

*Education
Support
Research*

Spring 2019

Aplastic Anemia & Myelodysplasia Association of Canada

NEWSLETTER

Message from the Chair

Happy New Year, dear friends and supporters,

In 2019, we look forward to a new slate of support group meetings across Canada. Our meetings make up the core of our mission to provide a seamless support network for every Canadian patient, family member, friend, and concerned healthcare provider dealing with aplastic anemia, myelodysplasia or PNH.

Beyond support group meetings, we are also keenly aware of how important scientific research is in advancing treatments for AA, MDS, and PNH. This is why we have recently approved funding for an important research study led by the SickKids Hospital for children with AA, MDS, and PNH. This study will be the only Canadian registry of its kind and we look forward to working closely with the lead investigator, Dr. Yigal Dror, and his team to share their findings with you as the study progresses.

For those interested in clinical trials that are testing investigational agents for AA, MDS, and PNH, AAMAC has also partnered with Antidote to host their 60-second clinical trial match app on our aamac.ca website. The website update is ongoing so make sure you watch for this as it goes live.

Finally, 2019 will be a busy year with key healthcare policy debates around the country. As your support group, AAMAC is actively involved to ensure that our patients' voices are heard. Of course, if you have any comments or concerns about what's going on in your community, feel free to let us know.

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 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.

BOARD OF DIRECTORS 2018/2019

Gwen Barry, Secretary
Marilynne Convey
Vivian Do, Treasurer
Jennifer Garvey
Haydn Liang, Chair
Ashley Oakes, Past/Vice Chair
Christine Pappas
Sanjeev Parmar
Jesse Prager
Pamela Wishart

MEDICAL AND SCIENTIFIC ADVISORY COMMITTEE

Dr. Y. Dror
Dr. L. Larratt
Dr. H. Leitch
Dr. K. Schultz
Dr. J. Storrington
Dr. R. Wells, Chair

LOCAL GROUP CO-ORDINATORS

Gwen Barry, Atlantic
Catherine Knoll, Ottawa

STAFF

Cindy Anthony, Executive Director
Robyn Hodes, Administrative Assistant
Darlene Edmonds, Ontario Support
Fiona Lewis, BC/Alberta Support

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:

Aplastic Anemia and Myelodysplasia
Association of Canada
2201 King Road, Unit #4
King City, Ontario L7B 1G2
(905) 780-0698 or 1 (888) 840-0039

bcsupport@aamac.ca
albertasupport@aamac.ca
ontariosupport@aamac.ca
adminoffice@aamac.ca
cindyanthony@aamac.ca

info@aamac.ca. www.aamac.ca Charitable
Registration Number 87557 2265 RR0001

Atlantic Region Update

By *Gwen Barry, Atlantic Region Coordinator*

Three patients/caregivers of our AAMAC Halifax Support Group passed away in 2018. Pamela Fortune died of MDS complications. Judy Smith, an MDS caregiver, passed away, as did Joyce Bond as a result of MDS complications. They will be missed.

The AAMAC Halifax Support Group held its annual Christmas party at the home of Jennifer Moss and Kirk White in late November.

Pictured below is the group singing Christmas carols with Jennifer Moss at the baby grand piano.

There were 16 people in attendance. Jennifer has her Masters in piano and gave us a recital. We sang Christmas carols, and had some great chats.

Jennifer has recorded a CD of her playing piano in support of her son, Christian, who has severe aplastic anemia. The CD liner asks people to donate to AAMAC. She gave each of us a copy of her CD.

It is sad news indeed to hear that Dr. Stephan Couban, the senior Hematologist at the Victoria General Hospital in Halifax, has retired from

his practice. He served his patients well for many years, and this is a loss for them, as well as for the staff in the hematology clinic. Dr. Couban also served for a number of years on AAMAC's Medical and Scientific Advisory Board.

Possible Patient Education Day in St. John's, Newfoundland and Labrador

AAMAC is currently looking into the possibility of a Patient Education Day in St. John's, Newfoundland on Saturday, September 21, 2019. If it pans out, travel bursaries will be available for residents of Newfoundland and Labrador. However AA/MDS/PNH patients and their caregivers from all four Atlantic Provinces are welcome to attend. More information will be coming out at a later date.

BC/Alberta Update

By *Fiona Lewis, BC/Alberta Patient Support Liaison*

We have two patient support group meetings scheduled for Alberta:

- **Calgary:** Tuesday, March 19, 2019 from 10 to 11:30 a.m.
Vivo for Healthier Generations™
11950 Country Village Link NE



Dr. M. Geddes will speak on the topic “MDS – What it is and how it is treated.”

- **Edmonton:** Saturday, April 6, 2019 from 10:30 a.m. to noon

Edmonton Public Library –
Abbottsville – Penny McKee
3410 118 Ave NW

Nurse Janet Bates will speak about “Managing the Side Effects of Treatment.”

In B.C., we are planning to host a meeting in Kelowna in late spring and a meeting in the Lower Mainland in June. Details will be posted on the AAMAC website as they are confirmed.

Exercise’s role in managing fatigue

At our recent patient support group meeting in North Vancouver, exercise physiologist and kinesiologist, Sarah Weller, spoke about the role of exercise in managing fatigue. Here are some key points from her presentation:

- Although research into fatigue with MDS/AA is limited, there is a lot of cancer-related research that is relevant.
- Fatigue is caused not only by the underlying condition, but also by the side effects of treatment such as pain, nausea, depression, stress and muscle weakness.
- Exercise is now the first line of treatment to reduce fatigue for people in cancer treatment trials.
- Exercise has demonstrated physical, psycho-social and clinical benefits. Studies of chemotherapy patients show that exercise can increase treatment tolerance (i.e. fewer side effects, improved surgical recovery, shorter hospitalizations, and less severe Graft versus Host Disease).

- Research has also shown that exercise is as effective as medication in reducing depression.
- Start slowly with any exercise program and monitor your body for negative responses such as an increase in pain and/or fatigue.
- Consistent exercise is more important than the intensity of the exercise. Avoid exercising so hard one day that you are exhausted for the next two days.

Sarah shared a number of resources that are available for patients in B.C. to get advice on their exercise program. These include the 811 telephone service (ask for Physical Activity Services for Cancer) and Inspire Health in Vancouver, Victoria and Kelowna. These are both free services for people with cancer or related illnesses.

Sarah had us all do a simple exercise of crossing our arms to touch our shoulders and then, while holding this position, get up and down from a stable chair a number of times. Even this simple exercise got our leg muscles working!

Sarah can be reached at sarahweller@treloarphysio.com.

Ontario Update

By Darlene Edmonds, Ontario Support Coordinator

Well I hope all of our readers are staying germ-free this winter. It’s been a tough season and we’re just getting started.

I’m looking forward to our Spring meetings, which means warmer weather and a time to re connect with each other.

Please mark the following dates on your calendar and try to attend one or two of the meetings near you.

- **Hamilton:** Saturday, April 6, 2019 from 10:30 a.m. to noon at Wellwood Centre.
- **Kitchener:** Saturday, April 27, 2019 at 10 a.m. to noon at HopeSpring Cancer Support Centre
- **London:** Saturday, May 4, 2019 from 10 a.m. to noon at Wellspring Cancer Support Centre/ YMCA.
- **Toronto:** Saturday, May 11, 2019 from 10:30 a.m. to noon at our new location, Runnymede United Church, 432 Runnymede Road.

At this time, I still haven’t been able to book any speakers, so right now we will host peer-to-peer support groups. Please watch our website and follow us on Facebook for any updates and changes to possible speakers at any of the support group meetings.

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

Stay warm and enjoy counting down the days until Spring!

Nurse Education: Meet Stephanie Dyer



Stephanie graduated from the Memorial University of Newfoundland in 1990 with a

Baccalaureate of Nursing. She also received her Canadian Nurses Certification in Oncology in 1992 and has continued to renew every five years since.

She has been working in the area of Hematology/Medical/Radiation since her graduation, starting as a Staff Nurse and for the last 10 years has been a Patient Care Facilitator. Stephanie has been supporting AAMAC by teaching other nurses about bone marrow diseases for several years.

On a personal note, Stephanie has been happily married for twenty eight years and has two adult children, Patrick and Rebecca. She and her husband love to travel, especially to Europe.

Celgene TEAM Award Presentation



Dr. Stephen Nantel from Vancouver General Hospital presents Dr. Heather Leitch the TEAM Award alongside AAMAC Board members Marilynne Convey (left) and Pam Wishart.

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.

AAMAC chose Dr. Leitch as the recipient this year because of the willingness and speediness with which she answers our questions and concerns, the many patient events at which she has presented providing a level of understanding of the need for iron chelation to transfusion-dependent patients, family members and others, her on-going participation as a member of AAMAC's Medical & Scientific Advisory Board and her relevant research.

Congratulations Dr. Leitch!

Remembering Dr. Freedman

By Caroline Laughlin

Dr. Melvin Harris Freedman 1939 - 2019

It is with deep sadness that we announce the death of Dr. Mel Freedman.

Born in 1939 in Saint John, New Brunswick, Dr. Freedman graduated as a top student of Dalhousie University. After training in Pediatric Medicine at Montreal Children's Hospital, McGill University and the Children's Hospital of Los Angeles, University of Southern California, he came to Toronto's Hospital for Sick Children in 1971.

For the next 34 years he led groundbreaking patient-related research concerning cancer and inherited and acquired bone marrow failure disorders. He wrote or co-wrote hundreds of research publications and abstracts in major hematology and oncology textbooks.

He received numerous prestigious awards, promotions and nominations including a full Professorship at the University of Toronto. He was asked to speak at hundreds of hematology conventions both here and abroad and

he was recognized as a world leader in hematology and oncology research. In addition to this busy research effort, Dr. Freedman continually made a tremendous difference to many patients and their families. His ability to listen attentively with empathy and then to explain with appropriate care his analysis of the situation and intended treatment was outstanding.

In 1987, Renee and Jeff Levine approached the Hospital for Sick Children to form a support group for patients with aplastic anemia. The hospital invited Dr. Freedman to be its first medical advisor.

With his guidance the then Aplastic Anemia Family Association of Ontario was born. Sick Kids provided the nascent organization marketing support. Under Dr. Freedman's excellent leadership, the association grew and was influential in many new and untried activities.

He encouraged us to support the Canadian Blood Services (CBS), to fundraise for research and to offer information to families affected by aplastic anemia.

In addition, he supported the Aplastic Anemia Association in lobbying CBS to create the unrelated bone marrow registry in Canada.

From small beginnings under his loving guidance we are now a national organization supporting patients with aplastic anemia, myelodysplastic syndromes and PNH known as the Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC).

On a personal note, the Laughlin Family members wish to express their condolences to Dr. Freedman's family. He was our daughter's doctor whom we came to trust and respect. We will miss him very much.



WOMEN, WISDOM & WINE

IN SUPPORT OF MYELODYSPLASTIC SYNDROME (MDS)/AAMAC

IN MEMORY OF MICHELLE STEEVES

MARCH 30, 2019 7PM

THE COCOA ROOM 391 COVERDALE RD RIVERVIEW

WWW.LBCEVENTS.CA



Spirit of Giving

We extend a warm thank you to everyone who supported AAMAC with a donation during last year's Giving Tuesday campaign.

Many supporters also generously organize third-party fundraisers – events to raise funds that are then donated to AAMAC.

One such example is an upcoming event in March called Women, Wisdom & Wine. This event is organized by Erica Steeves in memory of her mother Michelle, who passed in October of secondary MDS.

Our next article is also a wonderful example of how people support AAMAC through third-party fundraisers.

If you would like to organize a third-party fundraiser, please contact our office and speak to Robyn for guidance.

Pancake Breakfast Supports AAMAC

By Gary and Sylvia Scow

We started doing an open house pancake breakfast in 1992 before our son Sheldon was born as a way to include our friends and family in Christmas activities.

Our son Sheldon was diagnosed with aplastic anemia in April 2001 after being tested for a variety of things that were happening to him. After testing, Sheldon was admitted into the Nanaimo Hospital in BC and we were quickly flown over to Children's Hospital in Vancouver.

After three weeks in Children's Hospital and learning everything we could about the disease we wanted to give back especially when we found out that few in the population get the disease and there was not a lot of funding provided.

At our yearly pancake breakfast we used to ask for donations for the food bank and shortly after the diagnosis we started doing a fundraiser which includes our family and friends donating items and buying tickets for items.

We are lucky with our friends and family who donate gift baskets with different themes, prints, books and a variety of other items. I usually knit a number of scarves and throughout the year pick up items on sale.

This continues to be part of our Christmas tradition and we host the open house pancake breakfast the Saturday before Christmas from 10 a.m. to 1 p.m. We cook pancakes, sausages, fruit salad, cookies, coffee and chocolate.

Everyone comes together and helps out. We take photos, eat good food and visit. We usually have anywhere from 25 to 40 people who stop by during the time and some stay longer to visit and others dash in and buy tickets and leave.

It's an event that is filled with love and laughter and involves all of our family



including Sheldon and his sister Shelby who are now adults.

Pictured above are some of those who participated in 2018.

News of Note

New website launched

On November 27, AAMAC launched a more user friendly website to ensure anyone visiting our site is able to access the information they need.

There is information about our resources, peer-to-peer support programs and how to find out about a support group meeting.

Match Found for Roshlind

It is with great excitement that we share the news: Roshlind, who we told you about in our last issue of the newsletter, has now found her match!

Being someone of Filipino descent, she needed to find a stem cell donor from the same ethnic background. She and her family were devastated when they found out that no one in her

family was a match, and, even worse, only 1% of the stem cell registered donors in Canada are of Filipino descent. After more than 650 strangers around western Canada tested themselves to see if they were a match, what the family calls a “Christmas miracle” happened, somewhere in the world she found her match. The family expressed their tremendous gratitude to their daughter’s hero on Instagram.

“Although our search for Roshlind has now ended, our work has not. We are so blessed to have found a match for Roshlind and we want nothing more than to help other families find theirs as well; especially ethnic minorities who are so poorly underrepresented in the stem cell database.

Roshlind’s battle is not yet over and her road to recovery will not be easy but we are so beyond the moon excited and we can now enjoy the holidays blissfully before the next part of Roshlind’s journey starts in the new year!”

Save the Date Patient Education Day this October

Save the date for our Annual Patient Education Day & Annual General Meeting in Calgary on October 19.

Check our Summer and Fall newsletter for more details.

Rare Disease Day 2019

The Canadian Organization for Rare Disorders is hosting a reception at Ontario’s provincial legislature to mark International Rare Disease Day on February 28 from 8 to 9:30 a.m. Visit raredisorders.ca for details.

Third Time’s a Charm

Congratulations to our Executive Director Cindy Anthony and her husband who welcomed their third grandchild, Frances, early in January!

