

Aplastic Anemia & Myelodysplasia Association of Canada NEWSLETTER

Chairperson's Message

Well, finally, summer is on its way! And not a minute too soon; at least for us on the beleaguered east coast where the highest snow banks just melted on the Victoria Day weekend. The summer edition of this newsletter is always my favorite, because I look forward to receiving the Education Day registration form in the mail. This year, Education Day will be returning to Toronto on October 17th, and I hope as many of you as possible will be able to join us in this central and easily assessable location. Travel bursaries are available to be applied for, as well, so look for this information along with the event's agenda enclosed. It really is a wonderful day of guest speakers; and a great opportunity to meet fellow patients, family, caregivers and medical professionals.

If you are unable to travel to Toronto that weekend, we will be posting selected presentations on our website after the event so be sure to watch for that; or if you are in Alberta you may want to attend the Network of Rare Blood Disorder Organizations educational event in Calgary.

In addition to our Annual Education Day and AGM, we have been travelling across the country hosting patient meetings in various provinces. Recently we were in London and Montreal, and on September 26th we will be in St. John's, NL. As a groupie of our Atlantic Region support group, we are beyond thrilled to finally be able to present a provincial patient education day on the rock. Detailed information can be found in this newsletter, and is also being distributed to our Atlantic Canadian supporters as I write this. I hope to see many people from the province of Newfoundland and Labrador, as well as "come from away" folks at this event.

Our Nursing Education Program is now heading into the pilot stage. We will have more on this in upcoming newsletters. And our recent webinar on Iron Overload was very well received. We hope to present more of these, since it is an easy way to communicate to a large number of people and reach remote locations.

I would like to take this opportunity to say welcome back to our Administrative Assistant, Carol Fazari, who is back in the office after a medical leave. We are very happy that she is doing well and is back in the office.

And finally, I would like to extend a welcome the newest member of our Board of Directors, Steven Park. Steven was appointed to the board in April and brings with him a wealth of knowledge and experience in the financial advisory sector.

Have a great summer,
Jennifer Garvey
AAMAC Chair



**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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Charitable Registration Number
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BC Update

By Janice Cook

The BC chapter is still interested in hearing about patients having difficulty accessing Vidaza without lengthy travel to a centre where it is given. We'd also like to hear from you if you have chosen not to try it due to the inconvenience of travel and your thoughts about either of these circumstances.

We hope to have a meeting this fall, possibly in the Fraser Valley. We'll plan to have speakers and possibly set it up as a shorter day conference. If you have any ideas or wish to help please let us know.

We still have a small group of us meeting in Mission and would be happy to hear from you if you'd like to join us sometime.

Please phone me at (604) 826-7222 or Pam Wishart at (250) 590-6057 or email us at bc@aamac.ca if you are interested.

Enjoy your summer.

Atlantic Support Group Update

By Gwen Barry

Due to our horrible winter weather and atrocious road conditions in Nova Scotia, it was not advisable to plan any activities this past winter. However, we did manage in early April to have a tour of the new Atlantic Canada Blood Services Production and Distribution facility in Dartmouth, Nova Scotia.

Built in 2013, it is high tech, state of the art, and the most advanced such facility in Canada. The facility collects blood donations, and produces and distributes blood products to the three Maritime Provinces. We were highly impressed with the degree of security, safety, and logistics involved, in both blood production and distribution units.

Our tour guides, Ramona Coolen and Cindy Burchell, expressed their delight at meeting patients such as ourselves, who are the end users of their products. Following the tour, the group went to a local restaurant for refreshments.

We are hoping that in late May we will be able to have a group meeting in Halifax with a guest speaker on the topic of 'End of Life Considerations.' Once the arrangements for this event have been finalized, further details will be sent out by email, and will be posted on AAMAC's website.

The Atlantic Support Group is hosting a Provincial Education Day in St. John's, Newfoundland and Labrador on Saturday, September 26, 2015, with hematologist guest speakers from Newfoundland, Toronto and Halifax.

Travel expense funding will be available for residents of Newfoundland and Labrador only, for one patient and one support person per family. However, patients and their families from elsewhere are welcome to attend at their own expense.

Further details and the application form can be found elsewhere in this issue of the newsletter. Travel expense funding is limited, so get your application form in early.

Free Patient Education Day

Join AAMAC on Saturday, October 17, 2015 from 8 a.m. to 4:30 p.m. at the Novotel Toronto North York for a free patient education day.

Confirmed speakers include:

- Dr. Richard Wells, Co-Director Myelodysplastic Syndrome Program, Odette Cancer Centre Scientist, Biological Sciences –

Odette Cancer Research Program, Sunnybrook Health Science Centre, Assistant Professor, Department of Medical Biophysics, University of Toronto, and Chair, AAMAC Medical and Scientific Advisory Committee

- Dr. Karen Yee, Staff Physician, Leukemia Services, Princess Margaret Hospital, Assistant Professor University of Toronto
- Cindy Murray RN, NP, Malignant Hematology/Princess Margaret Cancer Centre, Member of the MDS Foundation International Nursing Leadership Board
- Daniela Fierini, RD, Clinical Nutrition Practice Leader, Allied Health, University Health Network/Princess Margaret Cancer Centre
- Tammy de Gelder, Nurse Practitioner, Hamilton Health Sciences

The Novotel is at 3 Park Home Avenue, Toronto, Ontario (Sheppard Avenue & 401 near the subway).

Optional hotel rooms are \$134 per night and must be booked prior to September 18, 2015. Call (416) 733-2929 or 1 (855) 285-5055 to contact the hotel about rooms.

A registration form is included in this newsletter.

For more call 1 (888) 840-0039 or email info@ammac.ca.

Make Sure You Don't Have a Hole in Your Bucket

By Janice Cook

Many of us have our own bucket list of places to visit. Many people with chronic illness travel frequently these days.

I've worked in a hospital emergency room for the past 16 years, in three different provinces. Something we see there is that accidents and illnesses can interrupt even the most carefully planned vacations, causing stressful circumstances and costly complications that impact not only the sick or injured person, but perhaps their entire family.

Even a quick trip "across the line" as they say in BC, can have consequences. On the other hand, I have seen the extraordinary arrangements made to transport someone home and directly to hospital without out of pocket expenses when that person had medical travel insurance.

Even travelling out of your home province in Canada may require some preparation when you have a pre-existing condition. Each province has its own list of formulary (covered) drugs, its own method of prioritizing care, its own cost for ambulances or medical equipment, and its own health records system.

If you seek medical assistance in some areas and have none of your records with you, there may be no way of accessing them until "8-4, Monday to Friday," but, in Canada, you will be cared for due to reciprocal provincial agreements. There are no such agreements with other countries. That is why I encourage you to consider travel insurance when you travel.

We all hear how costly health care is, even in Canada where we don't often actually see a bill for services. In listening to people over the years, I have heard stories of how withholding information or even making a mistake on an insurance form invalidated a policy making someone's claims for reimbursement denied. This can lead to catastrophic financial costs that our provincial governments may not cover. It is so important to ask questions and if you need to, get assistance to fill out the forms correctly. Having a pre-existing condition is a special circumstance,

you may need a letter from your doctor to confirm that you are fit enough to travel. Even if you are eligible for the insurance, your coverage is not guaranteed. There may be exclusions, and that list can be quite lengthy. You need to learn the definition of medically stable for the policy that you need. The length of time the condition needs to be stable may vary according to age, the medical condition and how long you need the coverage. Any changes in your medical condition (like new diagnosis, new medication or even dosage changes, new treatment, and hospitalization) within a very specific time frame prior to the trip can change your coverage.

I learned a lot of this from an insurance agent when she advised me about renewing prescriptions just prior to a trip. The date of a renewal could have been very important in our policy.

It may seem daunting to add this to your to do list before you plan to travel, but perhaps the peace of mind it brings will make the trip more enjoyable. Bon Voyage!

PS. I do not, and have never sold insurance.

Burlington family reeling from second major illness diagnosis

This article by Kathy Yanchus first appeared in the Ontario newspaper the Burlington Post on April 6, 2015 and is reprinted with permission.

Emily Erskine's parents' initial reaction was relief that their eight-year-old daughter did not have leukemia.

The diagnosis they did get early last December – aplastic anemia – was not, however, the lesser of two evils.

"We just got a different evil that is just as bad," said mom Melissa Erskine.

“With leukemia there are very distinct treatments and they work, but because this is so rare, it’s so unknown.”

Within 24 hours, after a visit to a walk-in clinic led to blood tests and an immediate transfer to McMaster Children’s Hospital for further tests, the Burlington family was reeling with the news that Emily had the rare but very serious disease that afflicts one in two million Canadians annually.

In aplastic anemia, the bone marrow stem cells do not make enough new blood cells, and usually, all blood cells are affected, white, red and platelets. It can come on suddenly, or slowly.

Emily had exhibited symptoms of bruising and paleness and she had had a string of throat infections.

As a competitive baton twirler, her parents chalked up her bruises to slip ups while learning new routines, but “hers (bruises) were worse than her peers,” said Melissa.

Once at McMaster, Emily was admitted and the family bombarded with distressing words like blood cancers, blood transfusions and bone marrow biopsies.

When eventually tests came back, it showed Emily as having five per cent bone marrow production, whereas the average range for a child of her age is between 85-90 per cent, said Melissa.

Two bone marrow biopsies confirmed the results.

“I had heard the name (aplastic anemia) but I had no idea what it meant.

The learning curve was so steep, it was just incredible. They’re very good at Mac though teaching and explaining things to you,” said Melissa.

“For some reason her bone marrow has stopped working and producing all those things; those factories have shut down and they’ve gone on strike,” said Melissa, looking directly at her daughter with a faint smile and repeating the simple explanation that no doubt had been used for Emily before.



Emily pictured with her aunt Bonnie at a recent blood donor clinic. Photo courtesy of Melissa Erskine.

If the couple had other children, they would have been tested immediately as the first and best option for a bone marrow transplant, said Melissa, but Emily is an only child. Both she and her husband were tested, but neither was a suitable donor. The next best option was a three-month immunosuppressant drug therapy program which was begun in January.

Since her diagnosis, the family visits to the McMaster 3F hematology/oncology clinic have gone from three to four times a week to at least once every week.

Upon Emily’s arrival, she always gets a “finger poke” which gives them a quick and accurate reading of her blood levels and whether or not she needs a transfusion, said Melissa.

“She doesn’t flinch,” added Barrie, recalling the times he would have to hold his daughter still while nurses tried to draw blood. Emily was what they call a “hard poke”, a situation that changed with the insertion of a PICC line.

While Emily was undergoing treatment, her genetic makeup and blood samples were sent to Sick Kids where bone marrow transplants are conducted through the onematch.ca program.

The family finds out imminently if the immunosuppressant drug therapy program has “kick started” Emily’s bone marrow production, or if she will undergo a bone marrow transplant, or

another round of immunosuppressant drug therapy.

“You can go into remission from it (the disease) with drug therapies but there’s also a good chance you could relapse,” said Melissa.

“Ultimately, a bone marrow transplant is the cure,” said Barrie.

The wait, the unknown, is agonizing and understandably, takes its toll physically and mentally on the couple.

“I am the most impatient person in the world. It is so hard to wait, so hard to wait not only for yourself, but because it’s your child. I like a plan, not having a plan is really hard. We are so grateful that they were concurrently planning for a bone marrow transplant. They have found some potential matches for her, they’re not perfect, but they’re good matches.”

Throughout the last three months, Emily has needed more transfusions closer together, rather than further apart, said Melissa.

“The ideal is the other way around,” added Barrie.

Compounding the family’s anxiety is the financial stress they are under. Melissa is now on medical leave from her job as a social worker and Barrie, an award-winning Metroland photographer, has been on disability since his MS diagnosis which came when Emily was just a year old.

Back then, before his diagnosis, Barrie underwent a battery of tests and symptoms. He would lose consciousness and become disoriented at home, and all of this Melissa had to cope with along with a fulltime job and a new baby.

“It was a scary time,” said Barrie, who had to give up his job and his driver’s licence.

Last fall, things finally stabilized for the family. Barrie got his licence back. He would pick Emily up from school and they’d head to the park.

“We spent a lot of time together after school and it was nice,” smiled Barrie. “Life was really good.”

With the stress of his daughter's illness, there are times when Barrie is not well enough to accompany Melissa and Emily to the clinic.

"Some symptoms creep up on me," said Barrie. "I'll get some days when I just can't function and fatigue sets in and my body says no it can't do it and I need to lie in bed most of the day."

"We're just reeling from how could this happen a second time? Two major illnesses in the family."

With Emily's immunity low, the family has to "tread carefully but the reality is she has to move," said Melissa. "She went to competitive baton twirling to.....we can't go to the indoor play gyms, it's been too cold to walk. It's been hard to keep her moving but we also can't bubble her."

Visits to grandparents have been welcome respites, as have non-busy times at a pottery studio.

Family and friends have been an incredible source of support and always have been, said Melissa, who is documenting Emily's illness in a blog emilysjourneyblog.wordpress.com/2015.

The blog is not only therapeutic for her, but is a convenient way to update family and friends.

Emily's Grade 3 teacher at Central Public School comes by twice a week with schoolwork which her parents supplement with home lessons.

Along her journey, Emily, who turns nine on May 25, has been an important member of her care team, which includes not just a hematology oncologist and a nurse assigned to her, but a child life specialist and social workers.

"She is the star of the team," said Melissa. "They're really great at giving her choices about some things."

Being surrounded by the caring professionals has helped the couple too, especially when it comes to discussing difficult subjects "that would be hard for us to say," said Barrie.

Emily's journey is also chronicled in the string of bravery beads she has accumulated - bright red for transfusions, dark red for pokes, lightning bolt-adorned white beads for trips to the emergency, purple for platelets, green for tummy upsets.

Because so many have done so much for the family, the Erskines (hosted) a blood donor drive the week of April 13-18 at the Burlington Blood Donor Clinic, located at 1250 Brant St. (Power Centre plaza). It (was) called Emily's Week and anyone, friends, family and strangers, (could) donate blood in her name.

"We've certainly taken our share of the supply," said Melissa, who recalled a "surreal moment" Emily's first night in hospital, as life saving blood flowed through her daughter's intravenous line.

"She's got the second rarest blood type as well B- and that was saving her life that night; someone had generously donated blood. It really hit home."

Annual Memorial Blood Donor Clinic Honours Late AAMAC Member

The following news release was issued by Canadian Blood Services on April 1. Although focused on the Easter/Passover weekend, blood donations are a great idea every long weekend!

As people gather with family and friends and prepare to celebrate Easter and Passover this holiday long weekend, Canadian Blood Services is asking that they also remember to give blood.

The need for blood and platelet donations never takes a holiday – especially over a long weekend. With many people away or busy with family activities, blood donations normally decrease. Canadian Blood Services

relies on the generosity of donors who make the time to book appointments to donate blood leading up to, during and immediately following the long weekend to maintain a strong blood supply for patients.

"We are asking Canadians to join the dedicated blood donors who visit our clinics to help patients in need," says Pamela Mullins, Canadian Blood Services' director of donor relations for Manitoba, Northeastern Ontario and Nunavut. "During a long weekend, platelets are a particular concern. They only have a shelf life of five days, so it's challenging to replenish the supply when so many people are busy celebrating the holiday."

Canadian Blood Services collects platelets as part of the blood donation. Platelets help with clotting and are used by patients receiving treatment for a variety of illnesses like leukemia.

Ottawa photographer Michelle Valberg has planned a different kind of family gathering over the long weekend.

"For eight years my father was blood transfusion dependent," says Michelle. "We found out just before he died that he received over 250 transfusions."

Michelle's father John Valberg lived with myelodysplastic syndrome, which over time progressed to acute leukemia. He passed away in 2013. In honour of her father, Michelle made blood donation a tradition by organizing the annual John Valberg Memorial Blood Drive (which took place this year from April 1 to 8 in Ottawa).

"He was so grateful for all the donors that helped him. If he was here today he would be really proud and thankful that we're donating to help others," says Michelle.

If you are able to donate, to book an appointment, use the GiveBlood App or visit www.blood.ca. Those with appointments are encouraged to keep

that appointment and, if possible, bring a friend or family member to donate with you.

Calgary Conference Announced

By Silvia Marchesin

The Network of Rare Blood Disorder Organizations (NRBDO) is a coalition of patient groups formed to share the best practices in health care delivery for people with rare blood disorders. One of the main objectives of the NRBDO is to raise the level of awareness and knowledge of patient groups and healthcare professionals in an effort to improve treatment for those suffering from rare blood disorders.

The NRBDO - Alberta has been meeting since 2006 to create a local network of collaboration and support for its members with each representing their own organization. The NRBDO - Alberta consists of members of the following organizations:

- Aplastic Anemia and Myelodysplasia Association of Canada
- Canadian Association for Porphyria
- Canadian Immunodeficiencies Patient Organization
- Sickle Cell Foundation of Alberta
- Thalassemia Foundation of Canada
- Canadian Hemophilia Society, and
- HAE Canada.

In March 2013, we held a successful patient Education Day in Edmonton. Building on the success of that conference and on the strength of our group, we plan to continue to focus on education to patients, families and health care professionals. On **October 17, 2015**, the NRBDO - Alberta will host its next Education Day with the central theme of "Comprehensive Care." We are excited to bring this event to Calgary to expand the patients who are reached.

By attending, you will gain a more complete understanding of what comprehensive care is and how this goal can be achieved. You will also have the opportunity to network with other patients with similar disorders and attend afternoon breakout sessions specific to aplastic anemia, PNH and MDS.

There will be a limited number of travel sponsorships available to out of town delegates who may need financial assistance with travel expenses to attend.

Save the date and plan to attend this exciting educational event. Further details and registration will be available closer to the conference date on the NRBDO website, nrbdo.ca/regional-affiliates/alberta.

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.

"Long Term Issues for Patients Treated for Aplastic Anemia and Marrow Failure Syndromes" Webinar
Tuesday, July 7 at 8 p.m. Eastern
Kirk R. Schultz, MD
Director, Childhood Cancer and Blood Research of BC Children's Hospital and Child and Family Research Institute
Director, Michael Cuccione

Childhood Cancer Research Program
Professor of Pediatrics, UBC
To register visit www.aamds.org.

Dealing with the Challenges of MDS (Myelodysplastic Syndromes)

Friday, June 26, 1:30 to 4:15 p.m.
Tom Baker Cancer Centre,
Auditorium, Calgary, Alberta

Presentations include:

- What are Myelodysplastic Syndromes?
- Community Supports for Patients with MDS, and Current Options
- New Developments for Treating MDS (by Dr. Lewis R. Silverman, Director, MDS Center, Mount Sinai School of Medicine, New York)

Patients, family, and friends are welcome. Please register by contacting Elysa Meek at (403) 476-2765 or by emailing her at elysa.meek@albertahealthservices.ca. Light refreshments will be served from 1 to 1:30 p.m. The agenda will start at 1:30 p.m.

U.S. Patient Conferences Planned

The AA&MDSIF still has four free patient and family conferences left in 2015: San Francisco, July 18; Boston, September 19; Chicago, October 24; and Tampa, November 14. For more information, visit aamds.org.

Save the Dates!

This year's national AAMAC 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.

MDS Facebook Page en français

SMD + échange d'énergie positive –
Syndrome Myélodysplasique
SMD + échange d'énergie positive –
se veut un groupe de soutien +
support + partage, pour discuter et
parfois échanger, s'informer,
apprendre et parfois reconforter, ou
encore faire part de ses expériences,
mais devant l'adversité, rester positive
+ !!! Rejoignez ce groupe sur
Facebook en allant sur ce lien:
<https://www.facebook.com/groups/4>

18236665006496/
Ou envoyez-moi un courriel:
louisfrancois22@yahoo.ca.

Congratulations Stephanie!

We wish Stephanie Johnston
congratulations for being awarded The
Brantford Expositor Trophy on
Thursday as the Brantford Track and
Field Club's athlete of the year.

Johnston, a Brantford Collegiate
Institute graduate, is a freshman at the
University of Concordia in Ann
Arbor, Michigan.

The Ontario newspaper which awards
the trophy reported that at
Concordia, Johnston has broken the
school's 5,000 and 6,000 cross-country
record, as well as the 800, 1,500, one-
mile, 1,000, 3,000 and 5,000 school
records.

It also recognized her efforts off the
track, for organizing a \$7,000
fundraising run for AAMAC.

Sending Love to Lydia

Hundreds of musicians, businesses
and residents came together in
Peterborough, Ontario this past May
for the "Love for Lydia" concert.

The fundraiser was organized in
support of Lydia Black, the 11-year-
old granddaughter of local musician Al
Black. Local media reported that the
event, featuring 25 performers, was
the largest benefit of its kind at the
venue. The funds raised will be used
to help cover costs for Lydia's family
when they travel to Toronto for her
treatment for MDS.

We wish Lydia and her family the very
best!

SAVE THE DATE

The Network of Rare Blood Disorder Organizations - Alberta Presents

Getting Your Health in Working Order
With Comprehensive Care



Rare Blood Disorders
Education Day
October 17, 2015
8:00am - 4:30pm
Calgary, AB

Porphyria
Thalassemia
Sickle Cell Disease
Immunodeficiencies
Hereditary Angioedema (HAE)
Bone Marrow Failure (Aplastic Anemia, MDS, PNH)
Hereditary Hemorrhagic Telangiectasia (HHT)
Hemophilia and Inherited Bleeding Disorders

For more information visit
www.nrbdo.ca/regional-affiliates/alberta





**Aplastic Anemia
&
Myelodysplasia**
ASSOCIATION OF CANADA

Join the *Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC)* for an opportunity to learn more about **Aplastic Anemia (AA), Myelodysplasia (MDS), & PNH.**

WHAT: Atlantic Region Patient Education Day featuring presentations about bone marrow failure diseases by experts in the fields.

WHY: To provide valuable, disease-related information to Atlantic Canadians with these diseases.

WHEN: **Saturday, September 26, 2015**
8:00 am to 3:00 pm

WHERE: Delta St. John's Hotel & Conference Centre
120 New Gower Street
St. John's, Newfoundland

WHO: Patients, family, and healthcare professionals living in Atlantic Canada (NL, NB, PEI & NS)

The day will include:

- Expert speakers with sessions on AA, MDS, PNH, Stem Cell Transplants, Iron Overload, and Psychosocial obstacles and options.
- A chance to meet others with bone marrow failure diseases.
- Informal discussions with lunch provided free of charge.

Travel cost bursaries are available only for residents of Newfoundland & Labrador, limited to one patient and one support person per family.

FOR MORE INFORMATION VISIT AAMAC.CA
or **EMAIL:** info@aamac.ca or **CALL:** 1-888-840-0039