useful to take away from each speaker. Please check the AAMAC website for more details and to register for a meeting.

I hope I get a chance to meet more of you over the coming months. I welcome your input regarding future meetings in BC and Alberta. I can be contacted at bcsupport@aamac.ca.

Quebec: *Save the Date!*

Save the date for our next Patient Meeting in Montreal:

***Saturday, February 23, 2019 from
9am to noon***

Guest speaker:

Dr. Léa Bernard, MD, FRCPC
Hématologue, professeur adjoint de clinique
Hôpital Maisonneuve-Rosemont
Université de Montréal

Location:

Centre St-Pierre
1212, rue Panet, Montreal, Quebec

Light refreshments will be served.

Registration details will be available on aamac.ca in the next few weeks.

From the Fall Desk of Darlene Edmonds

By Darlene Edmonds,
Ontario Support Coordinator

I'd like to spend a moment to reflect on the wonderfully busy fall we had.

On Saturday, September 29, 2018 in London, we had a fabulous turnout with 19 members on hand to listen to a presentation by Dr. Cyrus Hsia, and another very interesting talk on Cytogenetics and Molecular Testing in MDS. **Keep your eyes on our website www.aamac.ca for this presentation to be posted.**

The balance of the patient support group meetings in my region were merged together for a Mini Patient Education Day in Toronto on Saturday, November 3, 2018.

We were thrilled to be able to offer this meeting, and it would not have been possible without the support of our sponsors. We invited three nurse practitioners to present a variety of topics. We also had a nice mix of attendees: new patients, patients who had been to meetings in the past, caregivers, and AAMAC volunteers. Everyone appreciated what each of the speakers had to say:

- Tammy de Gelder (NP, Hamilton Health Sciences) on "Understanding MDS, The Bloodwork and Various Treatments"
- Cindy Murray (NP, University of Toronto, Malignant Hematology) on "New Studies Taking Place"
- Pamela West (recently retired NP in Oncology and Supportive Care) on "Quality of Life when dealing with a Chronic Disease"

We are still deciding on what type of meetings we will hold in the new year — whether smaller more local meetings or a larger meeting in either

Hamilton or Toronto. Please feel free to drop me a line at my email ontariosupport@aamac.ca for any suggestions on these patient support group meetings, topics of personal interest, or let us know how we're doing. I'd love to hear from you.

I also had the opportunity to attend the Patient Education Day in Ottawa. Although the weather was chilly, it was great to connect with many warm-hearted people, including two attendees all the way from my region of Ontario! One of the best parts of the education day was listening to the presentations of our wonderful speakers on the panel.

Thank you to everyone who attended and participated in these events, and thank you to all those involved in the work behind the scenes.

And some snapshots from our recent Patient Education Day...



Dr. Jill Fulcher after her talk on advances in MDS treatments (left) with Secretary of the Board, Gwen Barry (right). Ottawa, 2018.



Dr. Mitchell Sabloff after his talk on AA, PNH treatments, and new developments (left) with Secretary of the Board, Gwen Barry (right). Ottawa, 2018.



Patient panel from left to right: Catherine Knoll (AA), Christine Pappas (MDS), Ken Hutton (bone marrow donor), John Benson (bone marrow recipient), Nancy Benson (caregiver/supporter). Ottawa, 2018.



Registered Nurse, Lauren Cosolo, giving a webinar on bone marrow disease.



Registered Social Worker, Aimee Anderson, after her talk on 'Living with Chronic Disease' (left) with Past Chair, Ashley Oakes (right). Ottawa, 2018.



Dr. Sophie Chargé after her talk on how blood products are made in Canada (right) with Executive Director, Cindy Anthony (left). Ottawa, 2018.



From left to right: Tammy de Gelder, Pamela West, Cindy Murray, Samantha Scime (2018 Canadian Nurse Foundation Scholarship recipient). Toronto, 2018.

Meet Mona Walia: one of AAMAC's Nurse Educators



Mona is a Registered Nurse in the Leukemia / Bone Marrow Transplant Program of BC at Vancouver General Hospital. Selecting nursing as a second career (previously a Financial Analyst), she completed her initial nursing education in Vancouver in 2001 and later a Bachelor of Science in Nursing from Ryerson University in Toronto. She started her career in reconstructive orthopaedics as well as rural emergency triage, nonprofit seniors' care, private travel medicine, community medical, oncology, and infectious disease clinics.

Within her field, Mona works with in-patients in both hematology and daycare units, the latter being her home-base and where her heart is.

Teaching advancing nursing practice, and improving workplace systems are her professional interests. These are reflected in initiatives she's involved in: contributing as a clinical expert for VCH's Clinical & Systems Transformation Project, lead clinician for VCH's Team Based Quality Improvement Project, ambassador for L/BMT's nurse recruitment campaign, facilitator for a L/BMT Nurses' Journal Club, trainer for a Multiple Myeloma Resource & Learning Program, and nurse educator for those living with bone marrow disorders.

Mona is inspired by how supportive patients are of each other and finds it gratifying to be able to work with patients along their entire journey.

In her spare time, she participates in several sports, has season tickets to the theatre, and enjoys live music and figure skating events. Each year she travels to a new destination with hopes to eventually visit all of the "wonders of the world."

Expanding our Nurse Educator Network

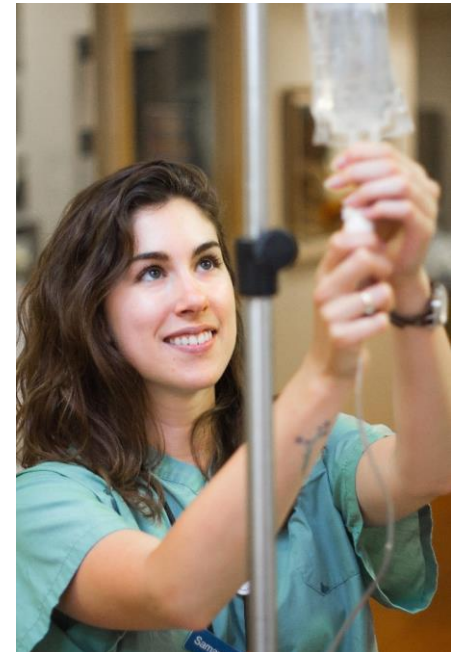
We warmly welcome our new Nurse Educators:

- Reanne Booker, BScN, MN, NP, *Palliative and End of Life Care Services, Foothills Medical Centre, Calgary, AB Nurse Practitioner*
- Angela Boudreau, RN, MN, CON(c), *Sunnybrook Cancer Centre, Toronto, ON Advanced Practice Nurse Hematology/Chemotherapy*

- Jo-Ann Edwards, MN, NP, CON(c), *BMT Program, Nova Scotia Health Services, Halifax, NS Nurse Practitioner*
- Tina Kusaian, RN, BScN, MScA *Nursing Professional Development Educator, McGill University Health Centre, Montreal, QB*
- Mona Walia, RN, BScN. *Leukemia/BMT Daycare Out-patient Unit, Vancouver General Hospital, Vancouver, BC Nurse Educator*

Nursing Scholarship Award recipient

Meet 2018-2019 Aplastic Anemia & Myelodysplasia Nursing Award recipient, Samantha Scime



My interest in oncology began at a young age. When I was in the sixth grade I read a series of novels about young adults with cancer and it was at that time I decided I wanted to care for these people. In high school, I pursued nursing with hopes of looking after patients with cancer and throughout my undergraduate degree I sought opportunities in this

field. Fortunately, over the past eight years, I have been able to grow my passion in a variety of roles within the oncology sector. I have been able to care for patients in all phases of the disease trajectory and have worked within both inpatient and outpatient settings.

I currently have the privilege to care for patients in a cancer treatment centre as well as an oncology specific urgent care clinic. Within these roles I've had the opportunity to lead a variety of quality improvement projects including an award winning patient education initiative aimed at alleviating the anxiety of patients receiving chemotherapy.

With my Masters, I aspire to create a positive impact in oncology nursing through a commitment to patient care, nursing education and research activities. My future research interests include the psychosocial care of diverse oncology populations including the LGBTQ2 community and Canada's Indigenous peoples.

Invest in nurses. See the difference in healthcare.



This 16-year-old girl is in desperate need of bone marrow

The following is adapted from match4roshlind.com and reprinted with permission.

Roshlind Kate Mance was born August 28, 2002 in Winnipeg, Manitoba to Filipino parents Benny and Jophine, and big sisters Adrienne and Kirsten. The family moved to Calgary, Alberta in 2007 and Roshlind was set to start her grade 11 year in the fall of 2018.



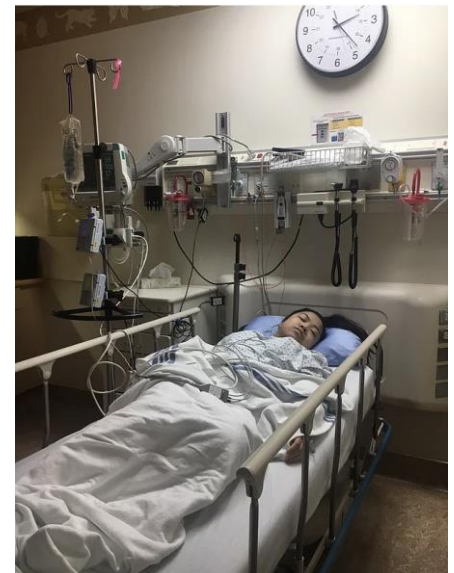
Roshlind Kate Mance, aged 16.

Our whole lives changed when Roshlind, aged 16, was rushed to urgent care on July 11, 2018 in what doctors said was a “life threatening condition.” Her blood cell and platelet counts were abnormally low and she was in excruciating pain. Her legs were covered in baseball-sized bruises. On that day alone she received multiple blood transfusions to keep her alive for the time being. Then, she underwent many tests, x-rays, blood cultures, and ultrasounds; all with no findings of what was causing her pain. She was then immediately rushed to the Alberta Children's Hospital.

During her three-week stay in the hospital she was diagnosed with Aplastic Anemia. This is a very rare autoimmune disease whereby a person's bone marrow fails to produce enough blood cells needed to sustain life. The outcome is that the bone marrow is empty and cannot make sufficient blood cells to keep the person healthy, the essential components of the blood that one requires to thrive. When this happens, it is nearly impossible to function — you may experience symptoms of fatigue and tiredness, bleeding and bruising, impaired cognitive functioning, increased risk for infections; most of all, at any

level of severity, Aplastic Anemia is terminal if not otherwise treated.

A week later our hearts broke a second time when the doctors also diagnosed her with Paroxysmal Nocturnal Hemoglobinuria (PNH), which is yet another very rare, chronic and life-threatening disease of the bone marrow that affects the blood and major organs. PNH causes red blood cells to break down sooner than they should and this early destruction can lead to symptoms like blood in the urine, and complications that range from minimal to severe, including leukemia, thrombosis and strokes. PNH affects 1 to 1.5 persons per million of the population.

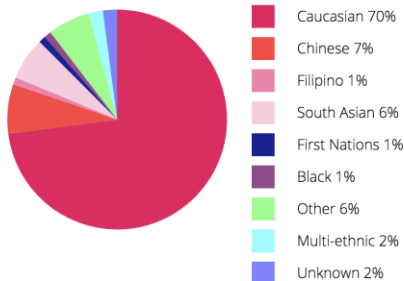


Roshlind in the hospital.

Since being discharged from the hospital, Rosh goes to the hospital twice a week as an outpatient to receive platelet and blood transfusions to keep her alive. Her treatment for aplastic anemia is called Immunosuppressive Therapy (IST). And her treatment for PNH is called Soliris. Soliris is unfortunately one of the most expensive drugs in the world. The cost bi-weekly is \$28,000. The monthly cost is \$54,000, and the yearly cost is \$500,000. Because PNH is so rare and the medication is so expensive, Roshlind's team of doctors had to apply for funding to the government

for eligible drug therapy where no other funding options are available through the public or private system. We recently found out that Roshlind's funding was not approved.

ETHNICITY MATTERS



Ethnic Composition of OneMatch Database
(December 31, 2016. OneMatch Stem Cell and Marrow Network)

The cure for both of Roshlind's diseases, if she does not respond to treatment, is a bone marrow transplant. While any sibling has at best a 25% chance of being a potential match for Roshlind, they have found out that no one in the family qualifies to save her life.

“Our world came crashing down when we found out that nobody in our family came out as a match for Roshlind.”

During this dark time our family found comfort in the story of Bille Nguyen and his family's quest to find him a match. Although the statistics of finding a match within the Asian community is stacked against us, we know that we are not alone in starting our own search for a potential match for Roshlind. We can't thank the Nguyen family enough for paving the way for families like us. And we can only hope to continue in their footsteps in raising awareness for different ethnic groups in registering to become a donor.

But there are ways you can help those like Roshlind...

Giving Tuesday is coming up

November 27 is Giving Tuesday, a day of international charitable giving and volunteering. As part of this global effort, AAMAC is seeking the support of Canadians across the country to continue the important work it does for Canadians with bone marrow failure disease.

AAMAC's mission is to educate, provide support to and advocate on behalf of Canadians with Aplastic Anemia, Myelodysplastic Syndromes, and Paroxysmal Nocturnal Hemoglobinuria. In addition to patient support, AAMAC works with Canada's leading medical professionals to fund research that will improve treatments and outcomes with a goal of finding a cure for these diseases.

But we can only do that with your help.

With your support, AAMAC can continue to reach and support more patients, fund important research and increase awareness of bone marrow failure diseases. You can do this several ways: Mail in the enclosed donation card; make a one-time or monthly donation via our website www.aamac.ca; ask your employer to match your donation; include AAMAC in your estate planning; or donate your time and skills to AAMAC.

GIVINGTUESDAY™
#ThankYouThursday
#GivingTuesdayCa

GivingTuesday



November 27th 2018

Please give. Roshlind and many others need you.

In Other News...

Canadian Blood Services marks 20th with renewed promise

Canadian Blood Services initiated a new chapter in its story with the unveiling of a renewed brand and expanded commitment to Canadian patients as it marked its 20-year anniversary.

“With the renewal of our corporate brand, we are positioning ourselves to move forward into the decades ahead. We will advance with invigorated purpose, ready to connect and engage the generosity of donors for recipients. We will use the discoveries of science to address the changing needs of patients, and continuously improve to ensure the sustainability of Canada's biological lifeline,” said Dr. Graham Sher, CEO, Canadian Blood Services.

The work that Canadian Blood Services began 20 years ago has changed over time. Born from crisis, the early years were about establishing trust in Canada's blood system. To earn the privilege of serving patients, it has relied on the collective efforts of a diverse community of committed partners and stakeholders, and will continue to do so, the organization said in a news release.

While it says it has moved beyond crisis to confidence, new technologies, evolving threats and growing demands are now impacting every aspect of health-care. Likewise, the role of Canadian Blood Services has grown beyond blood: today, the focus is on life essentials for transfusion and transplantation. To remain relevant and capable of delivering on its commitments in an increasingly competitive environment, the organization must continue to adapt and evolve.

“Our brand is much more than just a logo or a tagline. It is what sets us apart. It is what we believe in. And, it is how collectively, all of us will work together to deliver on our promise to Canadians,” added Dr. Sher.

This promise — to champion and safeguard Canada’s national lifeline for blood, plasma, stem cells, and organs and tissues — was broadcast across the country as donors, recipients, employees and volunteers came together to mark the milestone anniversary.

Renewing the brand is part of a multi-year plan by Canadian Blood Services to improve the donor experience and engage the donor of the future. The transition to a new visual identity, which is based on the universal symbol for infinity, will gradually be phased in. Many materials will only change as they reach the end of their life cycle, and as supplies are exhausted.

Canadian Blood Services is a not-for-profit charitable organization. Regulated by Health Canada as a biologics manufacturer and primarily funded by the provincial and territorial ministries of health, Canadian Blood Services operates with a national scope, infrastructure and governance that make it unique within Canadian healthcare. In the domain of blood, plasma and stem cells, we provide services for patients on behalf of all provincial and territorial governments except Quebec. The national transplant registry for interprovincial organ sharing and related programs reaches into all provinces and territories, as a biological lifeline for Canadians.

**Have you or your loved one been affected by
myelodysplastic syndromes?**

We want to hear from you to help guide future research.



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