

THE PULSE

for patients living with AA, MDS, PNH and the caregivers who support them



AAMAC Newsletter - Summer 2020



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A MESSAGE FROM OUR EXECUTIVE DIRECTOR

I trust that you are keeping safe and well as we all are facing these uncertain times dealing with the Covid 19 pandemic.

AAMAC has continued our work in supporting patients and caregivers working remotely to ensure you have access to resources during this time period. You can always reach out to us at info@aamac.ca or by calling our office number and leaving a message 1-888-840-0039.

We have organized a number of different webinars to keep you informed and updated about any new developments affecting our patients. Please continue to check our website for updates and follow us on social media.

We have suspended all in person meetings for the time being and have made the difficult decision to postpone Patient Education Day this year. Please reach out to us if we can be of assistance to you and your families.

Thank you.
Cindy Anthony



Photo credit: Patrick Moore

MEET A NURSE EDUCATOR: MICHELLE FORMAN



Michelle Forman is a Registered Nurse at the Cancer Clinic at Burnaby Hospital

Michelle graduated from BCIT in 1991 and worked in a variety of areas including acute medicine, IV therapy, and discharge planning before finding her niche in oncology. She has worked in oncology since 1995, obtaining further certification in oncology through the Canadian Nurses Association (CNA) in 2010, and is also a member of the Canadian Association of Nurses in Oncology (CANO).

Her current role in the outpatient cancer clinic includes treatment administration, patient education, symptom and side effect management, and staff education. Michelle is passionate about oncology nursing and feels that her knowledge and experience play an integral role in helping to provide for the physical and emotional patient care needs.

Michelle has also enjoyed the opportunity to be involved in many initiatives aimed at enhancing the cancer patient's experience as well as the educational needs of fellow oncology health care professionals. Teaching has been a focus for her for the past thirteen years.

She is also a founding and ongoing member of the organizing committee for the NACCC conference, an annual provincial conference in Oncology Nursing, and part of the planning committee for the annual Canadian Conference on Lymphoproliferative Disorders. In addition to her passion for oncology, Michelle has a strong interest in hematology. She has been associated with AAMAC for seven years and is a member of the AAMAC Nurse Education Network. In this role she has taught patients, their family and friends and other nurses about bone marrow diseases.

In her spare time Michelle enjoys a variety of sports, including hockey, skiing, and biking, and spending time with friends and family. She is grateful for the many wonderful opportunities to travel with her husband and two children, having visited six different continents.

EXCERPTS FROM AAMDS INTERNATIONAL FOUNDATION WEBINAR: Q&A COVID-19: BONE MARROW FAILURE AND INFECTIOUS DISEASE

with Dr. Amy DeZern and Dr. Veronica Dioverti with Johns Hopkins University School of Medicine, edited for clarity and brevity

Q: Are there any benefits to being a bone marrow failure patient in the time of COVID-19?

A: Dr. DeZern: Our patients are exceptionally well suited to deal with this right now because I think that a lot of bone marrow transplant patients, patients with high dose immunosuppressive therapy or chemotherapy like the majority of marrow failure patients are very accustomed to social distancing and they pay a lot of attention to cleanliness and avoidance of transmission.

Q: Does Vidaza have an antiviral activity?

A: Dr. DeZern: In this case? We wouldn't think so. There's no reason to think that it would actively in some way inhibit the viral replication of this. We have a pretty good sense from a hematologic perspective of the way that azacytidine or Vidaza works. But I don't think it would have any activity here.

Q: Generally, would it be a good idea to have a white cell transfusion to help with your immunity?

A: Dr. DeZern: Actually, no. It's something we do very rarely, can actually cause other medical issues and doesn't last for more than 24 to 30 hours.

Q: Does being on a small maintenance dose of cyclosporine after ATG treatment make a patient more susceptible to the virus? Does being on a prophylactic dose of acyclovir help provide protection from the virus?

A: Dr. DeZern: Maintenance cyclosporine is really important for patients who are treated with ATG to prolong the immunosuppression to treat the disease. It would by definition increase the immunosuppression to make a patient more susceptible to the virus. The acyclovir is intended for other conditions but I'll defer to my colleague.

Q: If an MDS patient is taking prednisone, does this suppress the immune system?

A: Dr. DeZern: Prednisone is a well-known immunosuppressant. Different doses have different amounts of immunosuppression.

Q: If you need to have a weekly/biweekly blood draw, is it enough to wear an N95 mask, not touch anything and stay 6' away from everyone? What about lab staff?

A: Dr. DeZern: I think you need to make it known that you are immunosuppressed. Lab personnel are well-trained and exceptionally cautious, so just tell them and they'll work quickly and carefully to protect you.

A: Dr. Dioverti: Don't be afraid to request that the tech or the health care provider that is coming in contact with you to wear a mask for your own protection. And they really should be doing that without you having to ask them that. You should feel very empowered to ask.

Q: Are 5+ year bone marrow transplant survivors with counts in the normal range at higher risk than normal people?

A: Dr. DeZern: I would say that this person is much more like normal people risk.


A: Dr. Dioverti: There are very few patients that are five years out of their bone marrow transplant who remain immunosuppressed and we tend to have a good idea of who those people are because they do come in with frequent infections. So if that's not you, then your immune system's probably quite close to that of the patient without a bone marrow transplant.

Q: Is it okay for patients with PNH and aplastic anemia to go to the grocery store or should they have other family members and friends picking up items for them and how would they keep these items safe being brought into the home?

A: Dr. DeZern: We all have to eat so practically, someone has to go to the grocery store. Practice the measures we've already talked about. Wash fruits and vegetables with soap and water, let non-perishables sit for a period of time before bringing them into the house. If you have to go to the store, wear a mask, go at off-peak times and maintain a social distance of at least six feet.

Q: Do we know what the long term effects of COVID-19 in healthy individuals would be vs individuals with an immunocompromised illness even after being recovered from the disease?

A: Dr. DeZern: Not quite yet. We're still learning as we go. Long term outcomes of this are going to take quite a few months for us to get a handle on. Right now most of our resources are diverted into controlling the pandemic and so we're still waiting for a lot of studies to come out to see what's going on. So we don't have the answer to that one yet.



HAPPY RETIREMENT GWEN



Gwen Barry (at right) and her sister, Thelma Moore, attend the Canadian Blood Services stem cell transplant drive, held in Sydney, N.S. in April 2013.

Usually when we hear the word retirement, we think of slowing down and taking things easy but that is not the plan for Gwen Barry when she retires from the AAMAC board and the role of Atlantic Region Coordinator this coming October. Gwen has big plans which include managing her emigration history and genealogy book business, writing two more books, and reconnecting with family and friends that she has lost touch with over the years. Gwen, a 78 year-old MDS patient, says, "Time is marching on. A recent statistic that has come out of the US suggests that only 10% of MDS patients are still living 15 years after their year of diagnosis. I've used up 12 of those years already, although the statistic is, of course, not set in stone."

Gwen has served as the Secretary of the AAMAC board for 6 years, a role to which she is very well-suited as a writer. She also made major contributions to the board's governance committee and the development of a policy and process for recruiting new board members. Gwen was involved in the board's effort to align AAMAC's bylaws and corporate articles with new not-for-profit legislation that came into effect in 2014. As her "indoctrination" into AAMAC, this work laid a strong foundation for her continued work with the organization.

Gwen reports that her role on the board gave her a window into many other initiatives including:

- Planned giving
- Research grants
- Nurse education
- Advocacy for new treatments

She was also able to keep abreast of the work of other organizations such as the National Rare Blood Disorders Organization, Canadian Blood Services, and the Canadian Organization of Rare Disorders.

As Atlantic Region coordinator, Gwen was instrumental in sharing information with patients and caregivers in the region, organizing Patient Education Days, and arranging Peer Support when requested. She has also been the leader of the Halifax Support Group which has developed into a friendly group that meets socially several times a year including an Annual Christmas gathering. Although stepping down as leader of the group, Gwen plans to stay in touch, “with this long-established group of amazing people.”

Board member, Jennifer Garvey, shared this message about Gwen:

“Gwen has been such an amazing asset to the board. I don’t even know where to start. She is so well-read and up-to-date on the latest developments and is the hardest working recording secretary I have ever had the pleasure of working with. She is a wonderful advocate for patients and families across the country but especially for those she meets in Atlantic Canada. She is truly the glue that holds the Halifax Support Group together and we are grateful she is not retiring from that. She is such a wonderful person - always checking to see how you are doing and offering assistance. It is hard to imagine the board without her and she will be greatly missed. Thank you, Gwen!”



MEETINGS & EVENTS

Visit AAMAC.CA for all meeting and event details and registration

Webinar

Brief Update on Covid-19 followed by a Q&A

Date: Friday, May 22, 2020

Time: 2pm ET

Speaker: Dr. Heather Leitch, Director
Hematology/Oncology Research (SPH),
Clinical Professor, St. Paul's Hospital

Webinar

Medical Decision Making

Date: Tuesday, June 23, 2020

Time: 12pm ET

Speaker: Reanne Booker, Nurse Practitioner

Due to COVID-19, we have suspended all in person meetings. We have organized a number of different webinars to keep you informed and updated!

Did you miss some of our past webinars?

Check out the [Resources](#) section on the AAMAC site to watch our recorded presentations

Annual General Meeting (AGM)

This year's AGM will take place virtually on Saturday, October 17th @ 2pm ET.

Please visit the [AAMAC website](#) for registration details.

Annual Patient Education Day

This year's Patient Education Day to be held in Halifax has been postponed until the fall of 2021. Visit the [AAMAC website](#) for updates on next year's event.

Volunteer with us

AAMAC is looking for a volunteer representative from Quebec to sit on its
Board of Directors

Visit AAMAC.CA for details





Aplastic Anemia & Myelodysplasia

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de l'anémie aplasique et de la myélodysplasie

**Aplastic Anemia and Myelodysplasia
Association of Canada**

2201 King Road

Unit #4

King City, ON

L7B 1G2

Phone: 1-888-840-0039

Email: info@aamac.ca

**Provincial Support Groups &
Regional Support Liaisons**

British Columbia

Fiona Lewis - bcsupport@aamac.ca

Alberta

Fiona Lewis - albertasupport@aamac.ca

Ontario

Kimberly Brunelle - ontariosupport@aamac.ca

Atlantic

Gwen Barry - gwenb@eastlink.ca

Other Provinces

Cindy Anthony - info@aamac.ca

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or Instagram?**

Want to connect with others who
have bone marrow failure disease?

Try searching these hashtags:



#AplasticAnemia

#StemCells

#Bonemarrow

#bmt

#myelodysplasia

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