

# Aplastic Anemia & Myelodysplasia Association of Canada NEWSLETTER

## Message from the Chair

In 1987, the concerned parent of a child with aplastic anemia founded the Aplastic Anemia Family Association of Ontario. One of the very first goals of the Association was to advocate for the formation of a national bone marrow donor registry in Canada. Today, the Aplastic Anemia and Myelodysplasia Association of Canada is a federally incorporated and registered national charity with the ambitious goal of providing a seamless support network for every Canadian patient, family member, friend and concerned healthcare provider dealing with aplastic anemia, myelodysplasia or PNH.

I would like to take this opportunity to introduce AAMAC's newest board member, and treasurer, Vivian Do! Vivian brings a wealth of knowledge from a financial background to our team and we are thrilled to have her on the Board.

Summer is a busy time of year for AAMAC as we gear up for our annual patient education day, this year taking place in Richmond British Columbia, within minutes of the Vancouver International Airport. Patient Education Day will be held on September 30<sup>th</sup> and 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.

There are a number of other events coming up across the country that may be of interest to you as well: AAMAC will be screening the film "*Mixed Match*" at the Japanese Cultural Centre in Toronto on September 28<sup>th</sup>. *Mixed Match* shows how multiethnic patients suffering from blood cancers and other blood diseases, struggle to find a stem cell or bone marrow donor match. The film aims to raise awareness and give voice to the patients whose survival relies on having more minorities and multiethnic donors join the stem cell registry and donate umbilical cord blood.

In addition to the upcoming screening of "*Mixed Match*", another film titled "*Thanks Mom 2017*" took place on May 13<sup>th</sup> at Metrotown Mall in Burnaby, 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 and 2012, and now return for 2017! The 100% volunteer grassroots *Thanks Mom* Committee, partners with 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.

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

Sincerely,

Ashley Oakes  
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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## **BC Update**

*By Janice Cook*

Watch for information about our Education day in this newsletter. We have most of our speakers in place and are enlisting people for the patient panel right now. I hope you will join us, it's a good learning day as well as a networking and social occasion. Even after attending eleven of these previously, I know there will be some new information for all of us.

The Kamloops BMF Guys and Gal has had another lunch time meeting, with two new people joining them. They are a very friendly group, who provide support to each other. If you would like to join them next time contact [bcsupport@aamac.ca](mailto:bcsupport@aamac.ca) or 604-826-7222 and I'll put you in touch.

I've had a question about travel after a transplant, and it is a good question. My first thought is that a person should talk to their own hematologist about this, before making plans. There will be specific things like timing and immunizations that need to be discussed. Then details about the where and how can be worked out. Travelling when immune suppressed or recovering from a lengthy illness, or even travelling with a chronic but stable diagnosis may all leave your doctor and family with similar concerns. There is travel within your own province and country, then similar countries and climates, and then adventure travel, or to places where facilities we take for granted may not be available. They will all involve different preparations that you may not think of. It probably isn't the time to go off on your

adventure alone. Talk to people who have done a similar trip, so you have a better idea of what to expect. Altitude, plane trips, public restrooms, restaurant food, hostels or budget hotels, local water, food borne illness, crowded public transportation, time zones changes, these can affect how you feel, and challenge you if you are not ready to travel.

I feel strongly that when you travel, most especially with a medical condition, extra medical insurance should be considered as a cost of the trip. It's better to speak to a professional about the details, and to read the fine print before a trip, than to try and figure it all out if it's needed. Your doctor may have to even provide a letter in advance of a trip.

Once you have a go-ahead from your doctor, and the planning has begun, your level of fitness needs to be taken into consideration. A human body has a "use it or lose it" type of policy. Sickiness that results in exercise intolerance is a quick and easy way to become deconditioned- which is a fancy way of saying you get weak and tired more quickly than you used to. Your stamina and endurance have probably decreased. You may have to work at it before you are ready for the strain of travelling. There may be adjustments needed to how you travel, your itinerary, even how much luggage you take and the size. For example, the London Underground will get you wherever you want in that city, but up to 4.8 million passenger trips are taken a day and it's crowded! Are you fit enough to stand? And if there is a security alert or a breakdown, you might have two or three levels of stairs to get to street level. There aren't always elevators or escalators.

It's a great incentive though, to get some exercise every day. And if you are fit and have been given the go ahead, planning and taking a trip is a great thing. Just spend extra time preparing, be flexible, allow for rest periods just as you have to at home, and choose your travel companion wisely, as they may have to pick up your slack, and your suitcase.

Even in your home province or another province in Canada, you can't just walk in to any hospital ER and expect to get your usual blood transfusion without prior arrangements. It's always a good idea to take a copy of your prescriptions and your pills in their original containers. (there are literally hundreds of white pills) And if you can't simply explain or pronounce the name of your rare illness, this is the time to take an AAMAC brochure along with you. Don't expect every health care professional to have heard of your disease-remember it is rare. There are thousands of rare diseases, they won't know them all, but with proper spelling they can look them up.

My husband and I took a trip to Europe eleven months after I had ATG for SAA. My remission had started, I was transfusion free, but my other counts were not 'normal' yet. I was on a prophylactic antibiotic and was extremely careful about handwashing and avoiding people with illness. I had been going to the gym to regain enough of my muscle and strength to return to work. The trip was to visit our daughter, but also a test for me, to see if I could handle my stressful and physical job. The trip was far more tiring than subsequent trips that I've taken. My husband handled all the arrangements, and

I don't remember a lot of the details about what we did.

But after the trip, I truly felt that I had my life back, and that made it all worthwhile.

If anyone has travel hints to share, or ideas about things to avoid, you can send them to me and I'll share them in the next newsletter.

## Atlantic Region Update

*By Gwen Barry*

The Halifax Support Group met for a pot luck lunch on Saturday, May 5<sup>th</sup>. It was good to catch up with everyone, after a long winter and snowy, cold March.

On May 11-12, I will be representing AAMAC Atlantic Region at the Annual New Brunswick Hematologists Conference, at St Andrews, N.B. The plan is to pass on AAMAC educational literature, on Understanding MDS, AA, and PNH, to a representative from all of the English and French Hematology Clinics in NB, to place in their clinic waiting rooms for the benefit of patients. It is also an opportunity to make NB hematologists aware of the services that AAMAC provides.

Anyone wishing to know more about AAMAC's program in the four Atlantic Provinces, please contact Gwen Barry at [gwenb@eastlink.ca](mailto:gwenb@eastlink.ca) or 902-864-8872.

## Ontario Update

*By Darlene Edmonds, Regional Support Liaison, Ontario*

I want to thank everyone who took the time to join us at the spring patient support group meetings that took place in Hamilton, London and in Toronto. We had some great information sharing. In Toronto we heard from Dr. Vicky Breakey, Pediatric Hematologist/Oncologist, McMaster Children's Hospital. At this meeting a mother and son shared their experience about living with AA for the last 3 years. – Thank you for sharing your journey with us.



*Dr. Breakey and youth that attended the May 6th meeting in Toronto*

**NEW MEETING:**  
Campbellford, Ontario  
**Saturday, June 10<sup>th</sup>**

This is the inaugural patient support meeting in the eastern Ontario region. We encourage those living from Oshawa to Kingston to join us. Come out and meet Executive Director, Cindy Anthony.



## SAVE THE DATES:

**Hamilton:** September 13<sup>th</sup>  
Wellwood, 501 Sanatorium Road

**London:** September 30<sup>th</sup>  
Wellspring Cancer Centre,  
Waterloo Street (In the YMCA  
Building)

**Toronto:** October – date TBD  
Please check [aamac.ca](http://aamac.ca) for  
meeting and topic updates.

Watch for another meeting for  
families of children with Aplastic  
Anemia late summer 2017.  
These meetings provide a safe  
environment for patients,  
caregivers and health care  
providers to come together to  
learn and share. We can all learn  
from one another.

If you have a topic suggestion for  
a meeting, or if you've heard  
someone present that you were  
really impressed with please share  
the details at [info@aamac.ca](mailto:info@aamac.ca) or  
call 1-888-840-0039. We are  
always looking for suggestions of  
speakers.

If you happen to visit a clinic,  
hospital or a Doctors office and  
don't see AAMAC information,  
please contact the national office.  
Information can be sent to them  
for patient reference.

## Alberta Update

We are happy to announce that  
Sue Miles has joined AAMAC as  
the Alberta Patient Support  
Liaison.

Sue joins AAMAC with a  
wealth of education and  
experience. She was diagnosed  
with MDS in October 2015, and  
is holding her own and proud of

it! She has a bachelors degree in  
sociology and psychology, and is  
a Professional Facilitator.

Her position with AAMAC will  
assist patients, families and  
healthcare providers in Alberta  
connect to support meetings,  
resources and services for those  
with AA, MDS and PNH.

For support in Alberta, you can  
reach Sue directly at:

[albertasupport@aamac.ca](mailto:albertasupport@aamac.ca) or 780-  
265-5452.

Please help us welcome Sue!

## SAVE THE DATE:

Edmonton: Saturday, October 28<sup>th</sup>  
Patient Support Meeting



*Sue Miles, Alberta Patient Support Liaison*

## 2016 MDS Research Summary Available

Looking for leading edge  
information and new research  
about bone marrow failure  
diseases?

Please reference the Aplastic  
Anemia & MDS International  
Foundation website:  
[http://www.aamds.org/summaries-  
patients](http://www.aamds.org/summaries-patients)

You will find presentation  
summaries of major

hematology/oncology scientific  
meetings containing up-to-date  
research and treatment of bone  
marrow failure disease.

## Thanks Mom Give Life 2017 Campaign

*By: Deanna Jones*

Expectant mothers in four cities  
across Canada are encouraged to  
donate life-saving umbilical cord  
blood to Canadian Blood  
Services' Cord Blood Bank when  
they deliver their babies.  
Umbilical cord blood is rich with  
blood-forming stem cells. Cord  
blood stem cell transplants are  
used for treating over 80 diseases  
and disorders, including aplastic  
anemia.

Canadian Blood Services' Cord  
Blood Bank is a national program  
that recruits healthy, volunteer  
mothers delivering at designated  
collection hospitals across the  
country.

Women who are over 18, who  
are carrying single pregnancies,  
and have reached 34 weeks  
gestation may be eligible to  
donate. Free translation services  
are offered in Punjabi and  
Chinese for mothers whose first  
language is not English or French.

Donations are taken at the  
Ottawa Hospital General and  
Civic campuses; the William  
Osler Health System's Brampton  
Civic Hospital; the Alberta Health  
Services Lois Hole Hospital for  
Women in Edmonton; and the BC  
Women's Hospital and Health  
Centre in Vancouver. As it is a  
public cord blood bank, donated  
cord blood units are collected at  
no charge.

Eligible blood stem cells from  
the umbilical cord and placenta  
are tested and stored at Canadian

Blood Services' Cord Blood Bank, and eligible units are available for any patient in Canada or world-wide in need of an unrelated stem cell transplant.

Hundreds of Canadians require a stem cell transplant each year, and more than 75% will be unable to find a match within their family. These patients will rely on someone they don't know to save their life.

By donating their baby's cord blood, expectant mothers can give life twice.

Visit [www.blood.ca/cordblood](http://www.blood.ca/cordblood) for more information

**On your mark.  
Get set. Let's Go!**

**Walk / Run / 5k**  
*In conjunction with  
Scotiabank Marathon*

**Vancouver June 25th  
Toronto October 22nd**

**Do you want to join the AAMAC  
Marrow Movers Team?**

Vancouver registrants, please contact the National Office at [adminoffice@aamac.ca](mailto:adminoffice@aamac.ca) or 1-888-840-0039. You will receive a package and be signed up as a Marrow Mover!

Toronto registrants can sign-up directly with Scotiabank Marathon at: <http://www.torontowaterfrontmarathon.com/stwm-charities/aamac-aplastic-anemia-myelodysplasia-association-canada/>

Go Marrow Movers!

## Movie Screening

Please join us on Thursday, September 28<sup>th</sup> at 7pm in Toronto for a screening of Mixed Match. Presented in conjunction with the Japanese Canadian Cultural Centre located at: 6 Garamond Court, Don Mills, Ontario.

This is a great opportunity to see an informative movie and assist AAMAC with fundraising. Funds raised will go towards assisting patients with bone marrow failure diseases.

Mixed Match is an award winning documentary about mixed race people suffering from cancer reflecting on their multiracial identities and complex genetics as they struggle to find bone marrow donors.

Additional details will be posted at [aamac.ca](http://aamac.ca) when available.



## Kamloops Resident with MDS Profiled

*This article written by Adam Williams originally appeared in Kamloops this Week on December 30, 2016 and is reprinted with permission.*



*Bob Davoren as photographed by Dave Eagles, Kamloops, BC*

Bob Davoren hasn't changed. It was in August of 2015 that Kamloops This Week published The Davoren Legacy, a feature on the then-71-year-old and a life that has led to him being known as Kamloops' unofficial sports historian.

At that time, Davoren was just months removed from being diagnosed with myelodysplasia syndrome (MDS), a cancer in which blood cells in the bone marrow don't mature properly. Doctors had said he could have as little as a few months to live. Now, just months away from the two-year anniversary of his diagnosis, the man they called "Bullet Bob" in his baseball days hasn't changed. He still has the same infectiously optimistic attitude, still loves to tell a good story.

Always the collector, he's giving away more items than he's picking up nowadays, but in almost every other way, the 73-year-old seems the same. "I don't quit," Davoren told KTW.

“You have days you think about it, but then there’s so much support — family and friends — it’s just incredible.”

Since speaking with KTW in 2015, life has gone on relatively normally for Davoren.

Of course, there have been the chemotherapy treatments at Royal Inland Hospital, but he still managed to get out for another hunting season and has been at Sandman Centre, an ever-faithful season ticket holder for the Kamloops Blazers.

He and his wife, Peggy, made a trip south to celebrate their 50th anniversary — making it to the milestone had been a goal when he was first diagnosed — and the two hosted Christmas for the family this month at their Sun Rivers home.

Life goes on.

“I just turned my 73, Peg and I did our cruise, got our 50th anniversary in, which was fantastic. Life’s not bad,” Davoren said, his face alighting with a smile, his hands still jumping with excitement as he spoke.

But there have been down moments, too. There are days Bob feels unwell and struggles with the idea he can only make plans a month or two in advance. Once avid travellers, he and Peggy miss their trips to Mexico.

But they have 25 years of memories from those trips to fall back on, he said.

He has been thankful to have this time to bring some closure to his life, to hand out his bits and pieces of Kamloops sports history, memorabilia, to people he knows will appreciate them. And, though it’s no secret the treatments he’s receiving are getting less and less effective, he’s grateful they worked at all.

Always the lucky man, Bob’s latest stroke of good fortune has been the therapy, which only works on 40 per cent of MDS patients and has given him nearly two more years with his family. Life won’t last forever, but he’s going to squeeze the joy out of every last moment, as he always has.

“Like I said a year-and-a-half ago, I was going to fight to get out and chase some big bucks around and get to Christmas and now I’m going to fight for the next one,” he said.

“Why not? There’s no quitting. You don’t quit.”

## Life-Saving Stem Cell Transplants

*Reprinted from ontario.ca News Release*

**New Facility at Sunnybrook Part of Plan to Expand Care for People with Blood Diseases February 7, 2017 10:20 A.M. Office of the Premier.**

Ontario is investing in a new facility at Sunnybrook Health Sciences Centre that will offer specialized treatment for people with blood cancers such as leukemia.

Premier Kathleen Wynne was at Sunnybrook in Toronto today to announce the government's support for a new Complex Malignant Haematology (CMH) site. Sunnybrook will become the second hospital in the Greater Toronto Area -- along with Princess Margaret Cancer Care -- to provide a full range of potentially life-saving CMH services, including stem cell transplants.

Ontario is also improving treatment for people with blood diseases by:

Renovating facilities at Sunnybrook Health Sciences Centre, the University Health Network's Princess Margaret Hospital, Hamilton Health Sciences and The Ottawa Hospital

Expanding CitiCall Ontario, a 24-hour emergency consultation and referral service, to help doctors caring for acute leukemia patients get better access to expert clinicians and services.

Investing to improve care for people with blood cancers and disorders is part of our plan to build a better Ontario by providing patients with faster access to the right health care.

Quick Facts:

- In 2015–16, 859 adults received stem cell transplants. This was up from 744 patients who received stem cell transplants in 2014–15.
- Approximately 15 patients received stem cell treatments outside the country in 2015–16.
- Stem cell transplants can save the lives of people suffering from various types of blood diseases. Chemotherapy destroys diseased cells, as well as bone marrow. Stem cells can regenerate bone marrow, which then produces new and healthy blood cells.



*When a new mother decides to donate her umbilical cord blood, she could be helping someone like 11-year-old Aaryan Dinh(center), who is living with Aplastic Anemia*

## World Blood Donor Day June 14<sup>th</sup>

World Blood Donor Day is celebrated globally each year on June 14<sup>th</sup>. We band together to raise awareness about the importance of blood donation and to recognize and thank the thousands of donors that give the gift of life.

This day has an additional purpose: to create wider awareness about the need for availability and (appropriate) use of safe blood and blood products.

There is always a need for blood donations. Please contact Canadian Blood Services to find a donor clinic near you.

Canadian Blood Services:  
1-888-236-6283 or  
[www.blood.ca](http://www.blood.ca)

## New Email Addresses

To help you find the support you need, AAMAC has created standardized email addresses.

### How to Find Us

General Inquiry - [info@aamac.ca](mailto:info@aamac.ca)

Inquiry Specific to your Province:

[bcsupport@aamac.ca](mailto:bcsupport@aamac.ca)  
[albertasupport@aamac.ca](mailto:albertasupport@aamac.ca)  
[ontariosupport@aamac.ca](mailto:ontariosupport@aamac.ca)

### National Office

Administration:  
[adminoffice@aamac.ca](mailto:adminoffice@aamac.ca)

Executive Director:  
[cindyanthony@aamac.ca](mailto:cindyanthony@aamac.ca)

## Anti-Spam Legislation



What is the Canadian Anti-Spam Legislation (CASL)?

CASL was developed to deal with electronic spam and has two main objectives:

1. To limit the ability of companies to send emails that are unwanted and unasked for; and,

2. To prohibit and control unwanted downloads of programs onto people's computers.

AAMAC has developed and approved a CASL policy and continue to ensure your communication preference is respected.



Currently, AAMAC sends paper mail to approximately 1300 patients each quarter. This translates into printing and mailing costs of approximately \$8,200 each year. If you are able, please help us save trees and costs and opt to receive the newsletter via email.

We are happy to continue providing support and sending paper mail if you do not use or do not like email.

**Please let us know your communication preference:**

*email or paper mail.*

**Contact us at:**  
[info@aamac.ca](mailto:info@aamac.ca)

**or**  
**1-888-840-0039**



# Tree of Life

The Tree of Life is a way of recognizing those who have been affected by AA, MDS or PNH.

To purchase a leaf, please contact the National office at:

1-888-840-0039

or

[info@aamac.ca](mailto:info@aamac.ca)



*This beautiful carved tree is on display at our Annual General Meeting and other meetings in the Toronto area, whenever possible. The rest of the time it hangs on the wall at the national office.*

## In Honour of:

Alan Patt  
Barbara Doiron  
Beatrice and David Murphy  
Bernice Teasdale  
Bill Gryba  
Bill Hunt  
Calogero Ciccarelli  
Cameron Root  
Caroline Laughlin  
Carrie Plotzke-Cleghorn  
Cindy Bell  
Don McIntyre  
Dr. Melvin Freedman  
Gord Sanford  
Heather Parsons  
Karlee May  
Kris Plotzke  
Liz Lemire  
Lois Henderson  
Lori Lockwood  
Paul Coad  
Pietro Di Ilio  
Renee Levine  
Rumi Guzder  
Ryan Rutherford  
Silvia Marchesin

Taylor-Marie Coupland  
Trevor Thompson  
William Laughlin  
Yvette Aloisi  
Nastor W. Bill Gryba

## In Memory of:

Albert H. Stahlke  
Alexander Bowen  
Alexandre Castonguay  
Angela M. Poto  
Aristotle John (Telly) Mercury  
B. Elaine Pond  
Barbara Culbert  
Barbara Jean Cronyn  
C. Donal Leach  
Constantine Deplares  
Daniel Orara  
Danny Carrick  
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Giovanni Arcuri  
Glenn D. Schwartzendruber

Gord Sanford  
Gordon Burgess  
Gordon O'Halloran  
Harry Alfred Roper  
Heather McIntyre  
Helen Robinson  
Herb Sixt  
James Novak  
Jim Smith  
Joe Burleigh  
John Maxwell Cameron  
John R. Barton  
Keith Curry\*  
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Kenny Wentzell  
Laurel Burgess  
Lauren Renaud  
Marcelle Gai Thomas  
Marko Lyshak  
Marnie Douglas  
Megan Locke  
Nicole Wilson  
Olive Lilian Sundal  
Paul Ullrich  
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