Education
Support
Research

Spring 2016

Aplastic Anemia & Myelodysplasia Association of Canada

NEWSLETTER

Executive Director's Message

AAMAC's mission is as follows: to provide a seamless support network for every Canadian patient, family member, friend, and concerned healthcare provider dealing with aplastic anemia, myelodysplasia (myelodysplastic syndrome or MDS) and paroxysmal nocturnal hemoglobinuria (PNH).

One of the most important ways we do this is through our patient education and support group meetings.

Included in this issue of our newsletter are some upcoming opportunities for patients, caregivers and medical professionals to attend a number of meetings that are being planned for the upcoming months. Please check our website, Facebook page or follow us on Twitter to get up to date on new meetings planned in your area.

AAMAC is blessed with many wonderful volunteers who assist with the organization of these meetings and support groups. We thank them for their ongoing work and encourage anyone who would like to be involved in volunteering with a group or meeting in their area to contact us.

In addition to our face-to-face meetings, we will be hosting three webinars with the assistance of the Aplastic Anemia & MDS International Foundation (AAMDSIF) and these dates and topics will be finalized in the coming months. These will feature Canadian doctors.

Our annual patient education day will be held in Moncton, N.B. on October 15, 2016. More details and registration information will be on the website as we get closer to the meeting date.

We continue to offer a number of printed resource materials and our patient tracker in both French and English and all can be ordered by emailing info@aamac.ca or by calling the office 1 (888) 840-0039.

Hoping to see many of you at a meeting this year.

Cindy Anthony

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.

The Aplastic Anemia & Myelodysplasia Association of Canada newsletter is published 4 times a year. For submissions, inquiries or comments, please contact us at:
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
Charitable Registration Number
87557 2265 RR0001

BC Update

By Janice Cook

Happy springtime everyone. I hope that the winter passed by without too much dreariness.

Dr Kirk Schultz, of BC Children's Hospital is currently planning a Paediatric Education Day to be held on June 18. Please check for details under News of Note or watch the website for further information on program and registration.

We have received a fairly quick reply to our letter to BC Cancer Agency asking about the lack of access that patients in the Fraser Valley have to Vidaza®. They have to travel to Vancouver for treatment.

Although non-committal, the response is an acknowledgement of the serious gaps in care for this small, often immuno-compromised, group of patients for whom travel can mean debilitating fatigue, and increased exposure to infections. We were assisted by two patients who wrote letters telling of their own experiences and we thank Robin M. and Guja M. for their help.

Any other patients or families who wish to be involved can contact us as we continue to advocate for these patients.

When we had our fall patient meeting, we heard from one caregiver on our patient panel. All of the patients had ideas and experiences to share that were helping them cope with their illness. Our caregiver didn't remember anything specific she had done to care for herself during the lengthy illness and recovery. I think we all can appreciate that a caregiver might be friend or family who has, by necessity, become nutritionist, cook, chauffeur, medical record keeper, errand runner, information translator and disseminator, nurse, cheerleader, consoler, companion, financial advisor, healthcare navigator… The list itself is exhausting. But who cares for the caregiver? Many people find it difficult to ask for or accept help or even to acknowledge their own fatigue, fears or stress. Their attention is focused upon the patient and his/her wellbeing as he/she tries to heal. They may not want to cause the patient any more worry or guilt. Their energy, empathy, and time may be in limited supply, and yet, when asked they may respond with "I'm fine."

I thought it might be helpful to see what, if anything, is available to someone who might not have the spare time or energy to look for help.

An amazing thing that I found out is that in BC alone, about one million people are family/friend caregivers to adults. Think of it – most of us have been, are currently, or will be caregivers at some point in our lives.

Family circumstances are as varied as the illnesses, and the needs. So I didn't look for bone marrow specific information, just information on caregiver need in general. And A LOT of information is out there if you have computer access. Just type "Caregiver" in a search and a lot of things come up, many disease specific.

For those who don't use computers, I would suggest the community library, a community or provincial health information line or a list from a family doctor or social worker.

The government pages of a telephone book (they are blue edged in mine for federal, and solid blue for provincial) have toll free numbers; 1 (800) 622-6232 for government of Canada programs and services. You can get information on how to find out if you might be eligible for disability or caregiver taxation deductions.

The BC provincial listing includes a number of listings under health, including food and nutrition, health and seniors information line, seniors advocate office, and of course information about Pharmacare medications. Health Link can arrange to have a dietitian answer your questions.

Your employer may have good Employee Assistance Programs (EAP) programs that include counselling. I found a website called Family Caregivers of BC that looks excellent. They offer 1) one-to-one support, 2) information and referral to community resources, 3) assistance in navigating the healthcare system, and 4) support groups and also webinars on various topics. They have a newsletter too. Their support line number is 1 (877) 520-3267. The website is www.familycaregiversbc.ca.

This looks like a one stop location for information on health and non-health related resources, both federal and provincial. Scrolling further will eventually get you to a listing of community resources found throughout the province. I also found a phone number for the BC Bereavement Helpline – 1 (877) 779-2223). I hope that if any caregiver is feeling overwhelmed by responsibilities and worries, they recognize that their health is very important too, and overwhelming stress is not a good thing.

These programs are supported by the governments in some cases, and some are registered charities or non-profits. They are there to help you.

I'd be pleased to hear from anyone who has had experience with any resource that they have found, as I do get questions about where to go for help.

Take care, Janice Cook
bc@aamac.ca

Atlantic Region Update

By Gwen Barry

The Halifax Support Group held its annual Christmas brunch at the home of Dolores d'Entremont on November 29, 2015.

We are still basking in the glow of a successful Patient Education Day held in St John's, Newfoundland, last September. We are now proud to be part of another AAMAC Education Day, this time for N. B. and P.E.I. patients and their support person(s). The event will be held on October 15, 2016 at the Delta Beausejour Hotel in Moncton, N.B. A limited number of travel bursaries will be available for patients who reside in N. B. and P.E.I, as well as for one support person per patient. Patients from the other Atlantic Provinces are welcome to register for this event, but travel bursaries will not be available. More information on this event will be available at a later date.

Apart from regional Education Days for patients and their support persons in the four Atlantic Provinces, we can provide a variety of services, including educational material about AA, MDS and PNH, matching patients up with another patient with the same diagnosis, as well as support by phone or email. We also have a small support group in Halifax which meets periodically. If you are interested in any of these services, or in joining the Halifax group meetings, please contact Gwen Barry, AAMAC's Atlantic Region Coordinator, at gwenb@eastlink.ca or (902) 864-8872.

Ontario Update

From the Desk of Darlene Edmonds, Regional Support Liaison, Ontario

Wishing everyone all the very best in 2016.

I'm looking forward to the upcoming patient support group meetings that have been planned for February and April. I've had the pleasure of meeting a few folks over the last month who have already registered for these events. See the listing of the meetings scheduled for Kitchener-Waterloo, Hamilton, Toronto and London.

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 with the AAMAC office. Plans are already under way for the second round of meetings that will be scheduled for early or late spring.

We are considering holding a meeting in the Sarnia/Windsor area. If you are interested in participating, please contact the AAMAC office.

Now I'm six months into my contract position, I'd like to extend a thank you for all the support that has been provided by Carol Fazari, Cindy Anthony and Caroline Laughlin to help me in this new position. Looking forward to the future!

Board Members Needed

By Gwen Barry

The Nominations Committee is seeking new members for AAMAC's Board of Directors.

We are seeking candidates who can represent the provinces of Alberta, Saskatchewan or Manitoba or Territories and/or one who can represent children with AA/MDS/PNH and/or who have legal experience.

It is an opportunity to be personally involved in carrying out AAMAC's mission to serve in the education of patients, caregivers, and medical professionals, and in our contribution to the advancement of medical/ scientific research into these diseases, as well as in advocating for drugs and treatments for patients.

Anyone wishing to apply should contact the AAMAC office at aamac_office@bellnet.ca or 1 (888) 840-0039 or (905) 780-0698.

CORD Calls for Rare Disease Strategy

Editor's note: The following news release was issued by the Canadian Organization for Rare Disorders (CORD) in January. AAMAC is a member of CORD.

Most of the 2.8 million Canadians with a rare disease experience extraordinary and unnecessary barriers getting the right diagnosis, specialist, and treatment. On the eve of Canada's Health Ministers' meeting in Vancouver, the Canadian Organization for Rare Disorders (CORD) and the Economic Club of Canada convened a panel calling for the immediate implementation of Canada's Rare Disease Strategy. This would immediately provide Canadians with rare diseases the same access and quality of healthcare available to those with common conditions like cancer, heart disease and diabetes.

Launched last May, on Parliament Hill, the Strategy calls for national standards for newborn screening, centres of expertise, sustainable access to treatments and dedicated funding for rare disease research.

"We have crafted a Strategy that is both ambitious and achievable," said Durhane Wong-Rieger, President and CEO of CORD. "Canadian strategies for cancer, heart disease, and diabetes have significantly improved quality and longevity of life," specified Wong-Rieger. "More than 30 other countries have national rare disease plans. With respect to drugs for rare diseases, patients have been waiting for over a decade for the national plan that was promised by Health Ministers in 2005. But we are hopeful that these Health Ministers will announce concrete steps towards fulfilling that commitment."

Nicklas Harkins, a 20-year-old from North Vancouver and student at UNBC in Prince George, was diagnosed with a rare disease (MPS I) at the age of five. Speaking at the event, Nicklas said, "Ten years ago, my parents and I, along with many other families, rallied at a similar Health Ministers meeting so that all Canadian patients with MPS I could access the same life-altering treatment I was receiving. We knew treatment would make the difference between progressive loss of mobility, hearing, and sight and a normal life. We were all thrilled when the Health Ministers agreed not only to fund the therapy, but also to bring in a national rare disease drug plan. Today, I am happy to be proof that the drug works, but I am also sad that rare disease patients are still standing in picket lines and appealing for live-saving treatment on a case-by-case basis. I urge the Health Ministers to honour their promise made in 2005 and provide other Canadians with rare diseases the same chance for life."

Fred Horne, former Alberta health minister and Adjunct Professor at the University of Alberta School of Public Health, moderated the event. "It's time for Canada to catch up with other countries and recognize that access to rare disease therapeutics is part of mainstream healthcare. Canada's Rare Disease Strategy is a plan that we can implement now."

"Canada, capitalizing on strong genomic research and an impressive clinical expertise, leads globally in the study of rare diseases such as genetic neurometabolic diseases," said Dr. Sylvia Stockler, researcher, professor and specialist with the Child & Family Research Institute, University of British Columbia and BC Children's Hospital. "Rare disease research also translates to benefits for common conditions."

Robin Sherrington, Senior VP Business and Corporate Development, Xenon Pharmaceuticals Inc., provided a perspective from the pharmaceutical sector. "Entrepreneurs, scientists, governments and investors, must embrace a Rare Disease Strategy that not only advances development and approval of innovative treatments but also assures access, which ultimately improve the lives of all patients and generates economic opportunities."

Based on extensive consultation, Canada's Rare Disease Strategy establishes five major goals specifying 20 practical actions. The five goals are: improving early detection and prevention; providing timely, equitable and evidence-informed care; enhancing community support; providing sustainable access to promising therapies; and promoting innovative research. For the complete plan, go to: raredisorders.ca/canadas-rare-disease-strategy/. Follow Cord on Twitter at #Canada4Rare.

CORD is Canada's national network for organizations representing all those with rare disorders. CORD provides a strong common voice to advocate for health policy and a healthcare system that works for those with rare disorders. CORD works with governments, researchers, clinicians and industry to promote research, diagnosis, treatment and services for all rare disorders in Canada.

National Office Update

Growing Pains

Over 20 years ago, AAMAC was gifted with a database called "ACT!". This database has allowed AAMAC to keep track of member addresses and contact information, donations, and other member information.

Sadly, it crashed in June 2015. We were able to recover most of the data; however, unfortunately the data was corrupted in the recovery. We have been diligently untangling this corrupted data and thank you for sending in your "clean-up" cards that were included in the annual letter mailing in November. If you have any further changes, please contact us.

We sincerely apologise for any mailing issues that you have experienced and appreciate your understanding.

We are carefully reviewing, updating and compiling member information to be moved to a new database (called Sumac), for completion this spring. We look forward to increased functionality, automation and record keeping ability with Sumac.

Again, we thank you for your patience while AAMAC experiences growing pains.

MDS Information Available in Over 100 Languages
The MDS Foundation provides information on MDS in many languages. To access this information, please go to www.mds-foundation.org. There is a box in the top right hand corner of the home page with a drop down menu listing over 100 languages in which MDS information is available. See snapshot of home page below:

The National Office has information booklets on MDS, AA and PNH in English, French and Spanish. Please contact us if you would like an information package in any of these languages.

Support Group for Parents & Guardians
We have heard from many parents of children with AA and we are listening to your needs. If you are a parent/ guardian of a child with AA in the Southern Ontario area and would like to meet with your peers to share information, compare notes and learn how others are coping and responding to treatment please contact us. If we receive a great enough response we will organize and host parent support meetings.

Random Act of Kindness
Thank you to Munich Re for the generous donation of $5,312.
In contacting Munich Re to thank them for this unexpected donation we asked why they chose AAMAC for the donation. Here is their response: they hold an annual raffle draw each year with a 50/50 corporate match. The winner of the raffle gets to choose which charity the money goes to. This year a co-op student won the raffle and conducted research to find a non-profit organization that, "no one knows about." She decided that AAMAC would be the recipient of the raffle this year.

Thanks so much for this wonderful, random act of kindness!!

Volunteer Needed
At AAMAC, we provide support to individuals, families and healthcare professionals dealing with AA, MDS and PNH. We also provide education, fund research and advocate for our members in an effort to improve the lives of Canadians touched by these diseases.
AAMAC is supported immensely by the generous assistance from volunteers.

Currently, we have a need for a volunteer with basic computer skills to assist once a month at the National Office. Duties will include assisting with: quarterly mailings, database implementation, and basic clerical duties.

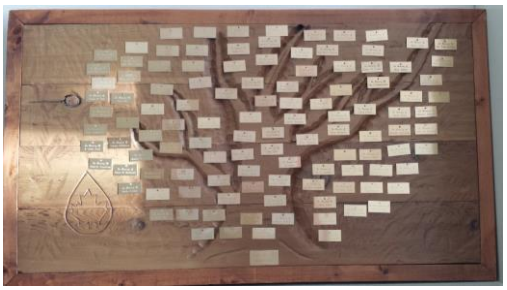
If you would like to assist and are able to come into the National Office in Richmond Hill, Ontario for a few hours each month, please call (905) 780-0698 or email info@aamac.ca.

Tree of Life Dedication
The Tree of Life is a way of recognizing those who have been affected by aplastic anemia, myelodysplasia, or PNH.

You may make a tax-deductible donation of $150 to have a special person's name insribed on a plaque on the tree.

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.

Please contact us if you would like a plaque on the tree created for a loved one and an order form will be sent to you. A copy of the form can also be printed off our website – you can find it under "How To Help." To reach the National Office about any of our updates, please call 1 (888) 840-0039 or email info@aamac.ca.



AAMAC Funded Research Update

New Research On Aplastic Anemia, Myelodysplastic Syndrome and Paroxysmal Nocturnal Hemoglobinuria In Children And Young Adults In Canada

By Dr. Yigal Dror

Aplastic anemia (AA) and myelodysplastic syndrome (MDS) are serious diseases with low blood counts. Many of the medical problems are similar in AA and MDS. In both conditions the bone marrow, where we make all our blood cells, fails to produce enough cells. MDS is a pre-leukemic condition that has some features of leukemia, but not all. A small portion of the patients with AA may develop MDS and leukemia.

Research has resulted in major advances over the last several years. The causes of the diseases can now be identified in about one third of the children with AA and MDS. Important changes in the AA/MDS bone marrow cells and their genetic material have been revealed, that are probably related to the development of leukemia. Also, medical treatments and bone marrow transplant regiments

have improved, and consequently also overall outcome.

Nevertheless, major challenges exist. Results of current treatments are still not satisfactory, and are not successful in about 10-20% of the children with AA and about 40% of the children with MDS. Further, treatment is frequently harsh and prolonged. For example, most children with AA are treated with drugs that suppress their immune system for 1.5 to 2 years. Other children with AA and children with MDS are treated with bone marrow transplantation. Both treatments may cause short and long term side effects.

In order to improve care for patients with a certain disorder there is usually a need for research that includes a large number of patients. In rare disorders such as AA and MDS, enrollment of sufficient patients for one project in a timely fashion is often impossible. Recently, we aimed to overcome this barrier to research in AA and MDS. We opened a registry and offer participation to all patients with AA, MDS and similar bone marrow failure in Canada. We named this registry: the "Canadian Aplastic Anemia and Myelodysplastic Syndrome Study" (CAMS). We will collect medical information on various aspects of the diseases, treatments and outcomes. We will also collect material when the patients have procedures for clinical purposes (e.g. blood and bone marrow samples).

After enrolling enough patients and having sufficient information, researchers of the CAMS consortium will try to better understand the diseases, their causes and ways to improve care and outcome.

The registry and sample repository is run by a multicentre consortium of investigators from 17 centres across Canada, headed by Dr. Yigal Dror at the Hospital for Sick Children. This consortium has been running a complementary registry entitled "The Canadian Inherited Marrow Failure Registry" (CIMFR) for over 10 years. The CIMFR has been very successful and resulted in publications of many papers in scientific journals.

A Perfect Match

By Chris Cakebread

Hi, my name is Chris and I want to share my story with you. I wanted to bring awareness to OneMatch, a bone marrow donor registry, through the Canadian Blood Services.

In the middle of July, I was diagnosed with AML, Acute Myeloid Leukemia. I was hospitalized right away and had a seven-day chemotherapy treatment. Since the chemo kills both the good and the bad blood cells, my white blood cell count would be zero and the risk of infection was high. I stayed in hospital for five weeks. When I was first diagnosed the doctors told me that the goal was the cure, and the cure was a bone marrow transplant once I was in remission. My siblings were tested to see if they were a match for me and were so very disappointed when they were not. The search is now on for a match through the donor registry.

To register as a donor you must be in good health and be between the ages of 17 and 35. Unfortunately this age category eliminated the majority of my family, friends and co-workers. Unless you know of someone with leukemia, most of us would not be aware of the need for donors. The need is there, not just for me, but also for everyone that needs a transplant, regardless of ethnic background. To get started it is just a simple mouth swab, and then if you are a match, more testing would be needed. If you, or anyone you know would be interested in becoming a donor, just go to OneMatch.ca or call 1 (888) 2-DONATE for more information.

What a wonderful thing to give the gift of life now. You could be the ONE MATCH for someone, somewhere, someday! Through the work of OneMatch, they have now found a perfect match for me. I am so very thankful and blessed. There are still over 1,000 people hoping for their match too.

Many, Many Thanks, Chris

Editor's note: We thank everyone who's already joined the registry and wish Chris the very best with her transplant!

Join the Match4Aary Movement

Editor's note: This article is adapted from a message on www.match4aary.com and is printed with permission from Aaryan and his parents, Jenny and Khalid.

Our 10-year-old son, Aaryan is the light in our lives. He has the ability to bring a smile to our faces, no matter when or where. Throughout his life, he has been an active playful child - baseball games, soccer tournaments and of course, video games. His consideration for others is astronomical, caring and concerned for others before himself.

Early in November, we noticed bruising on Aaryan, but had dismissed them as we knew our boy was being a typical boy. As each day passed, more and more bruising became visible. On November 13, 2015 Aaryan experienced extensive gum bleeding and was brought to Toronto's Hospital for Sick Children (or SickKids) Emergency Department. After numerous rounds of blood work, Aaryan was admitted into SickKids for life threatening low blood counts.

During his stay, Aaryan received numerous blood transfusions and a bone marrow aspiration/biopsy. Results came back and we were devastated to find out our son was diagnosed with Aplastic Anemia.

For the next several months, Aaryan will be returning to SickKids twice a week for routine blood work and blood transfusions. Without the transfusions, Aaryan becomes vulnerable to infections (viral and bacterial) and hemorrhaging (external and internal). Even though there are Drug Therapy treatments available for this condition, his best chance of a CURE is through a bone marrow transplant. As Aaryan is an only child, his best chance for a bone marrow donor match is through the registries.

Aaryan has continued to show his strength and bravery since his diagnosis. And we need your help to secure a match for him, so he can continue to spread his light onto every person he meets. A special thanks to the team at SickKids for the continuing care and effort to help Aaryan. To our family and friends, words cannot express our gratitude to you for all you have done and continue to do. You have been our strength during this difficult time, but together, we will overcome this!

To everyone out there, whom we have not met and who have shown your kindness and willingness to help – thank you, thank you, thank you!

Aary's chances of beating this rare disorder are best if he can undergo a bone marrow transplant within the next few months. A bone marrow match is not related to blood type.

Without any siblings and because it has now been determined that neither of Aary's parents is a match, it is crucial that we help grow the registry of potential donors. Today's medical technology allows testing of potential donors as well as actual collection of cells for transplants with little disruption to the life of the donor(s).

Testing to see if you are a match is as simple as a swab of the inside of the cheek. It will take approximately 12 weeks from your cheek swab to be added to the registry. When you donate to OneMatch or Héma-Québec in Canada or Be the Match (US), you are not matched specifically to Aary, you can be matched to any patient and bring hope to families anywhere in Canada or around the world.

It is most likely that a match will come from the same ethnic and ancestral background. This means that there is a great need for donors of Vietnamese/Asian and Afghan/ Central Asian ethnicities.

Unfortunately, because these groups are dramatically underrepresented in the National Bone Marrow Registries, the challenge is the small chance of finding a match in the current pool of donors recorded in the registres in order to help Aary. We need your help grow these registries, in these communities and beyond.

And if we push really hard, fast and use our networks to get our folks educated, mobilized and registered, we could not only help Aary be cured of this disorder but also save the lives of many others in these communities.

For more information about registry drives visit www.match4aary.com. To find out more about giving blood or joining the registry, visit blood.ca.

Staircase to AML

Reprinted with permission of McMaster University.

Many years ago, Dr. Mick Bhatia and his team resolved to answer a set of very difficult questions: Why do normal blood cells become cancer cells? How does this transition unfold? And finally, what can we do about it?

The team's specific interests lay in a particular type of blood cancer: Acute Myeloid Leukemia (AML). AML, like other leukemias, develops when blood stem cells change and become unable to grow or behave normally. In AML, it is the myeloid stem cells that become abnormal. These abnormal cells multiply uncontrollably, and in doing so they impair the functioning of healthy cells. AML is the most common acute leukemia among adults.

Although the cause of AML is not always known, there are several events that have been linked to increased risk of developing AML, such as myelodysplastic syndromes (MDS). Approximately 30% of MDS patients will develop AML. The trouble is that despite knowing 30% of these patients will develop AML, we have lacked the ability to accurately predict exactly which patients will fall into that category.

Enter the newest study out of the Bhatia Lab.

The study, published in the January 11 issue of *Cancer Cell*, demonstrates that early and accurate prediction of AML in MDS patients is a possibility. In determining that AML progresses in a

stepwise manner, and identifying two of these steps, the researchers found a tool that was able to predict disease progression and outcomes for these patients.

"We've found that the transition from healthy to cancerous blood stem cells happens in clear, compartmentalized steps," said Dr. Bhatia.

Using both gene-knockout and molecular fingerprinting techniques, the researchers were able to model and track the transition that healthy blood stem cells undergo on the way to AML. They found that removing one copy of the GSK-3 gene resulted in "angry, hyper-profilerative pre-cancer cells," consistent with MDS; then, when they removed the second copy of the gene, aggressive AML developed.

Seeking to apply these findings to human patients, our SCC-RI researchers entered into a collaboration with a team of Italian researchers who had been monitoring a group of MDS patients over a 10-year period, observing how the disease progressed in each individual. The retroactive study done on these samples proved that molecular fingerprinting was accurate in predicting which patients would develop AML, and which would not.

AML is designated as acute because if left untreated, it will quickly become fatal. Currently, we rely on the possibility of early detection and awareness of certain risk factors to improve our chances against cancer. Beyond those strategies, we are limited in our defenses against the disease. The ability to predict AML development from MDS before it occurs would add another defense to our arsenal and improve the prospects for many of the most vulnerable patients.

Moving forward, Dr. Bhatia wants to translate this work into interventions that could help patients in real-time: "We want to use this predictive gene expression as a target for drugs that could prevent AML from developing in patients altogether."

This research was funded by the Canadian Institutes of Health Research and the Canadian Cancer Society Research Institute.

Editor's note: AAMAC congratulates Dr. Bhatia and his team and wishes them continued progress. We remind patients that promising research can take years to reach patients if successful and any treatment decisions you make should be made in disucssion with your medical team. More information including a video interview with Dr. Bhatia can be found at: fhs.mcmaster.ca/main/////news/news_2016/predictive_staircase_to_leukemia.html

Mark Your Calendars

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

Quebec Meeting
Please join AAMAC for an opportunity to learn more about aplastic anemia, myelodysplasia (MDS) and PNH in Montreal on Saturday, April 16 from 9:30 to 11:30 a.m.

Maison du developpement durable
50, rue Sainte-Catherine Ouest, bureau 101, Salle Du Parc

Speaker: John Storring, MD, CM, FRCPC, Hematologist, McGill University Health Centre

Topic: Overview of MDS
Up and Coming Treatments for MDS
Genes involved & how this might give us a better way to approach the disease.

The Quebec Patient Support Meeting provides: support for those wanting to learn more about bone marrow failure; an opportunity to network with others living with bone marrow failure; the latest research presented by local experts, and; a friendly, relaxed environment for patients, family and healthcare professionals to share information and ask questions.

To register or for more information visit aamac.ca or call 1 (888) 840-0039.

Ontario Meetings

Saturday, February 27, 2016
10:30 a.m. to 12:30 p.m.
Refreshments will be served.
Guest Speaker: Dr. Brian Leber, MDCM, FRCPC, Hematologist
Topic: New Insights into MDS Development
Location: Wellwood, 561 Sanatorium Road, Hamilton

Saturday, April 2, 2016
10:30 a.m. to12:30 p.m.
Refreshments will be served. Guest Speaker: Dr. Richard Wells, MD, PhD, FRCPC, Hematologist
Topic: An Update on New Developments in AA, MDS and PNH
Location: Bloor Street United Church, 300 Bloor Street West, Toronto

Saturday, April 23, 2016
10:00 a.m. to noon
Refreshments will be served.
Guest Speaker: Dr. Cyrus Hsia, MD, FRCPC, HBSc, Internal Medicine & Hematology
Topic: MDS Management & New Research
Location: Wellspring Cancer Support Centre, 382 Waterloo Street, London

Please email or call the office to register for any of these meetings at info@aamac.ca or (888) 840-0039. Watch from more meeting details at www.aamac.ca, on our Facebook page or through direct member communications.

Ottawa Meetings
This year's meetings take place on the following Wednesdays from 6 to 8 p.m. at the Maplesoft Centre at the Ottawa Regional Cancer Foundation, 1500 Alta Vista Drive: February 10, March 9, April 13, May 11, June 8, September 14, October 12 and November 9.

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 coping and see how they are responding to treatments.

For further information, call the office toll-free at 1 (888) 840-0039 or contact info@aamac.ca.

What are you doing February 29?
World Rare Disease Day is February 29, 2016. This rare day will be celebrated worldwide. The Canadian Organization for Rare Disorders (CORD) will sponsor some activities to be announced. It has asked that certain Canadian structures such as the CN Tower be lit in honour of the day. Our members are among the estimated 2.8 million Canadians affected by various rare diseases.

Canadian Organization for Rare Disorders (CORD), Rare Disease Day 2016 Conference and Gala
March 9 - 10, 2016
Sheraton Ottawa Hotel, 150 Albert Street, Ottawa, Ontario
This two-day conference on March 9th and 10th showcases the talents, initiatives, and successes of the various sectors of the rare disease community, corresponding to the 5 pillars of the Rare Disease Strategy.

Rare Diseases, Rare Women, Rare Commitment Gala
Please join CORD in recognizing these "Rare Women" and other "Rarity Heroes" at its Rare Disease Day Gala in Ottawa. The celebration will be even more special in 2016, with Rare Disease Day actually taking place on February 29. Exceptional women from the Parliament, Ministry, and community have been chosen for public acknowledgement at this event. Awards will be presented at the Rare Disease Day Awards Gala starting with a cocktail reception at 6 p.m. followed by dinner at 7 p.m., with entertainment from the Cross Town Youth Chorus.

An Action Day is also planned on on March 2. Visit raredisorders.ca for registration and ticket information.

News of Note

Waterfront Walker
Last issue we told you about Clara Deabreu, 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. We neglected to share our thanks to all the individuals who supported Clara's efforts with a donation.Thank you donors!

International Partners
Did you know that AAMAC works together with other like-minded organizations for the benefit of Canadian patients?

MDS Alliance: MDS-Alliance is a global health initiative that aims to ensure MDS patients, regardless of their age, have access to the best multi-professional care. This initiative aims to provide patients and their caregivers and the health care team with the training tools and the information about MDS, including current treatment options. AAMAC is one of the founding members of the MDS Alliance and Cindy Anthony, Executive Director, is serving as Vice President for this group. Photo from meeting in Orlando ASH 2015. For more information visit www.mds-alliance.org. Representatives in this photo are from Germany, England, Spain, Mexico, U.S.A. and Canada.

AAMDSIF: The Aplastic Anemia & MDS International Foundation (AAMDSIF) is dedicated to supporting patients and families living with aplastic anemia, myelodysplastic syndromes (MDS), paroxysmal nocturnal hemoglobinuria (PNH), and related bone marrow failure diseases. They are located in the U.S. and AAMAC partners with them through webinars and the sharing of printed material. They offer a number of patient meetings across the U.S.A. each year. Vist www.aamds.org.

MDS Foundation: The MDS Foundation, Inc., located in Yardville, New Jersey, USA, is an international organization established in 1994 by world-renowned researchers dedicated to further scientific knowledge, patient support, and education in the myelodysplastic syndromes.

The MDS Foundation provides research grants for scientific investigators, sponsors international working groups of scientists and physicians for further diagnostic, prognostic and treatment techniques and distributes information on state-of-the-art research, clinical trials and treatments to the professional and patient communities. The Foundation also refers patients to its collection of 'MDS Centers of Excellence, maintains an electronic Message Board on its website to encourage interaction and support among patients and caregivers, and provides educational programs for both health care professionals and patients and their families.

Follow the MDS Foundation here.
Facebook: https://www.facebook.com/MDSFoundation/ Twitter: @MDSFoundation https://twitter.com/MDSFoundation Instagram: @mdsfoundation https://www.instagram.com/mdsfoundation

Helping MDS Patients in Multiple Languages
In need of patient and caregiver resource information in various languages? The MDS Foundation can

help! Recognizing the continuing need for the availability of MDS patient and caregiver information in a growing global environment, the MDS Foundation offers the following resources available in several languages.

In 2009 the Foundation created a patient and caregiver resource entitled "What Does My Bone Marrow Do?" This educational booklet was originally developed based on the needs expressed by attendees during Patient and Family Forums that were conducted worldwide. During these forums the Foundation asked the question: How many of you know what your bone marrow does? In most cases no more than two or three attendees had a clear, basic understanding of normal marrow function. This lack of understanding led to the development and distribution of this handbook.

In early 2014 this handbook was updated and re-released. These handbooks are now available, via the Foundation website, in the following languages: Chinese, Dutch, English, Russian, Turkish, Spanish, German, Italian and Portuguese. Visit www.mds-foundation.org/bone-marrow-handbook/. This has been a very popular resource as the text is patient-friendly and the graphics clearly complement the educational information provided. The Foundation has received requests for multiple printed copies of these translated handbooks to distribute to patients and caregivers in various regions, and additional translations have been suggested and are in process, including Danish and French.

In addition, along with Sandra Kurtin, Oncology Nurse Practitioner at the University of Arizona Cancer Center, the Foundation has developed a concept for distributing our patient educational pieces – Building Blocks of Hope (BBoH) - Patient and Caregiver Strategies for LIVING with MDS. This program is a global MDS Foundation patient advocacy initiative providing a personalized educational system for the patient and caregiver to prepare, participate, and LIVE with MDS.

This resource, originally developed in 2012, is continually updated to reflect the ongoing changes in patient care and treatment. The Foundation distributes printed copies of the BBoH on a print-as-needed basis to ensure that all printed copies contain the most updated information available. It fulfills all requests for the BBoH resource free-of-charge to patients and professionals.

The Foundation continue to receive many requests for additional translations and adaptations. Currently this resource is available in the following languages via the MDS Foundation website, www.mds-foundation.org/bboh/#International-Handbooks: English, Canadian French, Chinese, French, German, and Turkish. Current translations in process: Armenian, Australian, Dutch, Japanese, and Spanish.

Additional languages will be initiated as translators are identified and needs arise in the future.

Additional Resources: New to the Foundation is an additional resource. Please see the Foundation's Glossary of Commonly Used MDS Terms available on its website through the following link: http://www.mds-foundation.org/wp-content/uploads/2015/09/Glossary-of-MDS-Terms-Updated-August-2015.pdf.

In the future, this glossary will be available in a pocket guide and translated into several languages.

Leukemia and Lymphoma Society Offers Online Support en français

The Leukemia and Lymphoma Society of Canada (LLSC), in collaboration with the Centre hospitalier universitaire de Québec (CHUQ) and its partners, offers a new online support group for blood cancer patients starting Thursday, February 18, for 10 weekly sessions (Thursdays at 1:30 p.m.) led by experts in oncology.

The chat discussions are confidential and performed via a secure connection on the Cancer Chat Canada website. Sign up now by contacting Anne-Marie Veillette, at (418) 525-4444, ext. 20685 or by email at anne-marie.veillette@crhdq.chuq.qc.ca.

The meetings are for patients:

- Touched by blood cancer: leukemia, lymphoma, myeloma, Hodgkin's disease, myelodysplastic syndrome, myeloproliferative disorder.
- 18 years or older.
- Who have access to internet.
- Who have completed treatment or been in remission for less than two years.