

*Education
Support
Research*

Spring 2015

Aplastic Anemia & Myelodysplasia Association of Canada

NEWSLETTER

Chairperson's Message

You may be wondering why I am writing the Chairperson's Message this issue. Michelle Joseph, who was elected as Chair in October has unfortunately had to step down for health reasons, but we are delighted that she has agreed to remain as a member-at-large on the board. Her input is invaluable, and I would like to thank my colleague and friend for the work that she did in laying the groundwork for our upcoming year while she was Chair.

At our last board meeting, I was elected to the Chair position. I am honoured to have the opportunity to represent you in that role over the next couple of years. I am equally excited to announce that Ashley Oakes has been elected to the Vice Chair position that I vacated. She is going to do a great job. I also wish to thank Janice Cook, Claude Francoeur and Rolla Bahsous for their great contributions to the board. And special thanks to our Past Chair, Pamela Wishart, for all the wisdom and guidance she so generously shares with me on a regular basis, and Gwen Barry (our hardworking board Secretary and AAMAC Atlantic Co-ordinator) for all of the support that she and all of the members of AAMAC Atlantic have shown me.

Volunteering is what makes an organization like this work. We are indebted to our Medical and Scientific Advisory Committee; and people like our Treasurer (Anna Chamrai) and our newsletter editor (Chris Meyer) to name but two. We are currently seeking new members for our Board of Directors. So if you have ever considered volunteering for AAMAC, and would like more information, we would be interested in hearing from you.

I especially want to thank the person who is the backbone of AAMAC, our Executive Director, Cindy Anthony. It has been a very busy time for Cindy over the past few months and the board appreciates her dedication more than words can say.

As many of us are still digging our way out of winter and dreaming of spring, AAMAC plans are well underway for 2015. Our website will be updated this year and we will be hosting our second webinar very soon (details can be found in this newsletter so read on). As well, our Nursing Education Program will launch shortly with the first module focusing on MDS.

Our annual Education Day/AGM will be returning to Toronto on Saturday, October 17. This exciting day, generously funded by our sponsors, is full of interesting and informative presentations from excellent speakers, and is an opportunity to ask questions and meet people who have similar stories to your own. The agenda will be included with your next newsletter, along with the registration form and travel bursary information. And finally, I am thrilled to announce that the date for our patient education day in St. John's, Newfoundland, has been set for Saturday, September 26. Plans are well underway and details will be distributed soon.

Sincerely, Jennifer Garvey, *AAMAC Chairperson*



**Aplastic Anemia
&
Myelodysplasia**
ASSOCIATION OF CANADA

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.

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Aplastic Anemia and Myelodysplasia Association of Canada
11181 Yonge Street, Suite 321
Richmond Hill Ontario L4S 1L2
(905) 780-0698 or 1 (888) 840-0039

info@aamac.ca. www.aamac.ca
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BC Update

By Janice Cook

I've sent out information recently about an upcoming webinar about iron overload. Dr. Heather Leitch gave us the same information last October at our short format education day, so if you missed it, this webinar will be very helpful to you if you are dependant on blood transfusions. Iron overload can occur after about 20 units of transfused blood. I don't have email addresses for some of you, so if you would like a phone call before meetings or webinars please give me a call. We realize that as our newsletter is only four times a year, you might miss out on some timely information without a phone call.

We also have information about a Leukemia/Lymphoma Blood Cancer Education Event that may be of interest to MDS patients. It will be held on March 14 at the Van Dusen Gardens on Oak Street. It is called "Stepping Back into Life after a Cancer Diagnosis" and includes disease specific discussion groups and Art Therapy. For more information contact Sharon Paulse at (604) 733-2873 or sharon.paulse@lls.org.

We are very interested in knowing if anyone is having trouble accessing Vidaza due to the inconvenience of travelling to receive it, or even choosing not to take it for this reason. Please phone me at (604) 826-7222 or Pam Wishart at (250) 590-6057 or email us at bc@aamac.ca if you would like to discuss this.

Atlantic Update

By Gwen Barry

A support group meeting was held in Halifax in September 2014 at the home of Jackie MacDonald. A Christmas Brunch was held in Halifax on November 30 at the home of Dolores d'Entremont. Atlantic Support Group now has two members on AAMAC's Board of Directors, namely Jennifer Garvey as Chair, and Gwen Barry as Secretary.

We are planning to meet in Halifax in January, as the guests of the Leukemia and Lymphoma Society (LLS), Atlantic Support Group, to review videos made for LLS by some Atlantic AAMAC and LLS members, concerning caregiver issues and experiences. The videos are intended for eventual use in nurse training. We are hoping in the Spring to arrange a



Nov. 30, 2014 Atlantic Support Group Christmas Brunch. Front Row (left to right): David McFarland, Gwen Barry, Dolores d'Entremont, Linda O'Brien, Jan Mills, Tanya Hastings. Middle Row, seated left to right: Ken Sabean, June O'Brien, Goldie Sabean, Leona O'Brien, Diana Garvey, Jennifer Garvey, Judy Smith. Back Row, standing left to right: Laura Rawlings, Jackie MacDonald. Empty Chair – Mackenzie Davie (the photo taker).

tour of the new Canadian Blood Services Centre in Dartmouth, Nova Scotia. A provincial Education Day is also in the works for Saturday, September 26, 2015 in St John's, Newfoundland. More information will be sent out and will be posted on AAMAC's website, once the details of these upcoming events are known.

AA/MDS/PNH patients and their families are welcome to attend any events of the Atlantic Support Group. Please feel free to get in touch, should you wish information on activities and/or if you would like to be provided with educational material on these diseases. Contact Gwen Barry, Coordinator, Atlantic Support Group, Lower Sackville, Nova Scotia at gwenb@eastlink.ca or (902) 864-8872.

Blood donation: Did you know?

By Janice Cook and Pam Wishart

At AAMAC, we encourage people to donate blood, platelets and plasma, and to join the Canadian Blood Services' (CBS) OneMatch Stem Cell and Marrow Registry or register as a stem cell donor with Héma-Québec. As CBS' new umbilical cord banks get up and running, we encourage support and participation in those also. Héma-Québec already has a cord blood bank in place. We know that people who donate want to help others in a meaningful way.

We think most people know about the extensive screening process that is in place to protect the recipients of blood products from infections that can be transferred during infusion. People are not allowed to donate if they have new tattoos, piercings, or a history of travel in countries where blood-borne diseases like Malaria are endemic. Since the "tainted blood" problems in the 1980s, the focus in Canada has been on maintaining a supply of safe blood and blood products for all Canadians. We have toured both the Canadian Blood

Services national facility in Brampton, Ontario, and the Héma-Québec facility in Montreal and learned about the vigorous testing and strict standards for donated blood products required before they reach those who need them to survive. We trust our blood system and it helped to save Janice's life 10 years ago.

A person may donate only after a screening questionnaire and private interview to ensure the blood will be as safe as possible for the recipients. In BC this past fall, we heard of a case of a blood donor being refused (deferred) when they went to donate at a Canadian Blood Services clinic. They had already passed the first stages, health was good and they had no answers on the questionnaire that would cause them to be deferred. Then, while chatting, they mentioned they wanted to donate because their spouse was transfusion dependant. At this point the potential donor was told their blood could not be accepted. In order to understand why, we contacted Dr. Mark Bigham, the Medical Director for CBS in BC. This is what he told us:

Currently, a 12-month temporary deferral for donating blood is required after receipt of blood or blood products, such as red blood cells, platelets, plasma, or manufactured products like IVIG and factor VIII. This deferral is very precautionary, given the very low residual risk of blood-borne infections for which blood donors are routinely screened. As an added precaution, because many blood-borne infections can also be sexually transmitted, a sexual partner of a person who is receiving ongoing, regular treatment with blood, a blood product or clotting factor is also required to wait six months from the last sexual contact with that individual.

The temporary deferral for a sexual partner of a person receiving regular treatment with blood, a blood product or clotting factor is not new and it actually used to be a year-long deferral until shortened to six months by Health Canada to align with the deferral period applied for a number

of other potential risk factors for blood-borne infection, such as tattooing or skin piercing. The six-month deferral period is very precautionary and based on the potential incubation period of several diseases of concern, such as HIV, hepatitis B and hepatitis C. The deferral is in spite of the fact the donor's sexual partner received blood, or a blood product that was screened and tested for a range of blood-borne infections and manufactured by strictly regulated, quality controlled processes.

For some risk factors of concern for blood-borne infection, there is a 'capture' question on the donor screening questionnaire that will help identify the issue; for example, in the case of malaria (which can be transmitted through blood), donors are asked about travel in the past 12 months. Alternatively, a specific question may be asked on the donor questionnaire; so for example, there are specific questions related to either receipt of blood or a blood product in the last 12 months, or receipt of a clotting factor; and to sexual contact with a person receiving clotting factors in the last six months. However, for other potential risk factors (generally assessed as lower risk), neither a "capture" nor specific question may be on the donor screening questionnaire, which aims to strike a balance as a comprehensive, accurate, screening tool to identify risk factors of greatest concern, but which can be administered as efficiently as possible. Nonetheless, the questionnaire is very detailed and donors, indeed, even long-term experienced donors, may not recognize that a specific question applies in their context, one to which they may have replied "no" in the past.

Although Dr. Bigham acknowledges the extremely low risk associated with this, Health Canada and Canadian Blood Services have blood safety as their primary goal. Donor eligibility criteria undergo ongoing scrutiny and review and it is possible that eligibility criteria for partners of recipients of blood, blood products or clotting

factors (including recombinant clotting factors) may be reviewed in the foreseeable future. He is on a joint Canadian Blood Services/Héma-Québec working group that reviews these criteria.

So, currently, unfortunately, for those of you who wish to be blood donors, if your partner is transfusion dependant or using any of the products derived from blood plasma, your blood cannot be used for patients. There are other ways you can make a meaningful contribution. Volunteer your time at a donor clinic, hand out AAMAC brochures and tell donors why you appreciate what they are doing or donate money to the cord bank fund. Check out the CBS or Héma Québec website for ideas and specifics on what volunteers can do.

For those who live in, or periodically visit, Vancouver, there is another way a deferred donor can make a difference and this is through donating blood to be used exclusively for research. There is a centre, unique to BC, on the University of British Columbia campus called NETCAD. It is a CBS affiliate and centre for blood research where the deferred donor can donate. They must still meet certain criteria but the criteria are less stringent. The research is focused on improving the safety and effectiveness of transfusions so you would still be helping your loved one, and you would be treated and acknowledged just like a regular CBS donor. Information about this can be found on the CBS website, blood.ca, under Blood and then Blood for Research.

Canadian MDS Research Update

The following news release was issued in November. It is slightly adapted for this newsletter. Dr. Richard Wells Chairs AAMAC's Medical and Scientific Advisory Committee and Dr. Christine Ichim has volunteered with AAMAC and been profiled in past issues of this newsletter.

We congratulate Drs. Wells and Ichim on their continued efforts to help patients with MDS. We remind patients that research takes many years and treatment decisions should be discussed with your doctor.

Regen BioPharma Acquires University of Toronto Cancer Stem Cell Intellectual Property: *Company Aims to Use Small Molecule and Gene Silencing to Target "Root" of Cancer*

Regen BioPharma Inc. announced acquisition of patent application # US 13/652,395 with a priority date of November 2008 which covers a novel gene target essential for the survival of cancer stem cells. Inventors of the intellectual property on which this patent application was filed are University of Toronto Hematologist Dr. Richard Wells and Dr. Christine Ichim, Senior Research Consultant for Regen BioPharma.

The invention is based on findings that leukemic stem cells, which are capable of giving rise to aggressive leukemias, contained high levels of the NR2F6 gene, whereas leukemic cells that are less aggressive and cannot give rise to disease lack this gene.

Importantly, when the NR2F6 gene was silenced by shRNA in leukemic stem cells, the stem cells lost leukemia forming ability and turned into normal cells. Some of these data were published in the peer-reviewed literature(1). Subsequently, it was discovered that the same gene target NR2F6 is also found in cancer stem cells in other types of tumors such as breast, lung, ovarian, and colon(2).

"Dr. Christine Ichim has spent over 10 years in identifying the importance of NR2F6 in cancer stem cells and devising means of killing these tumor initiating cells by genetically or chemically blocking NR2F6. We are enthusiastic about adding this new piece of intellectual property to our developmental pipeline," stated David Koos, Chairman & CEO of Regen BioPharma. "The area of cancer stem cells is associated with extremely high valuation at early stages of clinical

development. An example of this is the \$155 million upfront payment in the Celgene-OncoMed deal last year for preclinical candidates and one candidate in early phase 1.(3) Through the acquisition of this intellectual property, which has such an early priority date, we believe we are well-positioned in this exciting new area at the interface between regenerative medicine and oncology."

Cancer stem cells are the subpopulation of cells in a tumor responsible for driving growth and metastasis of the tumor. These cells exhibit certain properties which include the capacity to divide and give rise to new cancer stem cells via a process called self-renewal and the capacity to differentiate or change into the other cells that form the bulk of the tumor. Common cancer drugs target bulk tumor cells but have limited impact on cancer stem cells, thereby not "hitting" the right target and allowing for cancer recurrence and metastases.

"Regen BioPharma has a track record of rapidly translating university originating intellectual property into products, as seen with granting of IND numbers for HemaXellerate and dCellVax. Additionally, the company has recruited top notch translational researchers such as Drs. Amit Patel, David White and David Suhy. I am very excited at the prospects of clinical implementation of the intellectual property that was assigned today," said Thomas Ichim, Ph.D.

About Regen BioPharma Inc.: Regen BioPharma Inc. is a majority owned subsidiary of Bio-Matrix Scientific Group, Inc. Regen is a biotechnology company focused on identifying undervalued regenerative medicine applications in the stem cell space and rapidly advancing these technologies through pre-clinical and Phase I/ II clinical trials. Currently the Company is focused on developing treatments for Aplastic Anemia and a gene silencing therapy for treating cancer. For more information: regenbiopharma.com. Company Disclaimer: This news release may contain forward-looking

statements. Forward-looking statements are inherently subject to risks and uncertainties, some of which cannot be predicted or quantified. Future events and actual results could differ materially from those set forth in, contemplated by, or underlying the forward-looking statements. The risks and uncertainties to which forward looking statements are subject include, but are not limited to, the effect of government regulation, competition and other material risks.

(1) Ichim et al. Leukemia. 2011 Nov;25(11):1687-96 (2) Safe et al. Mol Endocrinol. 2014 Feb;28(2):157-72 (3) www.drugs.com/news/celgene-oncomed-177m-cancer-stem-cell-deal-49294.html

\$10 Million Donation to Research Made in Memory of MDS Patient

The following news release was issued by the University of Calgary in December 2014.

The University of Calgary will study how cells detect and repair DNA damage, using this research to reduce cancer rates and improve treatments for cancer patients. The research will take place in the newly created Robson DNA Science Centre.

The centre was made possible by a \$10-million gift from Dave Robson – through the Dave and Val Robson Fund at The Calgary Foundation – to the Southern Alberta Cancer Research Centre (SACRI) at the Cumming School of Medicine.

“This gift, coming from a highly respected community leader and friend of the University of Calgary, will allow the Cumming School of Medicine to build on its strength in DNA research by recruiting top talent,” says President Elizabeth Cannon. “The Robson DNA Science Centre will provide critically important basic research for the future of cancer treatment in southern Alberta.”

Dave Robson, an award-winning Calgary businessman, made the gift in honour of his late wife, Val, who passed away in May 2014 from myelodysplastic syndrome – a rare cancer that affects bone marrow. The Robson DNA Science Centre will advance the understanding of DNA stability and repair, translating this knowledge into innovative cancer prevention strategies.

“Val and I wanted to do something meaningful, something that would make a difference to people who had been diagnosed with cancer, just like she had,” says Robson. “The importance of research can’t be overstated – the scientists in the Robson DNA Science Centre are doing life-saving research that will help improve the lives of Canadians in years to come.”

Robson worked with The Calgary Foundation to make his gift. The foundation was able to guide Robson toward the project. “The Calgary Foundation discovered what Dave Robson cared deeply about and brought Dr. Greg Cairncross, the director of SACRI, and Dave together. The rest is history,” says Eva Friesen, president and CEO, The Calgary Foundation.

In his business life, Robson was successful because he concentrated on the fundamentals. For this reason, he was attracted to the opportunity to honour his wife by investing in fundamental cancer research.

All cancers have one thing in common: a mistake in the DNA. DNA errors occur commonly in human cells, but are quickly repaired. However, sometimes mistakes in DNA accumulate, overwhelming the capacity of the cell to repair its DNA, thus setting the stage for cancer.

The aging process, and repeated exposure to toxins such as tobacco, asbestos, radon gas and UV light, are the usual causes of multiple errors in DNA. But occasionally, the DNA repair machinery itself is faulty, often because of an inherited weakness in

repair capacity; DNA errors accumulate for this reason. Inherited weaknesses in DNA repair are one of the major causes of cancers that run in families, such as those of the breast and colon. The core group of DNA scientists will contribute to cancer prevention by studying how cells protect and repair DNA.

One in every two men in Alberta, and one in three women, will develop cancer in their lifetime. Among Albertans affected by cancer, one in four will die from the disease. By 2030, as a result of population growth and aging, it is estimated there will be 27,000 new cancer cases each year in the province. The Robson gift will contribute to Alberta’s cancer strategy: to prevent as many cancers as



possible.

The Robson DNA Science Centre was made possible by a \$10-million gift from Dave Robson – through the Dave and Val Robson Fund at The Calgary Foundation – to the Southern Alberta Cancer Research Centre at the Cumming School of Medicine.

Beyond a Cure: MDS Survivor & Canada’s First Trained Cancer Physiatrist

By Helen Branswell, Canadian Press

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Treating cancer can't end when chemotherapy does; rehab medicine focuses on fixing physical toll

Dr. Eugene Chang lost 50 pounds he couldn't afford to shed, but found a calling when he underwent cancer treatment at age 25.

The challenges Chang faced battling his way back to physical health after his bout with his disease inspired the rehabilitation medicine specialist to rethink his career path.

He decided to pursue a subspecialty for which there is a growing need, becoming Canada's first trained cancer physiatrist. A physiatrist is a doctor who specializes in rehabilitation medicine. It's a field for which the need is growing, says Dr. Gaetan Tardif, medical program director for rehabilitation and physiatrist-in-chief at Toronto Rehab, where Chang now works.

Society isn't doing enough to help people with cancer minimize the physical toll the disease and its treatments take on patients, and recover from that impact, Tardif says.

While the notion of cardiac rehab after a heart attack or rehab for people who have had strokes or spinal-cord injuries is well established and even expected these days, the need to address the impact of cancer hasn't kept pace.

"If you have a stroke, nobody these days is thinking: 'Yeah, we'll send a physiotherapist for a few minutes a day and things should be OK,'" says Tardif. "But in cancer, we haven't developed that thinking that... we need a team of people."

"We're not quite going far enough in getting people to function optimally in the community."

Nick Marks knows from personal experience that it can be a real struggle. Marks, 70, is a semi-retired benefits consultant living in Toronto. In July 2013, he learned he had



Dr. Eugene Chang (left) works with cancer patient Nick Marks at Toronto Rehab. Photo: Nathan Denette, The Canadian Press.

multiple myeloma, a type of cancer that attacks white blood cells called plasma cells. The disease, which can be managed but not cured, impedes a person's ability to mount an immune response to invading pathogens like bacteria and viruses.

In the process of his treatment, Marks contracted *C. difficile* diarrhea, landing in hospital for two months. A slender man – and one who professes to hate exercise – Marks could not walk by the time his *C. difficile* was cured. He has been working with Chang to regain his mobility. "You really have to relearn to walk, and I'm still doing that," he says.

The two work on strengthening the older man's legs. Motivated to get rid of the cane he still uses, Marks is walking, climbing stairs and doing exercises that target his thighs. Chang too learned of the importance of this rehabilitation medicine first-hand.

In the autumn term of 2005, he started a residency in psychiatry at the University of British Columbia. "I thought I was going to do sports (rehab) or something like that. I had

no clue of my journey at the beginning of my residency," he admits.

An active guy who cycled to work and played hockey in his free time, Chang suddenly found normal exertion was making him breathless and fatigued. A blood test, followed by a bone-marrow test, produced an unexpected result – he had myelodysplastic syndrome, a cancer affecting the bone marrow.

Chang's medical career took a two-year hiatus as he underwent chemotherapy and then a bone-marrow transplant. The transplant was a success, and nine years later he remains cancer-free. But the treatments left him weak and in need of rehab medicine himself. Chang found he had to push to get the care he knew he needed. "That was a real eyeopener," he admits. "This was not a good thing and maybe this was a problem in cancer generally."

When Chang went to resume his rehabilitation medicine training in the fall of 2007, the experiences of his time as a cancer patient had changed his thinking about what his focus should be. Sports rehab was out. The cancer rehab was in.

Some of the effects of cancer care are specific to the type of the disease. For example, the problem of stiff shoulder can sometimes follow a mastectomy for breast cancer patients. Others are general – things like fatigue, muscle-wasting and sometimes neuropathy, the loss of nerve cells in feet and hands that can affect things like a person's gait.

Tardif says too often with cancer, people see the disease as a reason to give up on exercise and physical conditioning. Everyone pays the price for it, he says. "Are we quitting a little too early on the full community reintegration? Are we focusing too much on just fixing the medical problem? But then what? And the better we get in medicine at fixing problems, the more important the 'Then what?' is," he says.

"Frankly, I want somebody to save my life, but if I'm going to be miserable for the next 10 years at home, I'm going to have second thoughts about how good that deal was."

Mark Your Calendars

Please also check local provincial updates for regional support group meetings and education events.

Have you been diagnosed with myelodysplastic syndrome, aplastic anemia or PNH? Would you like to meet others with the same diagnosis? Check out our support group meetings. Patients, caregivers and health care professionals are welcome to attend.

Come out and meet other patients and families dealing with the same bone marrow failure diseases as yours. Share stories, compare notes, learn how others are managing and see how they are responding to treatments. For further information call the AAMAC office toll free at (888) 840-0039 or contact info@aamac.ca.

Ottawa Support Group Meeting

Join us for our monthly meetings which are held at the Ottawa Regional

Cancer Foundation, 1500 Alta Vista Drive, from 6 to 8 p.m. the second Wednesday of each month.

Upcoming dates planned in 2015 are March 11, April 8, May 13, June 10, July 8, August 12, September 9 and October 14. Please note that the November meeting will take place on November 18 instead of the second Wednesday of the month due to Remembrance Day.

Kitchener Support Group Meeting

You're invited to attend a support group meeting in Kitchener on Wednesday March 11, 2015 from 6:30 to 8:30 pm at the Hopespring Cancer Support Centre, 16 Andrew St #2, Kitchener, Ontario.

Our guest speaker will be Jacqueline Wells, BASc, RD who is a Registered Dietitian, Oncology at the Grand River Regional Cancer Centre.

Jacqueline will provide nutrition recommendations for survivorship – managing long term side effects of treatment as it relates to nutrition-related health concerns, recommendations for prevention of other chronic diseases for the cancer survivor – such as prevention of cardiovascular disease, Type 2 diabetes, and other forms of cancer.

A light dinner will be served. Please R.S.V.P. to info@aamac.ca or call (888) 840-0039.

Montreal Support Group Meeting

Patient Education Meeting
Saturday, April 18, 9 a.m. to noon
Maison du développement durable
50, rue Sainte-Catherine Ouest,
bureau 101, Ste-CATHERINE Room
Speakers:

Dr. Albert Moghrabi, Hémato-oncologue, Hôpital de Verdun

Line Bourgeois, Infirmière pivot hématologie/conseillère clinique en soins infirmiers, Hôpital général juif de Montréal.

Light breakfast will be served.

There is no charge to attend. Please RSVP to info@aamac.ca or (888) 840-0039.

Thank you to Celgene, Alexion and Novartis for sponsoring the event.

Iron Overload Webinar

The Aplastic Anemia & MDS International Foundation (AA&MDSIF) hosts an online webinar, "Iron Overload in Acquired Anemias" with Dr. Heather Leitch at 8 p.m. on March 25. Dr. Leitch is a hematologist at St. Paul's Hospital in Vancouver, B.C. and a Clinical Professor at the University of British Columbia. To find out more about this free event, visit aamds.org.

Toronto Support Group Meeting

Please join us and special speakers on March 28, 2015 at the Canadian Blood Services building, 67 College Street, 4th floor room 4A/B from 10 a.m. to noon:

- Diet and Iron Overload
Daniela Fierini, RD, Clinical Nutrition Practice Leader, Allied Health University Health Network/Princess Margaret Cancer Centre
- Building Blocks of Hope
(A handbook providing strategies for patients and caregivers living with MDS), Cindy Murray RN, NP Malignant Hematology/Princess Margaret Cancer Centre and Member of the MDS Foundation International Nursing Leadership Board

Please RSVP to info@aamac.ca or call (888) 840-0039. Light refreshments will be served.

U.S. Patient Conferences Planned

The AA&MDSIF has announced six free patient and family conferences in 2015: Baltimore, March 28; Cleveland, May 2; San Francisco, July 18; Boston, September 19; Chicago, October 24; and Tampa, November 14. For more information, visit aamds.org.

AA & MDS Awareness Week

The Aplastic Anemia and MDS Awareness Week this year will be held in the U.S. from March 1 to 7 in conjunction with the National Organization for Rare Disorders' Rare Disease Day on February 28. Rare Disease Day is also held in Canada.

Save the Dates!

This year's national Patient Education Day will take place in Toronto on October 17. A provincial Education Day is planned September 26 in St John's, Newfoundland.

News of Note

Call for Directors

Have you ever considered volunteering as an AAMAC Board member or know someone you think might be interested? Consider nominating yourself or someone else. AAMAC is currently in need of individuals with experience in finance, law and/or technology. We also welcome volunteers who have personal experience with a specific bone marrow failure disease such as PNH, AA or MDS. If you're interested, recommendations must be made to the committee at least 21 days before the annual general meeting in October. Contact info@aamac.ca for more information.

Calling Canadian Nurses

The Canadian Nurses Foundation's online process for the 2015-2016 scholarships applications is now open. The deadline is March 31. This includes the deadline to apply for the Aplastic Anemia and Myelodysplasia Association of Canada Scholarship which funds nurses focusing their research in the field of hematology or oncology. For more information, please visit cnf-fic.ca.

ASH Meeting Held in San Francisco

About 20,000 people including hematologists from around the world attended the American Society of Hematology annual meeting in December in San Francisco.

Many sessions focused on bone marrow failure diseases including MDS. If you're interested in hearing about the latest in research and treatments, you can visit hematology.org for summaries of the

sessions or purchase on demand videos of the sessions. Just keep in mind that the presentations are very sophisticated and technical because they were intended for hematologists and scientists.

The AAMDSIF has posted three ASH summary interviews with experts in AA, MDS and PNH for patients on its YouTube channel. A link to the videos can be found at aamds.org. ASH information is not intended to be treatment advice as everyone's situation is different and your situation should be discussed with your doctor.

Fatigue Survey

The AAMDSIF and MD Anderson Cancer Center in Houston, Texas know patients with bone marrow failure diseases experience fatigue. However, most of the scientific studies about fatigue are based on research with patients who have solid cancer tumors, not AA, MDS, or PNH. They want to learn more about patient experience with fatigue so they can better meet patient needs. AAMDSIF is working with Dr. Carmen Escalante at MD Anderson to conduct a research study to learn about fatigue and other symptoms in our patient community. This information will help them improve patient services and programs. If you are interested in sharing your experience please complete the online survey at aamds.org.

Wishing Young MDS Patient Well

AAMAC extends its best wishes to Cierra Singh, an 11-year-old Toronto girl with MDS whose search for a stem cell donor from the South Asian community received significant media attention last year. Fortunately for Cierra, who was one of an estimated 800 Canadians waiting for a transplant, a donor was found and she underwent the transplant in December. At the time of writing this, Cierra's mom had posted on Twitter that her daughter had reached Day 50 post transplant. We wish Cierra all the best!

Mixed Match Film Update

In 2012, AAMAC supported a project called Mixed Match. The film will

explore the need to find mixed ethnicity bone marrow and cord blood donors to donate to multiethnic patients suffering from life threatening blood diseases such as leukemia. Since then the film makers have filmed patients to help tell their stories and encourage people to join their national bone marrow and stem registries. As the film moves into the editing stage, you can find out more and watch clips and trailers at mixedmatchmovie.com.

AAMAC's 25th Anniversary



Thanks to all the volunteers, donors and guests who made AAMAC's 25th anniversary event in Toronto possible. Also, a special thank you to speaker Joe Macdonald who shared his experience at the event and to sponsors Celgene and Novartis. Pictured above are volunteer Caroline Laughlin and Executive Director Cindy Anthony.

Stars Raise MDS Research Funds

Paul Simon, James Taylor, Bobby McFerrin, Randy Brecker and Dianne Reeves performed at a January benefit concert in memory of Grammy-award winning saxophonist Michael Brecker who lost his fight with MDS in 2007. Funds raised at the first Nearness of You concert in New York City will go to MDS research at the Columbia Medical Center. The event was hosted by actor Hugh Jackman.