



AAMAC
ACAAM

Aplastic Anemia & Myelodysplasia
Association of Canada

Association canadienne de l'anémie
aplasique et de la myélodysplasie

Newsletter - Winter 2020

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



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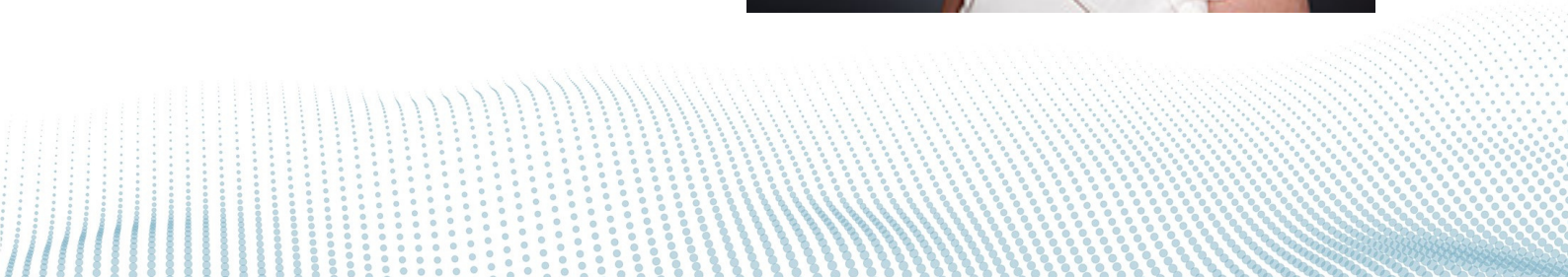


HAPPY HOLIDAYS

Welcome to a new look for AAMAC! We are excited to launch our new logo. A description of the meaning of our new logo is included in this newsletter. I hope you have had the opportunity to participate in one of our webinars over the past 8 months. AAMAC will continue to host these along with our online support groups in some areas until it is safe for us all to meet again in person. If you have ideas for a webinar or would like to be linked to a support group, please email us at info@aamac.ca.

While this holiday season will likely be different for all of us, on behalf of everyone at AAMAC, I wish you a happy holiday season and all the best for you and your families in 2021.

Cindy Anthony
Executive Director





**2020 AAMAC NURSING
AWARD RECIPIENT:
AMANDA BETTLE**



My name is Amanda Bettle and I have worked as a pediatric nurse at the IWK since 2002. Most of my time has involved working with the Hematology/Oncology population. I am passionate about my job as a nurse and have always had a vision to become a pediatric nurse practitioner (NP). I began the University of Toronto Pediatric NP program in September 2019 and am so excited to build on my career. I consider it a privilege to work closely with patients and their families during some of the most difficult experiences. I also love to mentor and work alongside my colleagues as well as new learners to make sure we provide the best possible care.

I think one of my biggest accomplishments right now is being able to effectively balance studies with work and my family. I have two young children who teach me so much about life and balance. My children have also taught me many lessons that I have brought to my practice. My empathy and ability to support families has increased and my nursing practice has improved as a result of the lessons I have learned from my children.

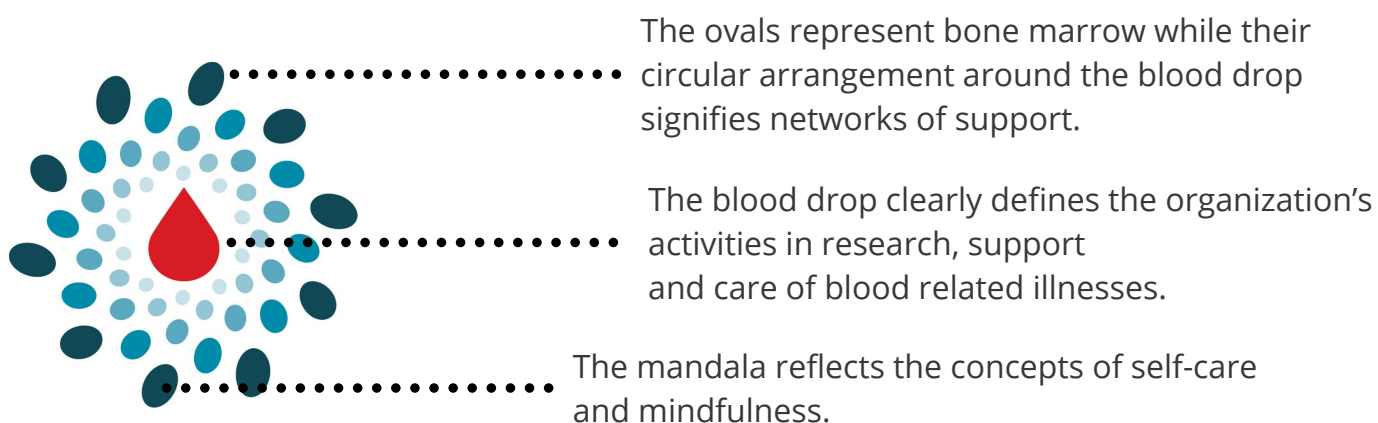
I think what I am most proud of is my positive attitude in life and in work. I strive to look for and build upon the strengths of my coworkers, patients and families. I know that when you look at the positive then more positive will follow.



AAMAC BRAND LAUNCH

With this newsletter, AAMAC is proud to launch our new brand and logo which will take us forward into the next decade.

The new AAMAC brand features a mandala design incorporating a blood drop surrounded by concentric ovals in shades of teal.



The organization's board and leadership selected this design as it captured the important activities of AAMAC while projecting a feeling of movement and change. In addition, the logo is highly legible and easily reproduced in a variety of formats.

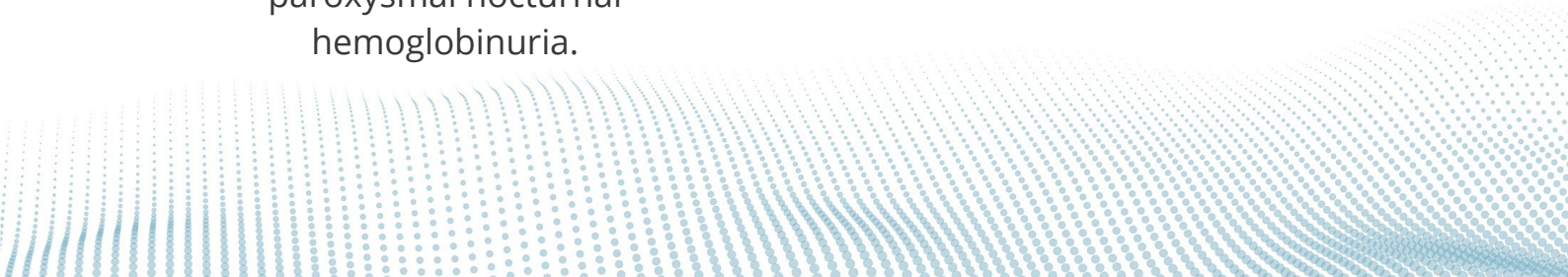
We hope you like the new brand as much as we do and come to associate it with the services AAMAC provides.

Our Mission

To provide a seamless support network for every Canadian patient, family member, friend, and concerned healthcare provider dealing with aplastic anemia, myelodysplasia and paroxysmal nocturnal hemoglobinuria.

Our Vision

To support all Canadians and their families and friends through diagnosis, treatment and remission stages of these diseases.





MEETINGS & EVENTS

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

Webinars

Self-Compassion for Caregivers

Date: Saturday, November 21

Time: 1pm ET

Speaker: Patricia Williams

Canadian Certified Counsellor

Iron & Iron Overload

Date: Saturday, November 28

Time: 1pm ET

Speaker: Dr. Cyrus Hsia,
Internal Medicine and Hematology
at the London Health Sciences
Centre and the London Regional
Cancer Program.

Clinical Trials in Canada

Date: Tuesday, January 19, 2021

Time: 3pm ET

Speaker: Dr. Mitchell Sabloff,
Director of the Ottawa Hospital
Leukemia Program, Division of
Hematology. The Ottawa Hospital.

National Patient Support Group

AAMAC is now offering a monthly virtual patient support group meeting. Join us from the comfort of your home - patients and caregivers welcome! Meetings will be held on the first Saturday of each month from 2pm-4pm ET. Our first meeting will be held on Saturday, December 5, 2020.

Sick Kids Marrow Failure and Myelodysplasia Patient & Family Conference

This virtual conference is for patients and families with bone marrow failure disorders and myelodysplastic syndrome, physicians, other health-care workers, fellows, residents and all others who are interested in the field. Adult patients are also invited. The conference will take place on Saturday, April 17th, 2021.



December 1 is **Giving Tuesday**, a day of international charitable giving and volunteering. As part of this global effort, AAMAC is seeking the support of Canadians across the country to continue the important work it does for Canadians with bone marrow failure diseases.

With your support, AAMAC can continue to reach and support more patients, fund important research and increase awareness of bone marrow failure diseases. You can do this several ways: Mail in the enclosed donation card; make a onetime or monthly donation via our website www.aamac.ca; ask your employer to match your donation; include AAMAC in your estate planning; or donate your time and skills to AAMAC.



RESEARCH NEWS

A recent report published at Healio.com highlighted the fact that low clinical trial enrollment is slowing the development of treatments for MDS.

A study published in Cancer on MDS trial participation found that trial eligibility criteria pose challenges for the MDS patient population in the United States. As the median age of MDS patients is in the 70's, many have other serious medical problems and/or difficulty travelling, which may preclude them from joining clinical trials. The study analysis showed that male gender, white race and shorter distance to the trial site were associated with a greater likelihood of trial participation.

The study author, Charlotte Brierley, concluded that adjustments to trial eligibility criteria will likely be needed to improve rates of clinical trial participation by patients with MDS. She also stated that steps need to be taken to make trials more accessible to patients in a variety of locations and circumstances.

You can learn more about clinical trials at the upcoming AAMAC webinar in January, 2021



Interested in clinical trials?

AAMAC works with partners to provide ways to participate in clinical trials near you. Visit our website where you can find several ways to find clinical trials
www.aamac.ca/clinical-trials



BOARD OF DIRECTORS UPDATE

Haydn Liang has resigned from the Board and we would like to thank Haydn for his years of service. Gwen Barry has agreed to remain as the Secretary for the next year and we are very thankful that Gwen will be serving for another year. We are beginning a search for new Board Members. If you are interested in joining our board, please contact Cindy Anthony for more information: cindyanthony@aamac.ca

SUBSCRIBE

If you've enjoyed this issue of the AAMAC newsletter and would like to receive it regularly, please subscribe. Help us reduce our costs by choosing to receive the newsletter by email.

- Subscribe online at aamac.ca
- Email info@aamac.ca or call 1-888-840-0039

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

Kim Brunelle - ontariosupport@aamac.ca

Atlantic

Kim Brunelle - atlanticsupport@aamac.ca

Other Provinces

Cindy Anthony - info@aamac.ca

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