

# Aplastic Anemia & Myelodysplasia Association of Canada NEWSLETTER

## Message from the Chair

Fall is here and bringing all its rainy and windy glory to the West Coast! Thank you to everyone who has supported AAMAC through our busiest time of year!

On September 30, we held our annual Patient Education Day in Richmond, BC and it was so wonderful to host in my home region! We had a wonderful turnout from across the province; thank you all so much for attending and I hope you found it as informative as I did. We are so very grateful for the wonderful slate of medical professionals who shared their knowledge with all in attendance. Many thanks to Celgene, Novartis, Alexion and Achillion for sponsoring Education Day and making this annual event possible. Also thanks to the amazing AAMAC volunteers who give of their time to help us with coordination and at the event itself.

Our annual education day also coincides with AAMAC's Annual General Meeting and meeting of the Board. We have one new Board member joining us this year: Jesse Prager. Jesse brings a wealth of knowledge to AAMAC and we look forward to his contributions in the year to come. We also said goodbye to long time board member Janice Cook. Janice has worked tirelessly for AAMAC for many years as a board member. She is an inspiration to us and many others.

Plans are well underway for regional support meetings across Canada in 2018; please keep an eye on the AAMAC website for information about events near you. In addition, we are able to confirm that Education Day 2018 will be held in Ottawa in October 2018. We will keep you posted with details as they become available.

Sincerely and best wishes for the holiday season,

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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 Darlene Edmonds, Ontario Support  
 Sandeep Gill, BC Support

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**New Board Elected**

In late September, AAMAC's 2017-2018 Board was elected at the annual general meeting. The members pictured above from left to right are: Jennifer Garvey (Past-Chair), Pamela Wishart, Gwen Barry (Secretary), Sanjeev Parmar, Vivian Do (Treasurer), Ashley Oakes (Chair), Haydn Liang (Vice-Chair) and Jesse Prager. Claude Francoeur also returns to the Board.

**Past BC Coordinator Receives TEAM Award**

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

In September, Janice Cook became the recipient of the 2017 TEAM Award.

Janice joined AAMAC's board in 2006 when she lived in Alberta. Two years later she was in BC where she took over the BC Chapter (now Group), assisted by another BC board member. Janice, an emergency room nurse until her retirement last year, has a passion: she wants to support and educate patients, their families and the professionals they meet. She has worked tirelessly on ensuring the BC patient list is up to date, not an easy task, and organized mini-Education Days as well as meeting patients and their families for coffee and chats.

AAMAC has an MDS Nurses Education Program which Janice was instrumental in organizing. Janice also served for many years as one of two AAMAC representatives on the National Rare Blood Disorder Organization, a group which works to improve the lives of those with rare blood disorders.

Janice retired from the Board this year because of family commitments after more than ten years of service. She will very much be missed by both the Board and everyone involved in AAMAC living in BC. AAMAC is sure that they will be able to call on her from time to time!

Janice, you're very deserving of this award. The vote was unanimous in choosing you!



Janice Cook (centre) pictured receiving the TEAM Award with Jill Kravinchuk, Senior Manager, Government & External Affairs, Celgene (left) and AAMAC Board Chair Ashley Oakes (right).

## Ontario Update

By Darlene Edmonds, Regional Support Liaison, Ontario

With the cooler fall temperature upon us, I just keep wondering, ‘where has the time gone?’ I’m excited as we are wrapping up the last of the fall patient support group meetings. These meetings have been fairly well attended overall.

In Hamilton, we only had one person out to the meeting, so we’ll do a bit more work in the area to build patient support awareness.

In London, we had an excellent discussion with Dr. Hsia about blood tests and understanding lab results including what the numbers all mean. We had 16 members, caregivers and new members out to this meeting.

In Kitchener, we had eight members and caregivers come together to share their personal experiences with MDS and AML. This was very helpful to two newly diagnosed members and their loved ones. We all have something to offer and share, that will give some comfort to someone else. We all have a priceless give to give – sometimes it might just be a friendly face around the table.

In Toronto we had 15 in attendance including members, caregivers and newly diagnosed members. Everyone participated in a very open and informative discussion and Question and Answer session with Dr. Richard Wells, a Hematologist / Oncologist from Sunnybrook Health Sciences Centre who also Chairs AAMAC’s Medical and Scientific Advisory Committee. Many excellent questions received informative answers and explanations from Dr. Wells. Everyone agreed it was a great way to spend a Saturday morning.

As I write this, I’m looking forward to a meeting that will be taking place in

Oshawa on Saturday, November 4. Our guest speaker will be Pamela West, Nurse Practitioner in Oncology and Supportive Care, Scarborough and Rouge Hospital, on the topic “Quality of Life when Dealing with Chronic Disease.” I hope we see many new members from that region out to the meeting.

A special thank you to all of the local community groups that allow us space to host our meetings. Hamilton meets at Wellwood, in London we meet at Wellspring Cancer Centre housed in the YMCA, in Kitchener we meet at HopeSpring Cancer Support Centre located at the back of the Inn of Waterloo, in Toronto at th3 Walme3r Centre, and in Oshawa at Hearth Place Cancer Support Centre. Thank you to all of the staff at these centres! Your assistance is greatly appreciated.

All the upcoming Spring 2018 meetings will be posted online and in the next newsletter. Stay tuned and I hope you can join us at the next patient Support Group Meeting in your community.

Wishing everyone a very Merry Christmas and all the best in 2018!

## BC Update

AAMAC welcomes Sandeep Gill who will be working for AAMAC with patients and caregivers in B.C. starting on January 1.

Sandeep loves dogs and has a lot of non-profit and volunteer experience. She currently works at The Justice Institute as a Program Assistant. She has a BBA degree. She was born and raised in the lower mainland and currently lives in Ladner.



Sandeep Gill

## Atlantic Region Update

By Gwen Barry

At the Annual General Meeting of AAMAC on September 30, 2017 in Vancouver, once again two members of AAMAC from Atlantic Canada were voted onto the AAMAC Board of Directors (Jennifer Garvey and me).

An Education Day for patients and caregivers has been scheduled for Halifax on Saturday, May 5, 2018 from 8:30 a.m. to 2 p.m. at the Halifax Marriott Courtyard Hotel.

The guest speakers will be presenting information on AA/MDS/PNH 101, Iron Overload, and Current and New

Treatments on the horizon. There will also be a Patient Forum.

While all Atlantic Canada patients and their caregivers are welcome to attend, travel bursaries will only be available for those attendees who live in Nova Scotia. Mark your calendar. The registration form will appear in the February 2018 edition of the AAMAC newsletter.

If you would like literature, or peer support, please contact me at (902) 864-8872 or [gwenb@eastlink.ca](mailto:gwenb@eastlink.ca)

## MDS Awareness Day

AAMAC staff and Board members supported MDS Awareness Day by wearing their “Marrow Mover” T-shirts.

MDS Awareness Day was held on October 25.

Pictured below from left to right are: Sanjeev Parmar (Board member), Jennifer Garvey (Past-Chair), Vivian Do (Treasurer), Cindy Anthony (Executive Director), Gwen Barry (Board Secretary), Pamela Wishart (Board member), Carol Fazari (Office Administrator), Ashley Oakes (Board Chair), Haydn Liang (Board Vice Chair) and Jesse Prager (Board member).



## Blood Transfusion Dependent Patient Opinions Needed

Are you an MDS patient and transfusion dependent? Would you like your opinions heard?

A team of experts in the field of hematology is conducting a survey specifically related to red blood cell (RBC) transfusion practices.

The purpose of the survey is to understand the landscape of RBC transfusions in dependent MDS patients.

The scope of the survey will cover: frequency of transfusions; location of transfusion; length of transfusion; travel time; impacts on quality of life (QOL); how to improve QOL; transfusion thresholds; transfusion waiting times once symptomatic, same day cross matches or not, etc.

The results will be disseminated widely (and published). What is learned will be used to plan a research study whose goal is to improve the RBC transfusion experience for patients.

The study team consists of:

- Rena Buckstein MD FRCPC Associate Professor, University of

Toronto, Department of Medicine, Division of Hematology/Oncology;

- Yulia Lin MD FRCPC Associate Professor, University of Toronto, Department of Laboratory Medicine and Pathobiology;
- Jeannie Callum MD FRCPC Associate Professor, University of Toronto, Department of Laboratory Medicine and Pathobiology; and
- Simon Stanworth MD Consultant Hematologist, NHS Blood and Transplant, Oxford University Hospitals NHS Trust.

The survey is available at the link: <https://www.surveymonkey.com/r/MDS2017TD>

## Giving Tuesday

**The season of giving is upon us...are you ready?**

Each year AAMAC reports back to you... our patients, healthcare workers, caregivers and donors on how we supported patients with Aplastic Anemia (AA), Myelodysplastic Syndrome (MDS), and/or Paroxysmal Nocturnal Hemoglobinuria (PNH).

- We had a record number of Patient Support Meetings this past year totaling 22 free meetings held across Canada. The meetings were held in BC, Alberta, Ontario, Quebec, Nova Scotia and New Brunswick.
- AAMAC provided Nursing Education Sessions to increase nurses' knowledge about bone marrow failure disease so they have the information and resources to better support patients.
- A quarterly newsletter was sent in both official languages –

providing valuable information about AA, MDS and PNH.

- Phone support was provided to 175 people.
- Patient resource packages were sent to 57 patients.
- Resource materials were sent to 32 hospitals across Canada.
- 10 patients received support from a “peer” provided by the Peer-to-Peer Support Program.
- A \$5,000 scholarship was given to Janelle Halldorson in conjunction with the Canadian Nurses Foundation to help Janelle on completing her Masters degree in Nursing – Nurse Practitioner.
- To ensure patient’s voices are heard, AAMAC liaised with the Canadian Organization for Rare Disorders, the Canadian Blood Services and Cancer Care Ontario, as well as, other organizations.

To continue these programs and support, we rely on generous donations to reach and support more patients, fund important research and increase awareness about bone marrow failure diseases.

## GivingTuesday



November 28, 2017

### What is GivingTuesday?

GivingTuesday is a National Giving Day. Most people know about Black Friday and Cyber Monday...

GivingTuesday is on November 28, 2017. *“We have two days that are good for the economy. Now we have a day that is good for the community too.”*

It is a new Canadian movement for giving and volunteering, taking place each year after Cyber Monday. The “Opening day of the giving season,” it is a day where charities, companies and individuals join together to share

commitments, rally for favourite causes and think about others.

### How to Help

To ensure AAMAC continues the important mission of supporting patients with AA, MDS and PNH, we ask you to:

- 1) make a one-time donation online at [www.aamac.ca](http://www.aamac.ca), by cheque to the National Office 11181 Yonge St., Suite 321, Richmond Hill, ON L4S 1L2 or by phone via 1 (888) 840-0039;
- 2) inquire about matching donations from your employer and ask them to make a donation;
- 3) include AAMAC in your Estate planning; and/or
- 4) volunteer your time and skills to AAMAC by sending an email to [info@aamac.ca](mailto:info@aamac.ca).

We thank you for your continued support and donations!

## 2018 Patient Tracker Available

Each year AAMAC produces the “My Progress Tracker” calendar. It is a tool to assist you in being an active partner with your health. The calendar allows you to track important contact information, appointments, test results, blood levels and treatments.

The Progress Tracker is provided free of charge and available in English or French. To obtain a Tracker please email [info@aamac.ca](mailto:info@aamac.ca) or call 1(888) 840-0039.

Watch for details soon about a new phone app to keep track of your appointments and test results.



## Cheryl's Run



AAMAC extends its congratulations and thanks to Norma Kennedy who organized Cheryl’s Run for Aplastic Anemia and all the volunteers and participants.

The event was held in memory of Cheryl Lynn Boyle who passed away on February 1, 2017.

“Cheryl’s Run was a great success for its first year,” says Norma. “We had 130 runners and walkers in the 5 and 10 kilometre events and about 50 kids in the fun run. The weather was great and the atmosphere was really positive.”

“We had 18 people get swabbed for the bone marrow registry and lots more take an interest in it,” she added. “We also raised about \$6,000 for the Stollery (Children’s Hospital Foundation).”

The event was held in Edmonton on September 23 and also supported AAMAC.

According to the event website [cherylsrun.ca](http://cherylsrun.ca), “Cheryl was a tenacious woman in her battle with Aplastic Anemia and the complications that arose from her bone marrow transplant. She fought hard right to the end. Her dream was to go back to the job she loved in Pediatric Oncology at the Stollery Children’s Hospital at the U of A (University of Alberta). She was a beautiful person, loved life, gave of herself and lived every day to the fullest! We want to continue her giving legacy through what we hope will become an annual event.”

## Marrow Movers Raise Funds

Following on the success of an earlier event in Vancouver, AAMAC was well represented at the Toronto Scotiabank Marathon in Toronto on Sunday October 22, 2017.

To date, the Toronto Marrow Movers raised almost \$5,000 in 2017 for AAMAC! We thank each of the Marrow Movers for their participation and we thank all the individuals who supported their efforts with financial contributions!

Please let us know if you're interested in participating in one of the regional Marrow Mover walks/runs next year. We'd love to have you join our team.



*Pictured above from left to right in the first photo are Marrow Movers Ethan, Danny, Erica and Macie. In the second photo are Clara, Jesse and Haydn. The third photo includes Haydn, Jesse, Vivian and Clara.*

## News of Note

### Canadian Blood Services Releases Annual Report

On October 30, 2017, Canadian Blood Services (CBS) released its annual report, *Tomorrow Changes Today*.

The report includes updates including:

- In June 2016, CBS' Cord Blood Bank shipped its first unit of umbilical cord blood for use in a stem cell transplant in Europe. At the time of the report's publication, five more shipments had followed.
- As of March 31, 2017, CBS had collected more than 15,000 cord blood units at five hospitals. Over 2,000 donated units were bankable for potential transplant use. Units that don't meet banking criteria may be used or shared for research via the Cord Blood for Research program.
- The OneMatch Stem Cell and Marrow Network grew by seven per cent in the past year to nearly 410,000 registrants. At year-end, CBS had facilitated 317 stem cell transplants.
- In 2016–2017, nearly 406,000 blood donors visited CBS collection sites.

To read the full annual report, visit [blood.ca](http://blood.ca).

### Newspaper Recalls Life-saving Difference Made by AA Patient, Family and Community

As part of its 125<sup>th</sup> anniversary celebrations, the Toronto Star is highlighting "stories that have inspired readers and changed lives" including that of Elizabeth Lue.

In 1990, her mother Phillipa began the "Save Elizabeth Lue" campaign to find an unrelated bone marrow match for the six-year old after she was diagnosed with aplastic anemia. Although a match was not found before Elizabeth died several months

later, the campaign is credited with adding thousands of registrants to the bone marrow and stem cell registry.

The article also highlights the story of an American woman who was saved by a matching donor who joined the registry as a result of the campaign. To read the full story, visit [www.thestar.com](http://www.thestar.com).

### 100 Huntley Street Founder Dies

According to the Waterloo Record, David Mainse, founder and host of Canada's longest running religious daily television program *100 Huntley Street*, died in Hamilton at the age 81 following a five-year battle with MDS and leukemia.

## Go Paperless!



Would you like to receive your newsletter and AAMAC communication via email? If so, please let us know!

Doing so would help keep our costs down by eliminating the need for printing and postage. It would also free up volunteer time currently spent on pulling the mailing together for other activities. And, it's good for the environment!

Currently the vast majority of our members receive this quarterly newsletter by mail.

Of course, we are always happy to send you a paper copy if that is what you prefer or if you don't have a computer, but please consider email if that's an option for you.