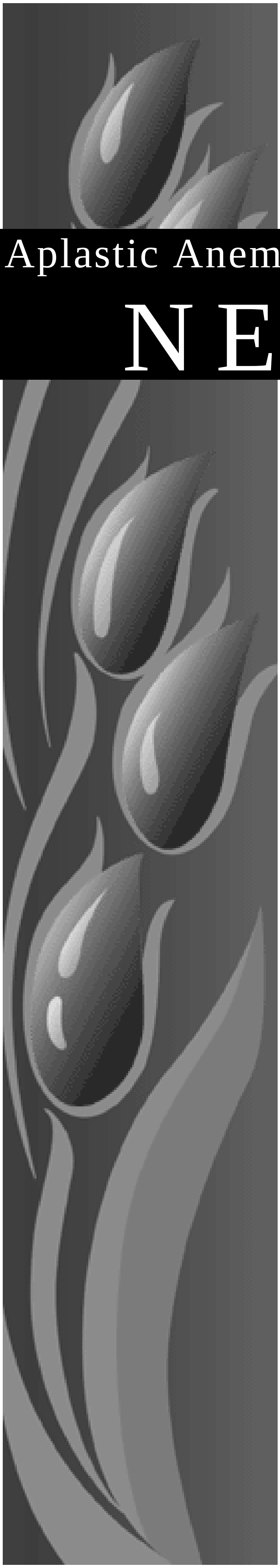
Education
Support
Research

Fall 2019



Aplastic Anemia & Myelodysplasia Association of Canada
NEWSLETTER

Message from the Executive Director

It is hard to believe that by the time you read this summer will almost be over. I hope you have had a good summer, enjoying the warmer weather and spending some time with family and friends.

Fall is always a busy time at AAMAC as we plan for our Annual Patient Education Day. This meeting and our Annual General Meeting will be held on Saturday, October 19th this year in Calgary, Alberta. The full agenda and registration form are included in this newsletter mailing. We hope to have a good number of patients and their caregivers at this meeting. We are also planning a meeting in Hamilton, Ontario on Saturday, November 2nd. Details for this meeting and registration information can be found in the Ontario section. Kimberley Brunelle, who has just started in the Ontario support person role, is organizing speakers for the meeting.

Attending meetings is not always an option for people and we recognize this. We have a number of different presentations through our website from previous meetings. A number of topics are covered in the presentations.

AAMAC is excited to be involved in a new research project with Dr. Yigal Dror from the Hospital for Sick Children in Toronto. Christine Pappas, one of our Board Members, recently interviewed Dr. Dror about the project and I know you will enjoy reading about the work being done.

One of the most important volunteer jobs with AAMAC is that of peer-to-peer support person. It is so comforting for new patients to be able to speak with someone who is able to share their story and give encouragement to newly diagnosed individuals. If this is an area that you feel you may be able to assist with, we ask that you contact the office by email at info@aamac.ca or by phone at 1-888-840-0039. We will provide more information about the peer-to-peer support role and send the necessary forms to complete.

Looking forward to seeing some of you at our fall meetings and for those of you who are not able to attend a meeting, please visit the website to access previous presentations and to watch for updates on more meetings to be held in the Fall.

Cindy Anthony
Executive Director

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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.

The Aplastic Anemia & Myelodysplasia Association of Canada Newsletter is published 4 times a year. The contents are not intended to provide medical advice, which should be obtained from a qualified health professional. No part of this publication may be used or reprinted without written permission. For submissions, inquiries or comments, please contact us at:

Aplastic Anemia and Myelodysplasia
Association of Canada
2201 King Road, Unit #4
King City, Ontario L7B 1G2
(905) 780-0698 or 1 (888) 840-0039

bcsupport@aamac.ca
albrertasupport@aamac.ca
ontariosupport@aamac.ca
adminoffice@aamac.ca
cindyanthony@aamac.ca

info@aamac.ca. www.aamac.ca Charitable Registration Number 87557 2265 RR0001

Patient Education Day in Calgary

Join us in Calgary on Saturday, October 19th, 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.

Presentations include topics such as treatment developments. We hope to see you there!

Ontario Update

By Kimberly Brunelle, Ontario Patient Support Coordinator

We will have one patient support group meeting in Ontario this fall. It takes place in Hamilton on Saturday, November 2nd, 2019 from 9 a.m. to noon at the Courtyard by Marriott Hotel, 1224 Upper James Street.

Dr. Dina Khalaf will speak on the topic of "MDS – What it is and how it is treated."

At this time, we are still working on securing a second speaker who would cover the topic of pediatric aplastic anemia. To register for this upcoming event, visit the 'Meetings & Events' section of our website, email us at info@aamac.ca or call 1-888-840-0039. Continue to check our website for any updates on speakers.

We are planning to host a meeting in London in the spring of 2020. Details will be posted on our website as they are confirmed.

Atlantic Region Update

By Gwen Barry

The AAMAC Halifax Support Group will meet for brunch at 10 a.m. on Saturday, September 7th, 2019 at the Bedford Basin Farmer's Market and Cafe, 397 Bedford Highway in Halifax (near Kearney Lake Road). All AA/MDS/PNH patients, caregivers and their families are welcome to attend. Please contact me at gwenb@eastlink.ca if you wish to attend, so we can reserve enough places.

Meet A Nurse Educator

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

Meighan Kozlowski graduated from the University of Saskatchewan with a Bachelor of Science in Nursing and also maintains the Canadian Oncology Nursing Certification.

Currently she works in Saskatoon on the inpatient oncology unit as a nurse educator.

She quickly discovered that oncology nursing was her career path when caring for a loved one through the stages of a cancer diagnosis, knowing that helping others was important.

Hematology has quickly become an area of interest along with the ability to connect with others and educating. Being a nurse educator is a great opportunity to do both.

Her love for hematology and leadership drive her work each day; offer knowledge, caring, and kindness to the cancer community.

She is also a mom of an amazing son who is already learning about hematology and bone marrow disorders as he loves knowing about mom's job.

The importance of enjoying each day and making a difference is a goal she tries to incorporate into work.

Meighan has recently provided education sessions sponsored by AAMAC on Myelodysplastic Syndromes (MDS) to 65 registered nurses in Saskatoon. The education included a disease overview, staging, treatment options and, most importantly, an introduction to the materials available to support patients.

She is hopeful this teaching will filter to the bedside and better support the MDS patient population in Saskatchewan.

She is happy to be a new part of the AAMAC community and is honoured to help support advancement of hematology with education.

Searching for a Cure: An interview with Dr. Yigal Dror

One of the primary objectives of the Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC) is to fund promising research into the areas of aplastic anemia, myelodysplastic syndromes (MDS), and paroxysmal nocturnal hemoglobinuria (PNH).

Dr. Yigal Dror is a recipient of AAMAC funding for a multi-year registry on aplastic anemia and myelodysplasia.

Dr. Dror is a Professor of Pediatrics at the University of Toronto and Staff Physician in the Hematology/ Oncology and Bone Marrow Transplantation Division, Director of the Bone Marrow Failure and Myelodysplasia Program, and Senior Scientist in the Genetics and Genome Biology Program at The Hospital for Sick Children (SickKids) in Toronto.

AAMAC sat down recently with Dr. Dror to discuss his latest progress on the research registry, called the Canadian Aplastic Anemia and Myelodysplastic Study, also known as CAMS.

Can you tell us a little about CAMS? I understand it involves the creation of a pediatric registry for rare bone marrow failure diseases.

The registry was established in 2014 and became operational in 2015. It is a Canadian registry with 14 paediatric centres across the country so far. Because these are very rare conditions, a research infrastructure that enables enrolment of patients on an ongoing basis is required to have a sufficient number of patients in order to launch studies.

Research registries and biobanks provide such a unique infrastructure, but it can take several years to accumulate enough patients to open a research project that tackles a specific research question. We currently have 68 children enrolled in the study.

Our goal is to establish a network of investigators to share ideas. While the focus is on research, the breadth and depth of discussions among CAMS networks of medical professionals and researchers are very significant.

Through the registry network, we aim to identify the gaps in clinical knowledge in order to open research projects that closes these gaps and advance patient care.

The discussions among the network also help devising national treatment guidelines. Hence, the patient is getting not just one doctor but many.

The age limit to be on the registry is 30 years. Isn't that unusual for a pediatric registry?

This is because there is not much difference between a 17-year-old child and a 25-year-old young adult in terms of the clinical features and biology of the disease. Frequently, oncology clinical trials, which include adolescents, are also open to young adults, up to 25 or 30 years of age.

The registry aims to include patients who were diagnosed in childhood, but are currently followed in adult centres. Some paediatric centres continue to care for patients who are 18 years of age.

There is currently no adult registry for aplastic anemia in Canada.

Can you share a real-life example of how the registry has been successful to date?

The CAMS has been approved by the Research Ethics Boards (REB) at SickKids and multiple other centres in Canada, and has opened for recruitment of patients in many provinces. A comprehensive electronic CAMS database has also been established to collect coded and anonymized data.

Although it has only recently been established, the CAMS registry was already the foundation for two specific studies that tackled important challenges in the field of pediatric myelodysplastic syndrome.

The first study demonstrated, for the first time, that using azacytidine in children with advanced MDS before bone marrow transplant, significantly improved the survival rate of these children (Haematologica 2015). The second study focused on borderline disease between MDS and leukemia [Shabanova et al, submitted for publication].

How is AAMAC funding helping CAMS reach its goals?

The registry questionnaires are very detailed and we need personnel to enrol patients, fill out questionnaires, obtain samples for biological studies, and send coded and anonymized data and material to the registry office at SickKids. The operation of the registry, collection of samples and high quality data, and performing analyses would not be possible without the support of AAMAC. We simply wouldn't be able to do this work.

What do you hope the registry will become? How will it expand in years to come?

I hope that pediatric centres in Canada that have not initiated or completed the steps necessary to open the CAMS will do so and start enrolling patients, so it becomes truly a Canada-wide registry with robust data and biological samples that enable research on multiple aspects of aplastic anemia, MDS, and PNH.

We have opened a secure online database for the registry located at SickKids. In the future, coded and anonymized information can also be entered by collaborators at their sites. At the main registry office at SickKids the data will be reviewed and analyzed. This will render data collection faster and more unified.

There currently is no curative treatment for MDS and for some patients with aplastic anemia and PNH other than bone marrow transplants. Is that discouraging to you as a researcher that so little process has been made?

Yes and no. Research over the last two decades has led to tremendous improvement and success with many bone marrow failure conditions.

First, progress in establishing a correct diagnosis (e.g. by genetic testing), refinement of transplant preparation and selection of donors has resulted in most patients with aplastic anemia and MDS in children. Second, alleviating the diseases by medications such as azacytidine (for MDS), eltrombopag (for aplastic anemia) and eculizumab (for PNH) resulted in major improvement in quality of life and life span.

On the other hand, many patients with MDS, aplastic anemia, or PNH are either not candidates for the above treatment, do not respond, develop leukemia, or relapse after bone marrow transplantation. Also, many of the current treatments have significant side effects. Therefore, major research endeavours are necessary to overcome these challenges and gaps.

I am optimistic and think that we are going to see substantial positive changes in the next decade. New research methodologies that involve cell cultures, comprehensive drug screening, genetics and others, give hope that new treatment options with better efficacy and safety profiles are found.

Is there anything else you'd like to share?

I'd like to thank AAMAC for supporting our research program. More information about our Marrow Failure and Myelodysplasia Program, our research and donations can be found in the following link: http://www.sickkids.ca/MFMP/.

Follow us on social media

The Aplastic Anemia and Myelodysplasia Association of Canada (#AAMAC) is on social media! Follow us on Facebook, Instagram, Twitter, LinkedIn and YouTube to keep up to date with the latest news!

Details of meetings and webinars hosted by both #AAMAC and others are posted as well as news items that may be of interest. Presentations from some support group meetings are also posted.

Examples include:

- Understanding Your Blood Counts by Mona Walia, RN BScN, Patient Care Coordinator, Ambulatory Clinics L/BMT Program of BC
- Quality of Life by When Dealing with a Chronic Disease - Pamela J. West, RN(EC), NP-ADULT, MSc. Nurse Practitioner (retired), Oncology/Supportive Care
- Coping with Chronic Illness by Aimee Anderson MSW RSW

These and other presentations are also available on our website at aamac.ca/resources.

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youtube.com/channel/UCEGce9YOSjhzOWNXK364hkw

Ontario drug access program goes digital

We recently received the following information from the government of Ontario and share it here with members.

As you know, many patients with aplastic anemia and myelodysplasia who are eligible for Ontario Drug Program coverage may require funding for drugs that are not on the general formulary. These drugs often require approval from the Exceptional Access Program.

The Ministry of Health is speeding up the processing times for Exceptional Access Program drug decisions by going digital – replacing the fax-based application process with an IT solution called the Special Authorization Digital Information Exchange (SADIE).

When fully rolled out, SADIE will accelerate drug decisions, and in many cases, give eligible patients a decision in real-time. Faster decisions will reduce the number of return trips to the doctor or nurse practitioner for prescriptions after receiving drug funding approval. Getting decisions to prescribers faster means in many cases patients can start drug therapies sooner.

In fact, use of SADIE among a pilot group of physicians and nurse practitioners has already reduced wait times to access drug funding for patients such as those served by your organization.

Please visit health.gov.on.ca/en/pro/programs/sadie/news/ for additional information on SADIE and helpful information bulletins.

News of Note

Patient Guides & Fact Sheets Online
The Aplastic Anemia and MDS International Foundation now has patient educational materials available for dowload. This includes information in languages other than English. A small number of print materials are available from the Foundation upon request. Please keep in mind that this information is American and some treatments referenced may not be available in Canada. Visit aamds.org/education/patient-guides-and-fact-sheets.

PNH may be highlighted on American soap opera, Young and the Restless
Media have reported that long-time Young and the Restless character Victor Newman may be diagnosed with PNH and require a bone marrow transplant. This isn't the first time a character in a soap opera has been diagnosed with bone marrow failure. For example, characters on soaps including One Life to Live and Days of our Lives have been diagnosed with aplastic anemia in the past.

Canadian Blood Services

By Pam Wishart and based on a Canadian Blood Services presentation

Canadian Blood Services
BLOOD
PLASMA
STEM CELLS
ORGANS
& TISSUES

The infinite power of connections

Based on the universal shape for infinity, this design represents the infinite lengths to which we must always go to save lives, while recognizing the connections that link us together – from donors to recipients, from transfusion to transplantation, from hearts to minds, from one to another.

Are you aware Canadian Blood Services (CBS) is now so much more than a blood collection agency for nine provinces and three territories in Canada? Québec is served by Héma-Québec (H-Q). CBS and H-Q work together to ensure the best outcomes for patients

CANADIAN
RED CROSS

Canadian Blood Services
Société canadienne du sang

Canadian Blood Services
Société canadienne du sang

In a recent study, CBS found that nearly 40% of the people asked still believe the Canadian Red Cross is responsible for managing Canada's blood supply. And this 21 years after the establishment of CBS and H-Q!

Those of you who donate are, no doubt, aware of the changes but those who are recipients may well not be.

Gone is the iconic blood drop, replaced by an infinity symbol. The infinity symbol was chosen to represent the interconnections between the services CBS now offers, so much more than blood alone.

The focus is now on life essentials for transfusion or transplantation including blood, plasma, stem cells and organs and tissues represented by the four colours of the infinity symbol. CBS, as always, continues to be dedicated to the safety of the system for patients and donors.

So, let your family and friends know of the changes and the reasons behind them and, please, encourage them to donate if they can and to spread the word.