

Aplastic Anemia & Myelodysplasia Association of Canada

# NEWSLETTER

## Message from the Chair

Dear friends and supporters,

As our friends on the West Coast have already found out, summer is finally rearing its head. Hope everyone's enjoying the warming weather.

The last few months have been quite eventful for us. **OHIP+** in Ontario got an update, our local **Patient Support Meetings** are going strong, and our amazing team is hard at work preparing for this year's **Patient Education Day**.

**OHIP+** is Ontario's healthcare plan for children. While its inception gave children broad coverage over their prescription medications much like the regular OHIP program, an update starting April rolled it back. Under the new OHIP+, patients with private insurance will no longer be covered, while those with no private insurance will remain eligible. You can find more information at [sickkids.ca/AboutSickKids/Newsroom/Past-News/2019/OHIP-changes.html](http://sickkids.ca/AboutSickKids/Newsroom/Past-News/2019/OHIP-changes.html).

We held several successful **Patient Support Meetings** including ones in Montreal, Kamloops and North Vancouver. If you haven't had one in your area in a while and you'd like to, let us know.

Last but not least, keep your eyes open for details about our annual **Patient Education Day**. For those who are new to AAMAC, our Patient Education Day is our once-a-year catch up among patients across Canada. The day will be filled with talks by leading Canadian hematologists, nurses, patient support specialists, and of course, patients and caregivers in our community.

We'll post more information as the event comes together. Follow us on [Facebook](#), [Twitter](#), [Instagram](#), [LinkedIn](#), and [online](#) for updates.

As always, thank you for your continued support and we hope to see you at our next patient support event near you.

With warmest regards,

Haydn Liang, PhD  
Chair of the Board, AAMAC



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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## BC/Alberta Update

By *Fiona Lewis, BC/Alberta Patient Support Liaison*

There will be a Vancouver Patient Support Group Meeting on Saturday, June 8 from 10 to 11:30 a.m.

Our speaker will be nurse Monia Walia, the patient care coordinator for the Leukemia-BMT Program at Vancouver General Hospital, who will speak about Understanding Blood Counts.

The meeting takes place at the Multicultural Helping House Society, 4802 Fraser St. in Vancouver. Street parking is available.

## Patient Education Day

Join us in Calgary on Saturday, October 19, 2019 for this year's Patient Education Day.

The registration form and agenda are enclosed with this newsletter. We have a great day planned and hope to see many patients and caregivers in Calgary.

## Ontario Update

By *Cindy Anthony*

We are pleased to welcome Kimberly Brunelle to the role of Regional Patient and Support Coordinator for Ontario.

Kimberly has worked with government programs and not-for-profit organizations throughout Ontario. She has worked with The Ontario Lung Association, the

Canadian Cancer Society and the Mississauga Halton Central West (MHCW) Regional Cancer Program.

Kimberly will start in her new role on June 1, 2019. She is eager to begin supporting patients and their caregivers in Ontario.

## Meet Two Nurse Educators

As part of our continuing series, we'd like you to get to know two nurse educators.

**Cindy Sheaves**



My name is Cindy Sheaves. I am a graduate of the class of 1990 Sault College Nursing Program. I have worked in many different areas over the years and it has given me the opportunity to expand my knowledge and assessment skills. Some of the areas which I have worked are Medical, Surgical and Long-term Care.

I have also worked as a Home Care Nurse concurrent with my employment at the Sault Area Hospital and was on the first IV Therapy and Palliative Care Team in the city with VON Algoma.

I have been a registered nurse working in Oncology for 17 years. My passion is Hematology and I have been in the role as Primary Nurse working directly with our Hematologist, Dr. Danny Hill, for six years. The Hematology group are a very diverse population of patients and it is both an honour and a

privilege to be able to support them through coordination of care, managing side effects of treatment, monitoring of bloodwork and being a liaison for them between other members of our multidisciplinary team.

I have an Oncology Certification through the Canadian Nurse's Association and also am certified in Chemotherapy and Biotherapy through the De Souza Institute which I maintain yearly.

I pride myself on being a lifelong learner. I took sign language classes for three years. Presently I am taking quilting classes and have found a passion for that. I have two grown children whom I am very proud of. They are both educated, independent and genuinely good people.

Most of us have experienced cancer in our families. I have also had family members who have had cancer. I lost my mother to breast cancer and my father was treated for Small Cell Carcinoma of unknown origin. My son is a survivor of childhood Lymphoblastic Lymphoma and received two years of chemotherapy. I am a very fortunate person that I still have my father and my son with me.

So, I take my work very seriously and love what I do. Because I know how it feels to hear those words, feel that fear, and know that even though you have to go through it you don't do it alone. People care and are there for you.

### Cindy Murray



My name is Cindy Murray and I am a nurse practitioner (NP) in the Complex Malignant Hematology Program at Princess Margaret Cancer Centre in Toronto. I work in a nurse-led day hospital with patients who have acute leukemia, MDS and aplastic anemia. I have been a nurse for 37 years and have always worked in the malignant hematology specialty – it is my passion. I continue to learn something new everyday and can honestly say I have never been bored.

I graduated from the University of Western Ontario with my bachelor's degree in nursing in 1982 and from the University of Toronto with my master's degree in 2001. I enjoy teaching and have a clinical appointment in the nursing program at the University of Toronto.

When I am not working, I am fairly active and love to ride my bike, hike, ski, kayak and travel. Last year my daughter and I hiked the Inca Trail to Machu Picchu. It was a great mother/daughter trip to celebrate her graduation from university. (No, she did not follow my chosen career. She is a talented artist.)

## Meet Our Volunteers

In honour of National Volunteer Week, AAMAC wants to recognize and thank the many volunteers across Canada who tirelessly give their time, generosity, strength and commitment to people living with bone marrow failure diseases.

These are the people who immeasurably improve and enhance our organization. The work they do every day on behalf of AAMAC is the ultimate gift and act of kindness. They let people know they are not alone, that there is someone to listen and to help.

To all of our volunteers, we thank you. We could not do this without you. We asked some of our volunteers

why they do what they do. Here is what they had to say.

### Clara De Abreu, Toronto



### What inspired you to volunteer at AAMAC?

I was inspired to volunteer at AAMAC through attending monthly support group meetings. When I was first diagnosed with MDS in 2004, I was told that it was a rare disease. By attending the meetings, I was with people just like me. I volunteer so that I can share my story with others who are recently diagnosed.

### Tell us a little about what you do.

For the past seven years, I spend my time giving back to Sunnybrook Health Sciences Centre, which saved my life. I volunteer on Tuesdays at the Breast Cancer Clinic and on Fridays at the Hematology/Oncology Clinic.

I enjoy meeting each patient and providing some comfort at a stressful time in their life. Once a month I oversee an AAMAC information booth where people can drop by and get information about blood disorders. It's also an opportunity for MDS patients to chat with me and I can share my journey with them. When speaking to others, I feel they get a sense of relief knowing that they are not alone.

### Do you have a story you'd like to share about your volunteering experience?

I'm passionate about finding ways to share my story and I have done through a YouTube video called "Clara's Story." With the support of Sunnybrook, I shared my experience of what life was like having MDS, about having to have regular blood transfusions and dealing with iron overload issues as a result.

**What would be your message to people thinking about volunteering at AAMAC?**

I would encourage everyone to get involved. The more we can share our message about MDS, the more we can raise awareness of this rare disease.

**Catherine Knoll, Ottawa**



**What inspired you to volunteer at AAMAC?**

I wanted to share my experience with other people and their families dealing with bone marrow failure disease.

When you are diagnosed with a rare disease you feel very alone. About six months after I was diagnosed, I went to a patient information day in Toronto. It was the first time I met another patient with aplastic anemia, and was able to hear their story and share mine. In addition, the informative talks and follow up with physicians helped clarify the treatment options available to me.

Later that year, I went to a national conference in the U.S. Learning from some of the leading research physicians in the field and having the opportunity to ask questions, as well as listening to peoples' stories was an amazing experience. There were different perspectives, different ways of coping and living with an illness, different reactions to treatments, and different outcomes. It was informative, encouraging and uplifting.

**Tell us a little about what you do.**

I chair the monthly Ottawa AAMAC support group. I have been involved with the support group since its inception in 2009, and took over as chair in 2010.

As a group we share our stories and information about treatment, and members leave the meeting not just better informed but also with a sense that they are part of a community.

**Do you have a story you'd like to share about your volunteering experience?**

It's not really just one story; it's a continuing story of empathy and community. It is the support group as a whole that helps new and existing patients and their families by giving them a place to tell their stories and learn from other experiences.

**What would be your message to people thinking about volunteering at AAMAC?**

It's extremely rewarding to support other patients in their journey. The support group is grateful for and appreciative of the support of others, and we are all better for leaning on and learning from one another.

**Caroline Laughlin, Toronto**



**What inspired you to volunteer at AAMAC?**

My husband Bill and I have supported AAMAC for over 30 years. Back then, there was no support for families affected by aplastic anemia. MDS was not being recognized and PNH was unheard of.

**Tell us a little about what you do.**

I volunteer at The Hospital for Sick Children in the Marrow Failure & Myelodysplasia clinic. I talk to patients and their families and offer support in any way I can. I tell them about AAMAC and its support group meetings and education days. I provide them with up-to-date information about the services offered by AAMAC and, if possible, I connect them with other families who are affected by any of the three conditions.

**Do you have a story you'd like to share about your volunteering experience?**

Just after leaving a support group meeting, I was approached by a young girl. She introduced herself and said she had been at the meeting. She then went on to explain that I had met her a few years earlier and told her about treatment for aplastic anemia. She took the information, had a transplant and was studying to be a clinical nurse in hematology. One never knows what a brief encounter will do to change a person's life.

**What would be your message to people thinking about volunteering at AAMAC?**

It has been the most rewarding experience of my life. People need to hear that they are not alone and that there are many people out there who sympathize with them and truly care. There is much more hope than there was just 30 years ago.

**Marilynne Convey, Victoria**



**What inspired you to volunteer at AAMAC?**

Having a diagnosis of aplastic anemia led me to connect with a friend who gave me lots of information. I am a

retired nurse and felt that my education and experience might be useful. I like to keep busy, and volunteer for other organizations in addition to AAMAC.

**Tell us a little about what you do.**

I curl and play bridge. I am a quilter. I volunteer at a costume museum and volunteer annually at the marathon finish line. I walk my dog with friends and also belong to a seniors' centre. I am member of a hiking club and participate whenever my health allows me to do so.

**Do you have a story you'd like to share about your volunteering experience?**

One of my responsibilities as a member of AAMAC Board is to facilitate the Nurse Education program across the country.

One of the best opportunities was attending the CANO (Canadian Association for Nurses in Oncology) conference in Charlottetown, PEI, last year. Over 400 nurses from across the country attended and I tried to meet as many as I could to share information on bone marrow diseases and the support offered through AAMAC. I also met the 2016 Canadian Nurses association winner of the AAMAC scholarship.

I was lucky to be able to recruit nurses to join AAMAC's Nurse Education network whose role is to help educate other nurses about our association and the diseases (AA, MDS, PNH). Currently our network has 16 nurse educators.

**What would be your message to people thinking about volunteering at AAMAC?**

It is very valuable to be able to talk to someone who has the same disease and similar health experiences. Open yourself up as you never know what might bring happiness to yourself and others.

**Vivian Do, Toronto**



**What inspired you to volunteer at AAMAC?**

I am an accountant by trade and wanted to get some board experience by starting out in the not-for-profit sector doing good for the community. AAMAC was looking for a Treasurer, which allowed me to really support the day-to-day operations of the organization.

**Tell us a little about what you do.**

I work at an executive recruitment firm in the accounting department. We work across Canada facilitating the search process for the client and placing candidates in their dream jobs.

**Do you have a story you'd like to share about your volunteering experience?**

My favourite part is hearing all of the positive feedback and anecdotes from patients who have felt supported by the organization. It makes me feel that I am part of something that spreads hope and strength, and touches the lives of people dealing with rare diseases.

**What would be your message to people thinking about volunteering at AAMAC?**

Everyone at AAMAC is so supportive, which is, after all, part of our mission – to provide support to patients. The team of volunteers, the board and everyone involved is out there every day trying to do a good job.



**Thank you to all of our amazing volunteers!**

# Remembering Dr. Couban

*By Gwen Barry*



*Dr. Stephen Couban (February 24, 1961 to March 19, 2019)*

AAMAC was sorry to hear about the passing of Dr. Stephen Couban on March 19, 2019, at the age of 58. He had a very short bout with terminal cancer.

From 1992 to 1996, Dr. Couban completed his training in Hematology at McMaster University, followed by training in blood and marrow transplantation as a Terry Fox Fellow at the Princess Margaret Hospital in Toronto. For 13 years, he was Chief of Service in Hematology at the QE II Health Sciences Centre in Halifax, including the Medical Clinic, the Blood and Marrow Transplant Program and the Medical Day Unit. Nationally, he had been President of the Canadian Blood and Marrow Transplant Group and President of the Canadian Hematology Society.

Dr. Couban hosted, and contributed financially to, an Annual Stem Cell/Bone Marrow Transplant Survivor's Dinner in Halifax. Patients attended from all over the Maritimes. The many serious and humorous patient testimonials about Dr. Couban, given each year at the Annual Dinner, are a good indication of the high regard in which his patients held him.

For at least 15 years, Dr. Couban had been a member of AAMAC's Medical and Scientific Advisory Committee. He was also AAMAC Atlantic Region's go-to person for queries and Patient Education Days, where he was a regular guest speaker.

Several members of AAMAC's Board of Directors attended his funeral. He will be sorely missed. AAMAC has made a donation in his memory to the QE II Health Sciences Foundation, and a leaf has been placed on AAMAC's Tree of Life in Dr. Couban's name.

## Tree of Life

The Tree of Life is a way of recognizing those who have been affected by AA, MDS or PNH.

To purchase a leaf, please contact the National office at 1 (888) 840-0039 or [info@aama.ca](mailto:info@aama.ca).

*A 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.*

### In Honour of:

Alan Patt  
Barbara Doiron  
Beatrice and David Murphy  
Bernice Teasdale  
Bill Gryba  
Bill Hunt  
Calogero Ciccarelli  
Cameron Root  
Caroline Laughlin  
Carrie Plotzke-Cleghorn  
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### In Memory of:

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Alexander Bowen  
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Barbara Culbert  
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Marian Elizabeth Peters  
Marko Lyshak  
Marnie Douglas  
Megan Locke  
Nastor W. Bill Gryba  
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Susan Laughlin  
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Trevor Thompson  
Valdemars Jankovskis  
Vern Coles  
Walter Salamandyk  
Wilfred Hinchey  
William Slawson  
William Terry McEvoy

