

Aplastic Anemia & Myelodysplasia Association of Canada

# NEWSLETTER

## Message from the Chair

Happy August! I hope the summer has been restful and you have found time to enjoy the beauty in our natural environment during the warm summer days. This Fall we are bringing the annual patient education meeting to Ottawa on October 13. This annual gathering is a chance to connect with fellow patients and caregivers, meet experts in the medical field and hear about the latest developments in patient care.

The agenda for Patient Education Day is enclosed within this newsletter and you will see that we have a diverse group of expert speakers as well as an inspiring panel of patients and caregivers joining us for the day. There is no fee to attend but we do ask that you pre-register. The registration form is also included with this newsletter.

As always, we will upload selected presentations to our website after the event for those of you who are not able to join us. We will also keep you informed of other upcoming educational opportunities across the country as we continue through the year. Information on these events can be found on our website, [www.aamac.ca](http://www.aamac.ca), and on our Facebook page, [www.facebook.com/AAMACanada](http://www.facebook.com/AAMACanada).

This newsletter marks my last as Chair of AAMAC and I wish to thank you all for an incredible past two years. AAMAC has grown to support more patients across the country through our patient support meetings and we have been able to fund interesting research and provide more scholarships and bursaries thanks to the generous support of our donors. It has been an honour to serve as Chair and I look forward to continuing to volunteer as a member of the Board of Directors.

All the best,

Ashley Oakes  
Chair, AAMAC Board of Directors



**Aplastic Anemia & Myelodysplasia**  
ASSOCIATION OF CANADA

ASSOCIATION CANADIENNE  
**de l'anémie aplasique et de la myélodysplasie**

The Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC) provides information about aplastic anemia (AA), myelodysplasia (also called myelodysplastic syndrome or MDS) and paroxysmal nocturnal hemoglobinuria (PNH) to the public; operates a nationwide support network for patients, families and medical professionals; supports Canadian Blood Services blood programs and OneMatch Stem Cell and Marrow Network; and raises funds for medical research.

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## Atlantic Region Update

By Gwen Barry

The Halifax Support Group met for lunch on August 4 at the Bedford Café and Bistro in Halifax. The gathering included patients representing AA, MDS, and PNH, stem cell transplant survivors, long-term survivors and caregivers. Several new people were in attendance, as well as new people from the May 5 Halifax Patient Education Day who took the opportunity to renew acquaintances.

We were delighted to meet Wendy Beazley and her son Luke, age 14, who had a successful stem cell transplant for AA when he was four years old.

Our next gathering will be a Christmas brunch at the home of Jennifer Moss. It will most likely be a Sunday brunch near the end of November. Jennifer has a baby grand piano, so I expect there will be a good round of Christmas Carol singing. More details will be available later this year on the AAMAC website and by email.

Pictured below at the August Halifax lunch are (left to right):



Jennifer Moss, Gwen Barry, Dolores d'Entremont, June O'Brien, David McFarlane, Jennifer Garvey, Wendy Beazley, Luke Beazley, Cecelia Morgan and Hugh Morgan.

## Ontario Update

By Darlene Edmonds, Ontario Support Coordinator

Well we have a busy fall lined up for everyone in Ontario.

I'm looking forward to connecting with many of you in Ottawa at the Fall Patient Education Day on Saturday, October 13, 2018.

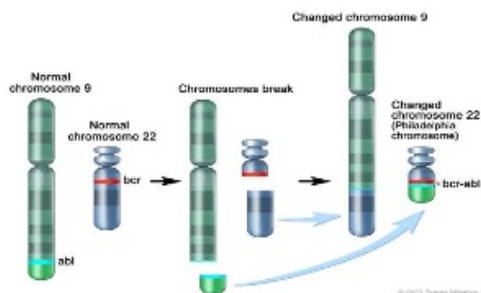
Here are other dates to put into your calendar:

Saturday September 29, 2018, we will be in London, Ontario from 10:30 a.m. to 12 noon. We'll host our patient support group and welcome Dr. C. Hsia back by popular demand. His new topic is Cytogenetics and Molecular Testing in MDS. There are three objectives for this meeting:

- 1) To describe the cytogenetics and molecular testing that are performed on blood and bone marrow.
- 2) To understand the importance of cytogenetics and molecular

testing in conditions such as MDS.

- 3) To describe the potential impact of cytogenetics and molecular test results in conditions such as MDS.



Please call the office and reserve your spot for the London meeting.

We've decided to try something a bit different for the rest of the GTA and Southern Ontario for the Fall; we will be hosting a mini education day on Saturday, November 3, 2018, in Toronto. Registration and breakfast available from 8 a.m. and the meeting will begin at 8:30 a.m.

We are fortunate to have three excellent and knowledgeable Nurse Practitioners (NPs) joining us.

- 1) Tammy de Gelder, NP, from Hamilton Health Sciences will present "Understanding MDS, the Bloodwork and Various Treatments."
- 2) Cindy Murray, NP, from the University of Toronto, Malignant Hematology, will discuss "New Studies Taking Place."
- 3) Pamela West, recently retired NP in Oncology and Supportive Care, will present "Quality of Life when dealing with a Chronic Disease."

The meeting will be held at the Novotel, Toronto, North York, near Hwy 401 and Sheppard

Avenue, close to the North York Central Station on subway Line 1.

You can also join us at The Grand Gardens in Sault Ste. Marie on September 15, 2018, from 8:30 a.m. to 3 p.m. Breakfast, lunch and snacks are included.

The following topics will be covered:

- symptom management,
- living with AA, MDS & PNH, and
- iron overload.

A more detailed agenda with more topics to be covered will be available on the website.

## Alberta Update

Join us for a Patient Support Meeting in Edmonton, Alberta, on November 17, 2018.

We'll meet at the Edmonton Clinic Health Academy at the University of Alberta from 1 to 3 p.m. Details on the topic and speakers will be posted on our website as soon as they are confirmed.

## BC Update

By *Fiona Lewis, BC Patient Support Liaison*

This past June a number of AAMAC members and caregivers attended a patient support group meeting in Vancouver. Our speaker was Michelle Forman, a registered nurse from Burnaby Hospital who spoke about Living Well with Your Disease: Strategies

to Manage Your Disease and Side Effects.

Michelle gave a brief overview of the incidence and manifestation of Aplastic Anemia, PNH and MDS. She then spoke about the important role of lifestyle in managing disease.

She stressed that taking good care of yourself involves:

- eating a healthy and well-balanced diet,
- exercising within your means,
- protecting yourself from infections, and
- relaxing and reducing stress.

Using a bit of humour, Michelle acknowledged that fatigue is often under-reported, under-recognized and under-treated. She showed a visual that said "I used to be able to pull all-nighters, but now I can barely pull all-dayers." She shared information on how to recognize, treat and manage fatigue.

Michelle then discussed symptoms of infection and strategies for managing the risk of infection.

She also covered the emotional aspects of coping with illness as well as strategies for dealing with the side effects of various treatments. The group added to the presentation by sharing their personal experiences of the issues Michelle raised.

I plan to schedule semi-annual meetings in Metro Vancouver and welcome any suggestions regarding topics, scheduling and location.

Join us in Vancouver for a Patient Support Group meeting on Thursday, October 4 from 10 to 11:30 a.m. at Canadian Blood Services, 4750 Oak St., Fraser Room. There are visitor parking

spots or street parking on Oak St.

Light refreshments will be served.

The speaker and topic are to be confirmed shortly. Please RSVP by October 2.

## Patient Story: Aplastic Anemia in Pregnancy

*By Ashley Oakes*

It was supposed to be the most exciting time in our lives. In September, 2010, my husband, Scott, and I moved home to Vancouver, British Columbia from Calgary, Alberta where we had been living for the previous three years. I was six months pregnant and so excited to be going back to the city where all our family lived to share this wonderful time with them.

We moved into a little house a few blocks from my mom and settled in to await the arrival of our little one. A few weeks after we moved, it was Thanksgiving and we had my whole family over for a feast.

Everyone was remarking at how pale I was, but I insisted I was feeling fine! I was a little tired, often out of breath, and it was difficult to go upstairs without needing a break. I assumed my alarming fatigue was caused by my pregnancy and nothing out of the ordinary.

The day after the dinner, I dropped an empty piece of Tupperware on my foot and it left a very large bruise. I went to see my midwife that afternoon for our regular visit and she asked me what happened to my foot. So I told her and we

had a good laugh over what a peach I was – always so quick to bruise! Two weeks went by and I was feeling more and more tired. At my next appointment, my midwife noticed my foot was still bruised. I also pointed out a rash that had formed on my legs. She sent me for a blood test that afternoon.

I went for the blood test at 2 p.m. and at 5 p.m. my phone rang. It was the midwife advising me to get to the hospital right away; she would meet me there. She told me that something was very wrong with my blood levels and that I should pack for at least three days in the hospital and that we would be delivering the baby right away.

I was terrified! I called my husband and he rushed home from work and got us to Lions Gate Hospital in North Vancouver.

We met our midwife in the maternity ward and she rushed us straight into a room. We were introduced to our nurse and advised that she would be our

private nurse in order to avoid infections as my neutrophil count was critically low.

I still had no idea what was happening at this point. Within an hour of arriving at the hospital, we were introduced to an oncologist and an internal medicine specialist and we were told they suspected I had leukemia. I was told that I was pancytopenic (red, white blood cells, and platelets are lower than normal) and that they would need to do a bone marrow biopsy first thing in the morning.

I was given two units of platelets and red cells that night. Upon admission to the hospital, my blood counts were: platelets 9, hemoglobin 76, white blood count 2, neutrophils 0.4.

The next morning, the bone marrow biopsy was done and a number of tests were performed to ensure our baby was well. They would perform a c-section as soon as we had a diagnosis. It took another 36 hours to get the results



of the biopsy, and once the results were in, I was diagnosed with severe aplastic anemia.

That day I was given multiple transfusions to prepare for the c-section. They successfully delivered our beautiful son, Cohen, on October 30, 2010. He was four pounds, 15oz and in excellent health considering he was delivered seven weeks premature.

He was transferred to the neonatal intensive care unit (NICU) and I was transferred to the post-partum ward with strict instructions to not have too many guests and to keep my mask on anytime anyone was in the room or anytime I left the room. I was also told that I would be transferred to Vancouver General Hospital (VGH) within three days to receive treatment.

VGH doesn't have a NICU so I would be separated from my son with limited access during my treatment. I was devastated to say the least and slipping into a deep sadness. Nothing was going as planned and I felt like the ground was falling out from under me.

On November 4, I transferred to Vancouver General Hospital to the Leukemia/Bone Marrow Transplant ward. I received a second bone marrow biopsy that evening. The next morning, I had a Hickman Line catheter inserted into my chest and finally met my hematologist. I was told I would be receiving horse ATG followed by cyclosporine. As I was over 30 and my sister wasn't a bone marrow match they preferred to try immune suppression treatment first.

My ATG treatment started three days later. I had terrible reactions to it and it was a daily struggle for them to manage the complementary therapies – steroids, Benadryl, and Ativan – to

get me through each round of treatment.

After two weeks at VGH and three weeks total in the hospital, I was finally allowed to go home and began outpatient therapy every other day.

Cohen was still in neonatal intensive care after I was discharged and so I began my daily visits to Lions Gate. We finally brought him home on November 29.

Thankfully, we had moved back home to Vancouver when we did, as it was because of the support of our families that we managed to juggle a newborn, outpatient treatment, and my husband having to be at work. I knew I had to stay away from crowds and so we didn't often leave the house except to go for short walks when I had the energy to manage it. Our families did the grocery shopping for us and looked after Cohen while I was at treatment.

Slowly things began to improve. My last transfusion was just before New Year's Eve 2010. The Hickman line was removed right before my 32<sup>nd</sup> birthday at the end of January. By Spring 2011, I was only in treatment once every two weeks and by the summer I was going for weekly blood tests at the lab close to our home.

By Cohen's first birthday in October, I was starting to feel almost normal. That Fall, I joined Team In Training and began training for my first half marathon which I ran in May 2012 and raised \$4,000 in support of the Leukemia & Lymphoma Society. March 2012 saw me go back to work in my career as a professional fundraiser and in August 2012, I competed in my first downhill mountain bike race.

In July 2013, I had been off cyclosporine for about ten months and was on a holiday in Ontario with my son, Cohen, and niece, when I got a small scratch that wouldn't stop bleeding. I knew something wasn't quite right and so when I returned home to Vancouver I went for a blood test.

That test revealed what I had feared. My platelets had dropped from about 155 down to about 100. In addition, my hemoglobin was low, as well as my neutrophils and white blood cells. Nothing was truly alarmingly low, but it was definitely heading in the wrong direction. An appointment was made with my hematologist and I was sent for bi-weekly blood tests.

At my appointment it was decided to try putting me back on cyclosporine to see if that might help things improve. After about six weeks, it became obvious that cyclosporine alone wasn't going to work and in late September, 2013, I was readmitted to Vancouver General Hospital to start the process all over again.

I had to quit my job, and my husband (Scott), son and I moved in with my in-laws for what looked to be a long road ahead.

ATG was harder on me the second time and my recovery post treatment was much slower. I was an outpatient for seven months before I could finally have my Hickman line removed and it took nearly a year for me to start feeling normal again.

Never one to sit still, over the past five years, while working on my recovery, I have participated in the Tough Mudder (10-12 mile team obstacle course) five times, begun running and mountain biking again, and returned to my work in non-profit management. My family and I now live in the beautiful

mountain town of Squamish, British Columbia to be closer to the nature we thrive off.

I continue to take cyclosporine and have my blood checked monthly but my health is overall very good now. It's been a roller coaster ride, but we have weathered the storm and are looking forward to a health-filled future.

I am so thankful for the support I have received from AAMAC and have been truly honoured to serve as Chair of the Board of Directors for the past two years. Working with the AAMAC board allows me to put my non-profit and advocacy experience to work supporting others with bone marrow failure disorders and give back to the community that has helped me so much.

## Patient Education Day Planned

Mark your calendar and plan to join us for our 12<sup>th</sup> Annual Patient Education Day & AGM in Ottawa on October 13, 2018.

The events will take place at the Ottawa Conference & Event Centre at 200 Coventry Road.

Seminars include:

- MDS: Treatment & New Developments with Dr. Jill Fulcher
- AA & PNH: Treatment & New Developments with Dr. Mitchell Sabloff
- Living with Chronic Disease with Aimee Anderson, MSW, RSW

We will also host a popular panel discussion featuring patients

sharing their experiences, successes and approaches to living well with bone marrow failure.

We hope you can join us! Check this newsletter for details and a registration form.

## Nurse Education

One of the goals of AAMAC is to support patients who have a diagnosis of a bone marrow disease, along with their families and/or friends. These diseases are rare and include Aplastic Anemia (AA), Myelodysplasia (myelodysplastic syndromes or MDS) and Paroxysmal Nocturnal Hemoglobinuria (PNH).

Nurses are at the forefront of caring for patients with these diseases, and we are fortunate to have a network of nurses across Canada who have expert knowledge of these diseases and who are eager to teach their peers. Some of them also present at our patient education days. We are also grateful to the organizations and physicians who support our nurse educators.

“Nurses Education Sessions” occur across the country and are usually half-hour presentations given by a nurse educator to fellow nurses. Currently we have two power point presentations (MDS and AA) which have been developed by a nurse and a physician and approved by AAMAC’s Medical & Scientific Advisory Committee.

Lauren Cosolo is combining our presentations into one on bone marrow diseases. Our inventory of presentations will now include an introductory one as well as the more specific ones on MDS and

AA. Our nurses have the ability to alter and include information making it more specific to their environment and/or patient population.

The following is a list of our current Nurse Educators:

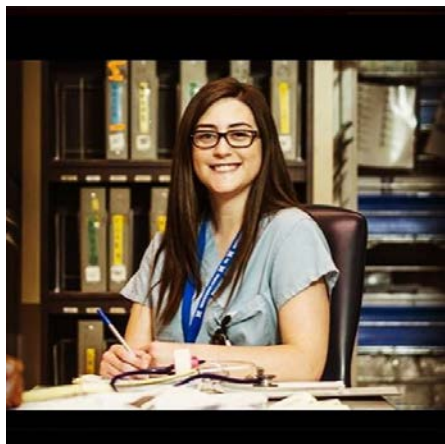
- Lauren Cosolo, BScN, MN, APN, Sunnybrook Health Sciences Centre, Toronto, Ontario. Advanced Practice Nurse for Complex Malignant Hematology.
- Nicole Crisp, BScN, MN, NP, University of Alberta Hospital, Edmonton, Alberta. Hematology Nurse Practitioner.
- Michelle Forman, RN, CON(c), Burnaby Hospital Cancer Centre, Burnaby, British Columbia. Nurse Educator.
- Barb Hues, RN, MSN, CON(c), Cancer Care, Winnipeg, Manitoba, Nurse Educator.
- Leah Palmer, RN, BScN, CON(c), Allan Blair Cancer Centre, Regina, Saskatchewan. Clinical Nurse Educator.
- Cindy Murray, RN, NP, Princess Margaret Cancer Centre, Toronto, Ontario. Nurse Practitioner in Malignant Hematology.
- Rebecca St. Jean, RN, BSN, CON(c), BMTCN, Leukemia/BMT, Vancouver General Hospital, Vancouver, British Columbia. Clinical Nurse Educator.
- Cindy Sheaves, RN, CON(c), Algoma District Cancer Program @ Sault Area Hospital, Sudbury, Ontario. Primary Nurse Hematology, Oncology Nurse, Chemo and Biotherapy Nurse.
- Mona Walia, RN, BScN, Vancouver General Hospital, Vancouver, British Columbia.

Educator on the Leukemia/BMT Daycare Outpatient Unit.

- Stephanie Dyer, RN, BN. Health Science Centre, St. John's, Newfoundland. Patient Care Facilitator.

AAMAC would also like to acknowledge Amanda Weatherford, RN, MSN, OCN, a Clinical Nurse Coordinator at the Seattle Cancer Care Alliance in Seattle, Washington for her assistance in providing feedback to Lauren Cosolo.

## Meet Lauren Cosolo - one of AAMAC's Nurse Educators



Lauren Cosolo is the Advanced Practice Nurse in Complex Malignant Hematology at Sunnybrook Health Sciences Centre in Toronto. She graduated with a Bachelor of Science in Nursing in 2013 and Master of Nursing from the Lawrence S. Bloomberg Faculty of Nursing at the University of Toronto in 2017. She started her career in 2013 at Sunnybrook in the trauma unit and surgical short stay unit before moving to oncology. Lauren has been a Teaching Assistant for undergraduate nursing courses at the Faculty of Nursing at the University of Toronto as well as a

Clinical Instructor for undergraduate nursing students in oncology. Clinical education, advancing nursing practice and delivering high quality patient care are her professional interests.

Lauren has one brother and, in her spare time, she enjoys spending time with her family. Her other passion is travelling and she has been to India, Peru, England, Italy, Portugal and Switzerland.

Lauren will be presenting at this year's Patient Education Day being held in Ottawa on October 13. Her nursing education session will be given during the lunch hour to other nurses and will focus on Bone Marrow Diseases (AA, MDS and PNH).

## Remembering Dr. Hans Messner

*Editor's note: AAMAC was saddened to hear of the passing of Dr. Hans Messner who treated countless bone marrow failure patients during his decades working at the Princess Margaret Cancer Centre in Toronto. Over the years we were fortunate to have him present at various patient events. He will be sincerely missed. The following tribute was written by the University of Toronto and is reprinted with permission.*

### **Dr. Hans Messner was a pioneer in stem cell transplantation**



*(Photo courtesy of University Health Network)*

Professor Hans Messner, a physician who pioneered stem cell transplantation at Princess Margaret Cancer Centre and helped thousands of patients during his nearly 50-year career, died at the centre on Tuesday.

A professor of medical biophysics, Messner completed his PhD at the University of Toronto under the mentorship of Professor Ernest McCulloch. His early research focused on studying the “mother” cells that give rise to all other blood cells. Messner was part of McCulloch’s team that began to explore the potential benefits of bone marrow transplants for the treatment of patients with leukemia.

In 1976, Messner completed his first bone marrow transplant in which he transplanted stem cells collected from a matching donor to the patient to suppress the disease – in this case leukemia – and restore the patient’s immune system. The procedure is formally known as an allogeneic transplant.

He went on to become a leader in the field of bone marrow transplantation. He developed and served as the first director of a clinical transplant program at the University Health Network’s Princess Margaret Cancer Centre (which was then called the Princess Margaret Hospital or PMH) and held the position of director of the Bone Marrow Transplant Centre until 2006. He was also a senior scientist at the Ontario Cancer Institute.

He was the founding president of the Canadian Bone Marrow Transplant Group and was a member of an expert working

group that developed the Canadian Standard for Transplantation of Cells, Tissues and Organs. He also served as director of PMH's Philip S. Orsino Cell Therapy Facility, where he developed the regulatory systems, supervised the facility construction and directed early clinical phases.

In 2007, Messner received the Canadian Blood Services Lifetime Achievement Award for being a pioneer of allogeneic bone marrow and stem cell transplantation in Canada.

Last year, he was presented with the American Society for Blood and Marrow Transplantation Lifetime Achievement Award, which recognizes people who have made continuous clinical and scientific contributions to the field.

In June, Messner reflected on his almost 50 years at the Princess Margaret as he inspired thousands of cyclists with a heartfelt message at the start of the annual Ride to Conquer Cancer, a fundraising event in which he was a rider for 10 years on his beloved "Heme Team."

Earlier this month, the stem cell transplantation program was renamed the Messner Allogeneic Transplant Program to honour his legacy.

Although Messner said he was retiring after 44 years, he never really did. In his final weeks, despite increasing frailty, he continued to come to work to consult with and advise his colleagues.

When one teased him saying, "I guess you're never going to retire," his reply was: "Might as well keep going!"

## News of Note

### Welcome Robyn!

AAMAC would like to officially welcome Robyn Hodes who joins as our Administrative Assistant following the departure of Carol Fazari. Robyn was previously a volunteer in our office so we're fortunate to have her!

### Understanding drug pricing

Patient groups in Canada shared in a recent survey that they struggle to understand the complexities of drug pricing policy in Canada and that they would like more information. In response, the Drug Pricing Policy Summit Working Groups have put together two web pages that outline various resources and learning opportunities to help patient groups learn more. Please take a look at what is available and share the links with others who would benefit.

- Drug Pricing Policy Learning Events:  
<http://survivor.net.ca/act/drug-pricing-policy/drug-pricing-policy-learning-events-patient-organizations/>
- Drug Pricing Policy Resources:  
<http://survivor.net.ca/act/drug-pricing-policy/resources-drug-pricing-policy-canada/>

### Blood Donor Eligibility Changes

Did you know that earlier this year Canadian Blood Services updated its donor eligibility criteria? If you have family or friends who were told in the past that they could not donate, let them know about the changes. They may now be able to donate and help patients in need of blood!

Based on the latest scientific evidence, CBS's changes include:

- **Tattoos or piercings:** After a tattoo or piercing, donors only have three months to wait before donating blood. This is half the time it used to be.
- **Marijuana and alcohol:** If donors are sober and can give informed consent, they can donate. Prior to these latest changes, donors had to wait 12 hours after resolution of intoxication.
- **Hepatitis, Jaundice:** No more lifelong deferral from blood donation for hepatitis, other than hepatitis B or C. Many cases of hepatitis or jaundice have non-infectious causes, or are caused by viruses (other than hepatitis B or C) that are not infectious once resolved. That's why CBS will only be asking about recent history of hepatitis – in the last 6 months.
- **Recipients of blood and blood products (and sexual partners):** Donors are eligible to donate blood as soon as six months have passed after receiving blood or blood products. That delay used to be one year.

CBS says these changes are safe for patients who rely on blood and blood products and that all changes are based on the latest scientific evidence and approved by its regulator, Health Canada.

While maintaining the safety of the blood supply, CBS aims to make blood donation as minimally restrictive as possible.

Visit [blood.ca](http://blood.ca) or contact 1 888 2 DONATE (1-888-236-6283) for more information.