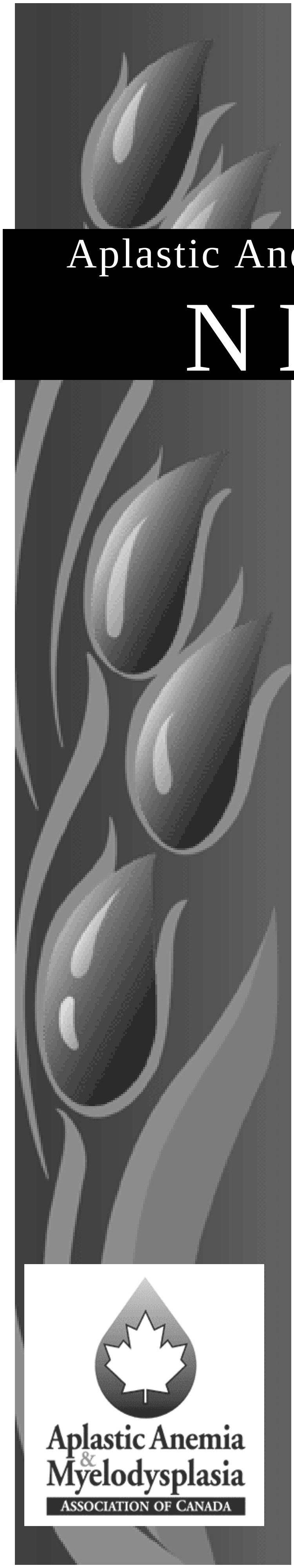
Education
Support
Research

Winter 2015



Aplastic Anemia & Myelodysplasia Association of Canada

NEWSLETTER

Executive Director's Message

December has arrived after a beautiful autumn season. We had the opportunity to meet many patients and caregivers over the fall at our meetings across Canada. We are so grateful for the medical professionals who gave presentations and answered questions for the participants. We also thank our sponsors Celgene, Alexion and Novartis. We also are so thankful for our many volunteers who assist with the planning and coordination of our meetings. Without the volunteers we would not be able to offer the many supports we have available. For the first time we recorded our annual patient education day in Toronto and these presentations will be available to view on our website by the middle of December.

AAMAC has a wonderful Board of Directors and we thank them for their ongoing service. This year we said goodbye to two board members Michelle Joseph and Rolla Bahsous. We thank them for their dedication over the past years and are happy they will continue to support AAMAC in other areas moving forward. We are looking for new board members and if you feel you may be interested in joining the board, please contact me by calling 1-888-840-0039 or emailing 4anthony@rogers.com.

Plans are well underway for meetings and webinars in 2016. We already have our Patient Education Day & Annual General Meeting planned for October 15, 2016 in Moncton, New Brunswick. Watch for details of other meetings as the dates become available on our website and in future newsletters.

I would like to take this opportunity to wish each of you a very happy holiday season celebrating with family and friends.

Cindy Anthony
AAMAC

The Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC) provides information about aplastic anemia (AA), myelodysplasia (also 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.

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:

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BC Update

By Janice Cook

Thank you to everyone who joined us in Surrey on September 26 for our education and support meeting. We had a variety of patients, from newly diagnosed to those we have met before, as well as quite a range of knowledge about bone marrow failure. We had two great speakers. Dr. Amrit Kahlon did a great job of explaining what everyone needs to know about their lab results, and the similarities and treatments for MDS, AA and PNH. She was followed by Michelle Foreman, an oncology nurse who works with MDS patients at the Burnaby Cancer Center. Her talk was about living with disease and managing side effects of treatment and the disease itself.

If you weren't able to come, Michelle's slides are posted on our website, www.aamac.ca. Check them out – there are lots of good ideas you can use.

After lunch we were privileged to hear from Ed, Robin, Loralee, Guja, Jim and Wendy, who reminded us that caregivers need caring too. They told us their stories, and they shared ideas about coping with their own illness. We heard about maintaining a good relationship with your health care team, empowerment through knowledge, making treatment decisions, and lifestyle choices that included family, friends, meditation, exercise, tai chi, diet choices, travel and above all a positive attitude.

Thank you so much to all of our speakers for making it a really great day of learning and meeting others.

AAMAC has many previous education day sessions on our website site for viewing. As well, there are webinar sessions posted on the AAMDSIF site, aamds.org, if you are interested. If you have trouble explaining to your family or friends what the doctor has told you, directing them to these resources can help.

Pictured at the Surrey meeting from left to right are Ed, Robin, Loralee, Guja, Wendy and Jim holding up their AAMAC volunteer t-shirts.

A little reminder to everyone that flu season is here, and it's time to ask your doctor if you should get a flu shot. If not yourself, then maybe those you live with could. It's another way you can be protected.

Atlantic Support Group Update

By Gwen Barry

On September 11, the Halifax Area Support Group had a meeting in the new Halifax Public Library. The guest speaker for the occasion was Gredi Patrick, Critical Care Nurse, QE II Health Sciences Centre. Gredi spoke on Personal Directives (Living Wills). Her talk was most informative, and certainly gave the group some food for thought.

Guided by AAMAC's Executive Director, Cindy Anthony, four members of the Atlantic Region, (Linda O'Brien, Dolores d'Entremont, Allana MacDonald Mills, and yours truly) were involved in the development and conduct of an Education Day in St John's, Newfoundland and Labrador on September 29. In addition to the attendance of 15 Newfoundland patients and their support persons, this Education Day was attended by 15 Registered Nurses. The nurses took in the full day's slate of speakers, as well as a separate MDS lunch and learn session designed by AAMAC especially for nurses. It is the intention of the Newfoundland and Labrador Health Sciences Centre's Hematology Nurse Educator to have another such

MDS session in the near future for those nurses who were unable to attend the first session. The four hematologists and the psychiatrist who spoke were most informative. And it is noteworthy that they gave up a valuable Saturday to be with us for the benefit of patients, support persons, and nurses alike.

AAMAC plans to hold another such Education Day in the Atlantic Region in the Autumn of 2016. It is expected to be in Moncton. There will also be an AAMAC Annual General Meeting of registered members at this gathering.

Plans are also in the works for our Annual Halifax Support Group Christmas Brunch on November 29, 2015, with arrival at 12:30 p.m. for brunch starting at 1 p.m. It will be a pot luck affair. Anyone in the Halifax area wishing to attend, should contact Dolores d'Entremont by email at dodent10@gmail.com or phone at (902) 477-0958.

Ontario Support Group Update

Join us for a FREE Patient Support Meeting

Kitchener Waterloo:

Tuesday, February 9th
6:30 - 8:30pm
Location: Wellspring Grand River
Guest Speakers: Lia Kutzscher & Margaret Mayer

Hamilton:

Saturday, February 27th
10:30am - 12:30pm
Location: Wellwood
Guest Speaker: Dr. Brian Leber, MDCM, FRCPC, Hematologist

Toronto:

Saturday, April 2, 2016
10:30am - 12:30pm
Location: Bloor Street United Church
Guest Speaker: Dr. Richard Wells, MD, PhD, FRCPC, Hematologist

London

Saturday, April 23rd 10am - 12pm
Location: Wellspring Cancer Support Centre, 382 Waterloo Street, London
Guest Speaker: Dr. Cyrus Hsia, MD, FRCPC, HBSc, Internal Medicine & Hematology

To Register:

Call: 905.780.0698 / 1.888.840.0039

Email:aamac_office@bellnet.ca

Rare Blood Disorders Education Day 2015

"Getting your Health in Working Order with Comprehensive Care"
By Silvia Marchesin

The 2015 Rare Blood Disorders Education Day was held October 17 in Calgary. This collaborative event is the third conference held in Alberta organized by the Network of Rare Blood Disorder Organizations – Alberta (NRBDO-AB). The NRBDO-AB is a dedicated group of volunteers associated with these rare blood disorder patient groups:

- Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC)
- Canadian Association for Porphyria (CAP)
- Canadian Hemophilia Society (CHS) – Alberta Chapter
- Canadian Immunodeficiencies Patient Organization (CIPO)
- HAE Canada
- HHT Canada THH
- Thalassemia Foundation of Canada (TFC)
- Sickle Cell Foundation of Alberta (SCFOA)

The 200 people who attended the Education Day were overwhelmingly supportive of the event. The day was divided into two sections: presentations in the morning that included topics of interest to all of the attendees and breakout sessions in the afternoon where each patient group had a separate room and agendas specific to their rare blood disorder.

There were advantages in bringing these groups together such as to:
a) educate patients, families and healthcare workers via speakers with a variety of expertise in rare blood disorders
b) allow patients to connect to patient groups that can provide them ongoing education and support c) to provide an opportunity for informal networking between patients, organizations, and healthcare professionals
d) showcase the Rare Blood Disorders clinic in Calgary, and
e) raise the level of understanding of comprehensive care for each of the disorders.

AAMAC included a presentation on Bone Marrow Failure by Dr. Michelle Geddes, hematologist and bone marrow transplanter in Calgary. Dr. Geddes did a great job outlining the three diseases of aplastic anemia, PNH and myelodsyplasia (MDS) as well as talking about the topic of iron overload. She basically did a full education day in the afternoon! She was very open to patient concerns and questions. We appreciate Dr. Geddes sharing her time and expertise with us.

Financial support by the following sponsors allowed us to host the education day free of charge and to provide travel bursaries to those living outside the city of Calgary. Our thanks to: Alexion Pharma Canada, Alnylam Pharmaceuticals, Bayer, CSL Behring, Grifols, Novartis Canada, Octapharma Canada, Recordati Rare Diseases, Calgary Old Time Hockey Players Association, Calgary Foundation and the University of Calgary.

Patient Education Day

Thank you to all the volunteers who made this year’s annual national Patient Education Day such a success! This year the event was in Toronto.

Congratulations to long-time AAMAC volunteers Caroline and Bill Laughlin who received the 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 includes a $5,000 donation to AAMAC.

We also congratulate Philiz Goh of the University of Toronto who received the 2015-2016 AAMAC Canadian Nurses Foundation Nursing Scholarship and joined us at Education Day.

In announcing the person selected for this year’s nursing award, Annette Martin of the Canadian Nurses Foundation noted that “Philiz cares for oncology patients throughout their cancer journey and thanks to your investment in nurses, plans to mentor and support nurses to provide quality care for all oncology patients.” She added, “Your contribution to nursing excellence is greatly appreciated by CNF staff, award recipients, and the oncology patients who benefit from improved health care.”

Philiz is pictured here with Executive Director, Cindy Anthony, above.

Canadian Nurses Foundation AAMAC Nursing Grant Recipient

By Philiz Goh, 2015-2016 grant recipient

My passion to provide the best quality patient care possible began eight years ago when my father was diagnosed with terminal brain cancer. I observed the care that the nurses had provided my father and my family, and upon my father’s passing, I decided to do research with the Odette Cancer Centre focusing on palliative care. This allowed me to publish three books and do multiple presentations nationally and internationally. It was such an eye opening and life changing experience. Soon after my mother was diagnosed with breast cancer, I took on the role as the primary caregiver. This experience helped me affirm my decision to pursue a nursing career in oncology.

I currently care for oncology patients throughout their cancer journey, which I believe is a true privilege. I plan to be in a leadership position to mentor and support nurses to provide quality patient care. I also plan to continue to do research, continue to publish and present at national and international conferences, and continue my leadership roles at regional and national levels with the Canadian Association of Nurses in Oncology (CANO).

I would like to thank the Canadian Nurses Foundation and the Aplastic Anemia & Myelodysplasia Association of Canada for this prestigious award. This award will help further assist me in achieving my educational and career goals as an oncology nursing leader. Without a doubt, this award will prove to be extremely valuable in helping to reduce the financial burdens of pursuing a Masters degree in Nursing.

AA Survivor’s Second Chance

By Regan Clark

It was April 2013 and I was heading into what promised to be a great summer. That all changed after a sudden and frantic appointment with my general practitioner (GP) and the wheels fall off my summer and my life. We found out my bloodwork was at an all-time dangerous low and I may have leukemia.

After a series of appointments with a hematologist and a few transfusions, we discover I have a rare bone marrow disorder, Aplastic Anemia. Now, most people have never heard of this autoimmune disorder and as I delved into more information about it, I learn the cause of this type of anemia is quite diverse. My medical team couldn’t figure out why I had come down with this disorder so it was termed idiopathic, which means there wasn’t a definitive answer to the cause. For other patients the disease was brought on by specific drug therapy, long term exposure to radiation and / or exposure to benzene. There wasn’t any genetic markers for me either so the anemia literally came out of left field. Who knew!!!

Diagnosed on July 4, 2013, which just happened to be my 50th birthday, I can't tell you what a shock it was. It was overwhelming, scary and fraught with so many questions. I had bruising on my feet and a low platelet count that would have done me in had I been hit my head accidentally. What a wake up call!!!

So the big question was how did this happen? The inner critic in my head was whirling with the question and I kept thinking that maybe I had done something wrong that God didn't like and I was being punished or maybe I was exposed to some wicked virus that took me down an uncharted road. I eventually stopped dwelling on this and focused on what I needed to do. I had to put my game face on and be the positive person that I am to get through my treatment and eventual bone marrow transplant.

As I journeyed through the process of getting my life organized and preparing for the next steps I was connected to AAMAC and was fortunate to meet a mentor, Michelle, who became a tremendous support. She was a great sounding board for the many questions that one has when going through a transplant. We are now good friends in kind. She had her transplant 20 years ago and is living a fabulous, normal life. I now understand how important it was to have a mentor who understood what the "drill" was. We chatted weekly throughout and it was comforting to know that I was understood. My family and friends were also amazing. They kept in touch, drove me to treatment and hung in there with me when I was puking my guts out.

My initial round of treatment began in July 2013 with a round of immunosuppression ATG horse serum. I was admitted on July 9 and was as nervous as hell because I had not spent a night, never mind a week in hospital. My hematologist, bless his soul, came in to calm the waters the first day and give me the details on how all this was going to work over the course of the week. I had my own pharmacist, nurse, hematologist, nurse practitioner and social worker visit as well. By the evening I was feeling pretty important… ya right… but a bit more at ease. My family has a wicked sense of humor and many jokes were made at the onset of the said horse serum series. They called me Seabiscuit and my sister took it upon herself to call me daily and serenade me with her rendition of horse related country ditties. We laughed a lot during that week.

Day one treatment went well until evening hit which was when my body decided to go into the rigours. This would have scared the tar out of anyone other than the medical staff and I was glad that there wasn't anyone visiting. The rigours are basically caused by an allergic reaction so needless to say I was fairly gorked out by the time all the antihistamines and narcotics hit the bloodstream. Possibly the highest I have ever been in my life. The moments of said lucidness that evening were fraught with complete and utter BS that spouted willfully out of my trap. I did provide some entertaining moments for the evening staff and one of my friends on the phone. It's one of those moments you remember… well sort of… and are reminded of by the people who witnessed the maniacal behaviour. So in short… never give Regan narcotics or you will be in for the monologue of the century. The rest of the week went as planned and they kept me very medicated to make sure the allergy thing wouldn't raise its ugly head again. The next steps were outpatient care for three months to see if I went into remission.

As October approached we decided to do another round of treatment because my situation hadn't changed. This round would now be a series of ATG from a different source, rabbit. Crap by the time this was finished I would be running the trifecta at breakneck speed. This was a bit of the the same approach but a bit easier on the body. And yes… my new nickname became Wabbit. There was a bit of a bounce back from this second treatment but not enough to put me into remission. So, I wasn't up at the horse races running the track so we know the first treatment didn't work and well. I wasn't running rip shod throughout the neighbourhood eating everybody's vegetable gardens so I guess the big decision was around the corner. My family was then asked to go for testing to see if any of them were a match for bone marrow transplant. My older brother came back as a perfect match with the exact same blood type so this was a card in our pocket that we were going to draw from. He was so excited about being a match and that, my friends is how I was cured of the disease. By the way, it is very rare to have a sibling match. Truly an act of God I think!!

I must admit if anyone had said to me that I was going to be up for a bone marrow transplant going into my fifties I would have said they were insane. But here I was and this was/is a cure for my disorder so we went for it. The thing was once you made the decision there was no turning back. There were moments of what I call "holy crapness" where I was a bit anxious about the prospect of chemotherapy prior to transplant.

Then the "what if" syndrome where you are reading too much stuff on the internet about the effects of chemo and possible things that could happen after transplant. Well holy cow you wouldn't step outside the door of your home if you believed all the stuff written on the net. So the deal was to draw on all the courage that I could muster and I have a ton. This took me above and beyond when I was in the throws of getting organized for what I would term an awesome adventure to wellness. Know this, I was in really good physical condition and had little illness to deal with before diagnosis. In fact I was still running long distance and exercising like a fiend until I was admitted into the hospital.

While I was in hospital and preparing for transplant there were six days of full on chemotherapy. First I had to have a Hickman line put in my chest for the IV meds and eventual bone marrow infusion. That was a trip!! All drugged up again and talking throughout the whole procedure. The surgeon asked me to shut the cake hole at one point because I wouldn't shut up. Yup, I was higher than a kite again and we know what happens with that. Regan and her BS monologue!!!!! Having said that, I did extremely well chemo week and I was able to work out every day. With my brother being ten out of ten as my match, I was feeling pretty confident about my recovery going forward. After chemo week I was moved to the isolation unit and was there for 26 days. The staff and I placed bets on my discharge date. One of the nurses won that bet.

After 26 days I was homeward bound. I stayed with a good friend for two weeks to make sure I felt ok before I gathered my dog up and headed home to recover on my own. I slept the days away the first week. I got up in the morning for protein shake, did an hour of exercise and went directly back to bed each day. I was completely bushed and needed the rest. I weighed in at 118 lbs and at 5'6" that is rail thin. So my dear friend Sue made sure that this skinny wicket would eat breakfast lunch and dinner without fail. My stomach was fairly off most of the time from my meds so it was hard to eat too many exotic meals. Mashed potatoes were a "go to" along with a few other weird things. I had this penchant for oranges for weeks on end so there wasn't any continuity in what I was eating. Eventually the appetite returned and by October of that year I was off all of the rejection drugs. What a relief!!

Going back to home was a huge because I would now have to muscle through on my own and after being around so many people every day coming in and out of my room I was a bit nervous the first month. There was a 100-day isolation rule to abide by as well so that I didn't get sick during my recovery. I had to make sure I wasn't being exposed to any virus etc. so I had to wear a mask when I went out of my home. I had Community Care Access Centre (CCAC) come in once a week to change the dressing on my Hickman line which I had to keep in until day 100. When the Hickman removal day came I was over the top excited to get rid of this thing that I wrestled with every night when I would go to bed.


Regan Clark

On day 100 I had small party to celebrate my recovery and getting rid of the mask as well as the Hickman. I had a nice bottle of champagne that was opened and enjoyed by all along with some lovely appetizers. The rest of that summer was a complete adventure in recovery.

I had never been off work for an extended period so it felt very strange. I took advantage of every moment of good weather. I hung out in the park with my dog, read a ton of books, exercised daily, ate healthily, rested when I needed to and had the occasional visit with friends and family.

I eventually took on a part time job doing cycling wine tours down in Niagara-on-the-Lake later that summer which really enhanced my recovery. The first few bike tours I was a bit nauseous but I was able muscle through the rest of the season by changing the time of day that I took my meds. Bit of a juggling act but I did it and very grateful that it worked out.

Today is so different now. I appreciate the small things like waking up healthy every day and feeling like I have a new lease on life. Remembering and writing this article really drives it all home. Life can change in a second and here's what I know to be true today.

What I have learned throughout this process that is paramount to a successful recovery is that you need to champion your own wellness. You also need to actively participate in your recovery. You need to connect with the people that can offer support. You also need to know your body and your limits. If you feel that your meds are a problem, say so; if you aren't feeling well, let your medical team know; if you need help, ask for it; if you feel your treatment plan needs to change, make it happen.

Communication is key and only you know how you feel so step up your game and speak your truth! After all none of us are mind readers.

Today, I am now 621 days post transplant and doing well. I am back working, cycling, teaching downhill skiing in the winter and loving life. Every day is a blessing and I am so happy to have my life back. I am grateful for all my friends and family who gave me support and help when I needed it. I am so thankful to my hematologist Dr. Walker and his group who were key to this transplant success.

Most of all I am very fortunate to have had the opportunity for a second chance!

A second chance at life, love and freedom. No words can explain how thankful I am for my brother who saved my life! He is a hero and he helped me champion my wellness!

Canadian Blood Services Update

By Pam Wishart

Canadian Blood Services (CBS) has a National Liaison Committee (NLC) and 5 Regional Liaison Committees (RLC) set up across the country other than Quebec which has its own blood service, Héma-Québec (H-Q). The NLC is made up of blood/blood product user representatives, health professionals and a representative from each of the RLCs. The NLC and the RLCs meet twice a year. AAMAC has a representative on the NLC, currently Ashley Oakes. I am on the BC and Yukon RLC. Discussions include the safety of the blood supply which I used to think of as how safe is the blood but now realize also includes how to ensure a supply of blood to meet the demands. Ways to increase the donor base are always on the agenda.

Following the "tainted" blood scandal of the late 70s and early 80s, men who had had sex with another man since 1977 (MSM) were not allowed to donate blood in Canada other than for research purposes. The margin of error in the screening tests then available was too great to protect the safety of the blood supply. Over the years, the Lesbian, Gay, Bisexual, Transgender, Two-spirited, Queer Community (LGBTTQ) has continually lobbied for a change in the permanent deferral for MSM and has received a lot of support from university student groups.

Since the mid-90s, testing for sexually transmitted diseases has improved dramatically. In 2013, CBS and H-Q felt there was sufficient evidence that the safety of blood would not be adversely impacted and they requested that Health Canada change the deferral for MSM from an ever-increasing number of years to 5 years. The change was approved and there was an understanding that the deferral would be reviewed in two years, i.e. in 2015.

It is now 2015 and CBS has been working with blood user groups and the LGBTTQ community as well as others to discuss the evidence available and the impact a change to a one-year deferral for MSM would have on blood safety. I was invited to attend a meeting in September as AAMAC's representative as Ashley was unable to go. Other patient organization representatives were present as well as representatives from the LGBTTQ.

From the data gathered since the change from a lifetime to a 5-year deferral, Dr. Dana Devine, CBS, was able to tell us that rates of transmissible diseases in our blood donors have not changed. In addition, evidence from countries such as Australia and Great Britain, where 1-year deferrals were introduced in 2000 and 2011 respectively, has not shown an increase in the rates of transmissible diseases in their donors since the change. Blood operators in the United States where the lifetime deferral is still in place have received draft guidance to adopt a change to a 1-year deferral from their regulator, the U.S Food and Drug Administration.

Some participants still felt that the change to a 1-year deferral is not enough and would prefer to see a deferral based on one's behaviour, i.e. is your sexual behaviour risky or is it not? Dr. Devine explained that while Italy and Spain have gender neutral risk behaviour based criteria for donors, their blood services and donor base differ from ours and, at present, there is insufficient data to determine whether or not this is a safe approach.

One patient organization representative has received blood donations regularly for decades and spoke very eloquently about her fears during the tainted blood crisis, refusing the blood was not something she could do. Her comments obviously resonated with some of the men who want to donate but can't; it helped them appreciate the feelings of regular users of the blood system.

The overall consensus of the participants was that we support the change as long as it is safe. In addition, a majority want CBS to proceed with gathering the data needed to change to a gender-neutral questionnaire/policy for donation and to allow gay men in long-term monogamous relationships to donate.

CBS and H-Q are preparing to submit a request to their regulator, Health Canada in early 2016 for a change to a 1-year deferral for MSM.

And, by the way, CBS is always looking for donors, and, in particular, encouraging young donors for whom blood donation can become a lifelong habit. So donate if you can, ask others to donate for you if you can't and let your younger family members and friends know how important a safe and sufficient blood supply is.

News of Note

Thank you Melanie!
We left off an important name in our last issue's article about nurses' education. The MDS program was created for our use by Melanie Burke (née Anderson) RN,NP. Melanie was a previous AAMAC nursing scholarship winner as well as an AAMAC Board Director, and worked with the BMT program at the Tom Baker Cancer Center in Calgary, Alberta. Thank you Melanie from everyone at AAMAC.

Board Members Needed
By Gwen Barry

AAMAC's Nominations Committee is seeking three new members for our Board of Directors. We need one new member with legal experience, as well as a new member who can represent the Province of Alberta, and one who can represent children with AA/MDS/PNH. It is an opportunity to be personally involved in carrying out AAMAC's mission to serve in the education of patients, care givers, and medical professionals, and in our contribution to the advancement of medical/scientific research into these diseases. Anyone wishing to apply should contact the AAMAC office at aamac_office@bellnet.ca 1(888) 840-0039 or (905) 780-0698.

Waterfront Walker
Clara Deabreu (pictured) is a MDS survivor, currently in remission. In September, she walked the Scotiabank Toronto Waterfront Walk for charity to raise awareness about MDS and raise money for AAMAC. As of this writing, she raised $735 with some donations still to be received. Thank you Clara!

Canadian Stem-cell Scientists Redefine How Blood is Made

The following news was shared by the Princess Margaret Cancer Foundation in November. We remind members that it can take a long time before research results in treatments for patients.

Stem-cell scientists led by Dr. John Dick have discovered a completely new view of how human blood is made. The findings, published online in the journal *Science*, prove “that the whole classic ‘textbook’ view we thought we knew doesn’t actually even exist,” says principal investigator John Dick, Senior Scientist at Princess Margaret Cancer Centre, University Health Network (UHN).

“Instead, through a series of experiments, we have been able to The research also topples the textbook view that the blood development system is stable once formed. Not so, says Dr. Dick. “Our findings show that the blood system is two-tiered and changes between early human development and adulthood.”

Co-authors Dr. Faiyaz Notta and Dr. Sasan Zandi from the Dick lab write that in redefining the architecture of blood development, the research team mapped the lineage potential of nearly 3,000 single cells from 33 different cell populations of stem and progenitor cells obtained from human blood samples taken at various life stages and ages.

For people with blood disorders and diseases, the potential clinical utility of the findings is significant, unlocking a distinct route to personalizing therapy.

Dr. Dick says: “Our discovery means we will be able to understand far better a wide variety of human blood disorders and diseases – from anemia, where there are not enough blood cells, to leukemia, where there are too many blood cells. Think of it as moving from the old world of black-and-white television into the new world of high definition.”

There are also promising implications for advancing the global quest in regenerative medicine to manufacture mature cell types such as platelets or red blood cells by engineering cells (a process known as inducing pluripotent stem cells), says Dr. Dick, who collaborates closely with Dr. Gordon Keller, Director of UHN’s McEwen Centre for Regenerative Medicine.

“By combining the Keller team’s ability to optimize induced pluripotent stem cells with our newly identified progenitors that give rise only to platelets and red blood cells, we will be able develop better methods to generate these mature cells,” he says. Currently, human donors are the sole source of platelets – which cannot be stored or frozen – for transfusions needed by many thousands of patients with cancer and other debilitating disorders.

The discovery, funded in part by The Princess Margaret Cancer Foundation, builds on Dr. Dick’s breakthrough research in 2011, also published in *Science*, when the team isolated a human blood stem cell in its purest form – as a single stem cell capable of regenerating the entire blood system.

“Four years ago, when we isolated the pure stem cell, we realized we had also uncovered populations of stem-cell like ‘daughter’ cells that we thought at the time were other types of stem cells,” says Dr. Dick.

“When we burrowed further to study these ‘daughters,’ we discovered they were actually already mature blood lineages. In other words, lineages that had broken off almost immediately from the stem cell compartment and had not developed downstream through the slow, gradual ‘textbook’ process. So in human blood formation, everything begins with the stem cell, which is the executive decision-maker quickly driving the process that replenishes blood at a daily rate that exceeds 300 billion cells.”

For 25 years, Dr. Dick’s research has focused on understanding the cellular processes that underlie how normal blood stem cells work to regenerate human blood after transplantation and how blood development goes wrong when leukemia arises. His research follows on the original 1961 discovery of the blood stem cell by Princess Margaret Cancer Centre scientists Dr. James Till and the late Dr. Ernest McCulloch, which formed the basis of all current stem-cell research. finally resolve how different kinds of blood cells form quickly from the stem cell – the most potent blood cell in the system – and not further downstream as has been traditionally thought,” says Dr. Dick, who holds a Canada Research Chair in Stem Cell Biology and is also Director of the Cancer Stem Cell Program at the Ontario Institute for Cancer Research.

Did You Know?

They say an apple a day keeps the doctor away, but if you need a doctor your Apple phone might be able to help. Medical ID is a freaqture in the new iOS 8 operating system which can provide important medical information in the event of an emergency. If you have an Apple phone check it out. And also check for similar offerings if you carry another phone. As always, check to see what security features are included.

Don’t have a cell phone or not comfortable loading personal informaiton into your phone? You can still check out medicalert.ca for a wide range of jewellry options for both genders.

Tree of Life

Each year, we publish the list of people who have been remembered or thanked with a leaf on AAMAC's Tree of Life.

The Tree of Life was created by David McTavish. 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 is kept at the head office.

The Tree of Life is a way to recognize those who have been affected by AA, MDS or PNH. You may make a tax-deductible donation of $150 to have a special person's name inscribed on the tree.

If you are interested in honouring your loved one(s) through the Tree of Life, please call the office at (905) 780 -0698 or 1 (888) 840-0039 and we will send you the form to complete. The form is also on our website.

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
Deborah Armstrong *
Donald J. Highfield
Dr. Peter McClure
Earl J. Banford
Ed Glazier
Elizabeth Rose Herman
Elmer Kerbes
Erin Lawless
Geof Smith
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*
Kenneth Kwok Shing Mok
Kenny Wentzell
Laurel Burgess
Lauren Renaud
Marcelle Gai Thomas *
Marko Lyshak
Marnie Douglas
Megan Locke
Nicole Wilson
Olive Lilian Sundal
Paul Ullrich
Philip Doiron
Pietro Di Ilio
Robert M. MacDonald *
Rodney W. Crocker
Roger Fortin
Sheila Rivest*
Sheryl Hylton
Stanley Foch Willis
Stephanie Dawn Temple
Sterling Ruggles
Susan Laughlin *
Talsa Coon
Trevor Thompson *
Valdemars Jankovskis
Vern Coles
Walter Salamandyk
Wilfred Hinchey
William Slawson
William Terry McEvoy

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

**Indicates this person has more than one leaf on the Tree of Life*
Last updated: October 21, 2015 / cf