



AAMAC
ACAAM

Aplastic Anemia & Myelodysplasia
Association of Canada

Association canadienne de l'anémie
aplasique et de la myélodysplasie

Newsletter - Fall 2021

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

Message from the Executive Director

I trust everyone has had a good summer and you have been able to see some family and friends. Typically we take a break from meetings over the summer, however, this year our online support groups have continued to meet and we will be continuing the groups into the fall. As you will read in this newsletter, we now have 4 groups across the country that patients and caregivers can participate in. I want to thank Kim and Fiona for taking leadership of these groups. I know they are very meaningful and we hope more patients and caregivers will join in the fall.

Also in this issue we have news on an exciting new research project we are funding. AAMAC has supported many research projects over the years. This is an area that is very important to our organization and we are looking forward to hearing more about this project as it progresses.

At this time we are still uncertain of when our in person meetings will resume. We will continue to monitor the information Province by Province and of course will keep everyone informed of our upcoming meetings, both in person and online. We are excited to partner with the MDS Foundation to host a webinar on Saturday, September 25th from 2 – 4. More information can be found in this issue and you can register at www.aamac.ca.

I would like to take this opportunity to thank Fiona Lewis for the wonderful work she has done with AAMAC over the past years. Fiona and her partner are retiring and are looking forward to some travel experiences. We will miss Fiona and wish her all the best.

Cindy Anthony

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TREE OF LIFE

The beautiful carved tree hangs on the wall at the National Office. The Tree of Life is a way of recognizing those who have been affected by AA, MDS or PNH.

You may make a tax-deductible donation of \$150 to have a special person's name inscribed on the tree. To purchase a leaf, please contact the National office at: 1-888-840-0039 or info@aamac.ca

In Honour of:

Alan Patt
 Barbara Doiron
 Beatrice & David Murphy
 Bernice Teasdale
 Bill Gryba
 Bill Hunt
 Calogero Ciccarelli
 Cameron Root
 Caroline Laughlin
 Carrie Plotzke Cleghorn
 Chris Meyer
 Cindy Bell
 Don McIntyre
 Dr. Melvin Freedman
 Gord Sanford
 Heather Parsons
 Karlee May
 Kris Plotzke
 Liz Lemire
 Lois Henderson
 Lori Lockwood
 Paul Coad
 Pietro Di Ilio
 Renee Levine
 Rumi Guzder
 Ryan Rutherford
 Silvia Marchesin

Taylor-Marie Coupland
 Trevor Thompson
 William Laughlin
 Yvette Aloisi

In Memory of:

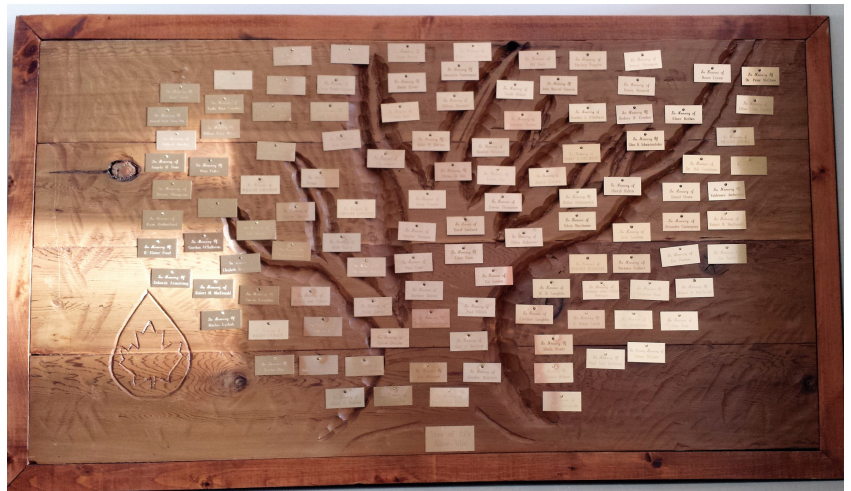
Albert H. Stahlke
 Alexander Bowen
 Alexandre Castonguay
 Angela M. Poto
 Aristotle John (Telly) Mercury
 B. Elaine Pond
 Barbara Culbert
 Barbara Jean Cronyn
 C. Donal Leach
 Claude Francoeur
 Constantine Deplares
 Craig Allen
 Daniel Orara
 Danny Carrick
 David Charles Williams
 Deborah Armstrong
 Dennis Kadatz
 Donald J. Highfield
 Dorothy Gregg
 Dr. Peter McClure
 Dr. Stephen Couban



In Memory of:

Earl J. Banford
 Ed Glazier
 Elinor MacLean
 Elizabeth Rose Herman
 Elmer Kerbes
 Erin Lawless
 Gai Thomas
 Geof Smith
 Giovanni Arcuri
 Glenn D. Schwartzendruber
 Gord Sanford
 Gordon Burgess
 Gordon O'Halloran
 Harry Alfred Roper
 Heather McIntyre
 Helen Robinson
 Herb Sixt
 James Novak
 Jim Smith
 Joan MacDonald
 Joe Burleigh
 John Maxwell Cameron
 John R. Barton
 Judy Bridges
 Keith Curry
 Kenneth Kwok Shing Mok
 Kenny Wentzell
 Laurel Burgess
 Lauren Renaud
 Marcelle Gai Thomas
 Marian Elizabeth Peters
 Marilynne Convey
 Marko Lyshak
 Marnie Douglas
 Megan Locke
 Nastor W. Bill Gryba

Nicole Wilson
 Olive Lilian Sündal
 Paul Ullrich
 Paul van Bolderen
 Philip Doiron
 Pietro Di Ilio
 Robert M. MacDonald
 Rodney W. Crocker
 Roger Fortin
 Sheila Rivest
 Sheryl Hylton
 Stanley Foch Willis
 Stephanie Dawn Temple
 Sterling Ruggles
 Susan Laughlin
 Talsa Coon
 Trevor Thompson
 Valdemars Jankovskis
 Vern Coles
 Walter Salamandyk
 Wilfred Hinchey
 William Slawson
 William Terry McEvoy





GOODBYE

FIONA LEWIS, BC/ALBERTA PATIENT SUPPORT LIAISON

I will be retiring from my position as Patient Support Liaison for Western Canada at the end of September. My partner and I are going to do some travel, starting with Europe this fall and Mexico in the winter.

I have very much enjoyed my 3 years with AAMAC. I learned a lot, not only about blood disorders, but also about the strength, perseverance, and resilience of those living with these disorders. I have also appreciated the skills, good humor, and dedication of my colleagues, Cindy, Robyn and Kim. I wish you all the best and will stay in touch over social media.



Fiona Lewis

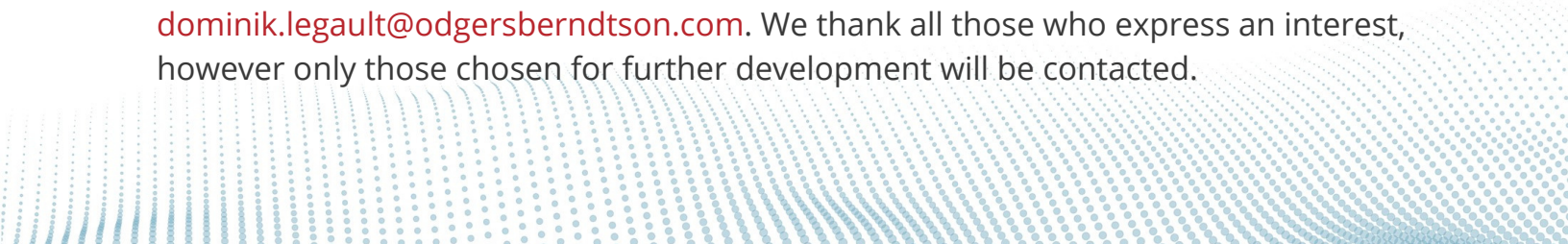


BOARD DIRECTOR - WESTERN CANADA

The association is now looking for a volunteer representative based in Western Canada to sit on its Board of Directors with a mandate to establish educational and support programs for patients and their support teams to ensure that they are aware of AAMAC's services. Ideally with an already established network of contacts within the medical community, they will organize information sessions with key experts with the help of volunteers and increase the reach and visibility of AAMAC's services to reach and support all affected individuals. Experience in governance, community building and a legal background will be considered important assets.

Applications are encouraged immediately and should be submitted online at <https://www.odgersberndtson.com/en/careers/17215>.

For more information, please contact Dominik Legault of Odgers Berndtson at dominik.legault@odgersberndtson.com. We thank all those who express an interest, however only those chosen for further development will be contacted.





CORD BLOOD DONATION

July was cord blood awareness month in Canada. Help raise awareness for the incredible benefits of donated umbilical cord blood stem cells as a medical treatment for more than 80 diseases and disorders, including bone marrow failure diseases.

Here is some additional information about cord blood from the website of Canadian Blood Services:

What is cord blood?

Cord blood is the blood left in the umbilical and placenta after a baby is born. It is rich in lifesaving stem cells that can help treat over 80 diseases and disorders.

What unique advantages do cord blood stem cells have over bone marrow or peripheral blood stem cells?

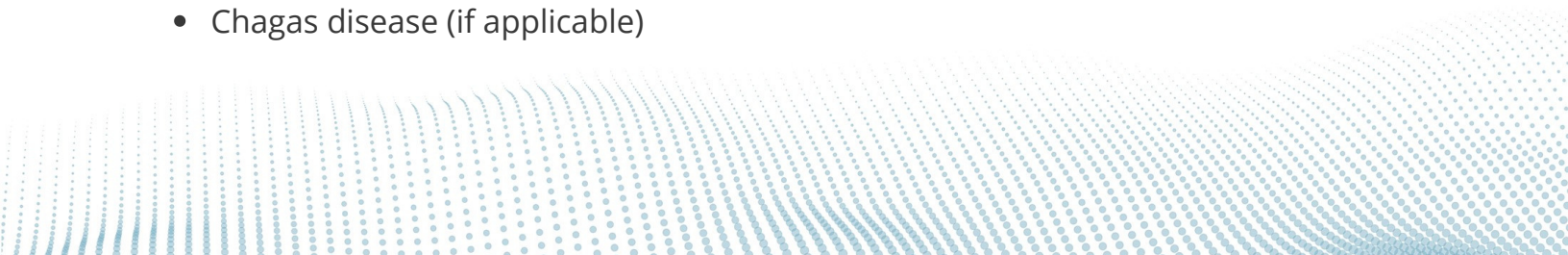
Cord blood stem cells have unique advantages over bone marrow or peripheral blood stem cells.

- They are collected in advance, stored and ready for use immediately when needed, decreasing patient wait times associated with the search for a marrow or peripheral blood stem cell donor.
- Donated cord blood does not need to be an exact match to a patient. It can be a great option for ethnically diverse patients who cannot find a match within the stem cell registry.
- Cord blood transplants are associated with a lower risk of graft-versus-host disease (GvHD), a common and serious immune-mediated side effect of transplantation.
- Transplanting cord blood stem cells can also reduce the risk of transmitting viral infections such as cytomegalovirus (CMV) that can potentially be lethal for transplant recipients.

Is cord blood tested?

Yes. Cord blood is tested to identify the presence of any of the following:

- Human immunodeficiency virus (HIV, the virus that causes AIDS)
- Hepatitis B and C viruses (HBV and HCV)
- Human T-lymphotropic virus (HTLV), syphilis and West Nile Virus (WNV)
- Chagas disease (if applicable)





Cord blood is also tested for markers that will match donated cord blood to a patient for blood type (ABO), cytomegalovirus (CMV) and hemoglobin abnormalities such as sickle cell disease. Only the mother requires a blood test. The tests for baby are done on the donated cord blood itself.

How long can cord blood be stored?

Cord blood stem cell donations are kept in liquid nitrogen at a temperature of -196 degrees Celsius and can be stored for a very long time before being used. There are examples of cord blood stem cells being transplanted after 16 years without any detected deterioration in quality.

What is the process for donating cord blood?

Donating cord blood is free and easy. Start by being fully informed. For detailed information, visit www.blood.ca/en/stemcells/donating-cordblood

Help spread the word about cord blood donation by speaking to friends and family members who may be having children. Consent to donate cord blood must be given during pregnancy, in advance of the birth, so give people lots of time to consider this option.

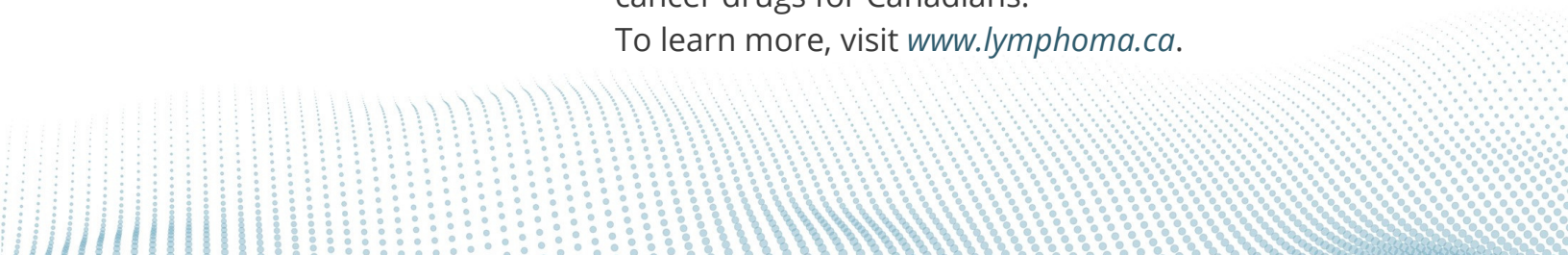
The pandemic and the restart of surgeries across Canada have created a high need for blood donations at both [Canadian Blood Services](#) and [Héma-Québec](#). Please visit their respective websites for donor eligibility information.



LYMPHOMA
CANADA

Lymphoma Canada has led the development of an updated White Paper that addresses existing challenges with regulatory, health and technology assessment, and provincial funding agencies that delay access to innovative cancer therapies in Canada. With the support of 22 cancer groups, including AAMAC, they are calling on these agencies to develop collaborative solutions to improve timely access to cancer drugs for Canadians.

To learn more, visit www.lymphoma.ca.





RESEARCH PROJECT NEWS:

AAMAC is very pleased to have recently approved funding for a project at B.C. Children's Hospital entitled: *Single cell profiling of hematopoietic stem cells in pediatric aplastic anemia*. We spoke with co-investigator, Derek Chan, a pediatrics resident physician to learn more about this study.

What is this study about?

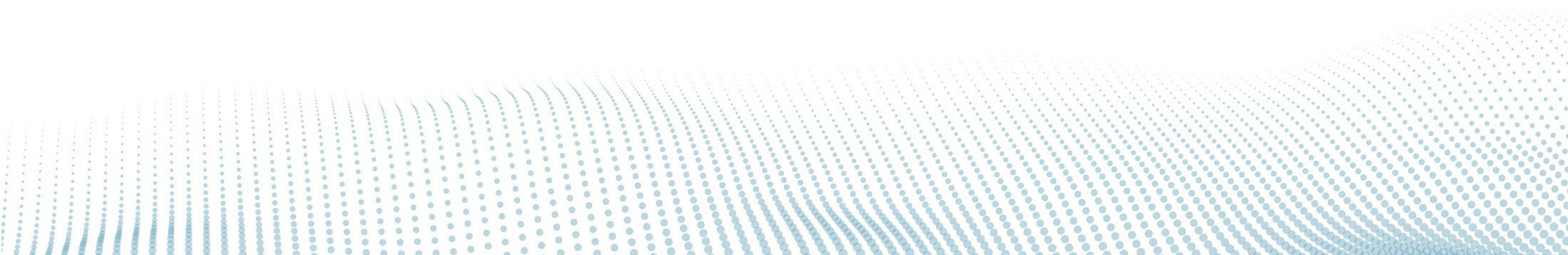
Healthy lifelong blood production depends on normal functioning stem cells in the bone marrow. Blood stem cells in aplastic anemia (AA), while known to be partially destroyed, are also dysfunctional in their ability to regenerate the blood system. However, the reasons for these underlying deficits remain poorly understood. To advance insights into this area, our study will use the latest sequencing technologies available to profile stem cells in pediatric aplastic anemia at the single cell level to determine if there are distinct biological pathways that explain why AA stem cells fail to restore blood production.

What are the potential benefits to patients?

Our rationale to compare pediatric AA stem cells to normal stem cells at such high resolution rides on the hope that we may be able to eventually identify targetable pathways to correct the underlying issues within AA stem cells. This profiling approach provides a critical blueprint that may ultimately lead to future novel target-oriented therapies that stimulate sustainable blood production in AA as an alternative to stem cell transplants and/or as an adjunct to immunosuppressive therapy.

What got you interested in this topic?

During my final year of medical school, I was moved by how ill pediatric patients diagnosed with AA can get. While a large majority of adult-centric AA research has led to new therapies such as Eltrombopag, a unique thrombopoietin receptor activator, clinical trials in pediatric AA have not shown a parallel benefit, hinting at potentially different underlying biology and importantly underscoring a widening knowledge and clinical translation gap for these children. With this project, we hope to be able to shed direct light into pediatric AA and into ways for which blood production may be rescued in this particular patient population.





What is the timeline for the project?

Having access to pediatric AA samples alongside healthy donor samples through the B.C. Children's Hospital Biobank has provided critical foundations for our study. While the turnaround for single cell profiling itself may be relatively quick, it will take time to make sense of the large datasets that come out of our cell sequencing efforts. We expect to have some preliminary results within 12 months, but in-depth analysis and validation of the results will likely take 2-3 years.

What does the AAMAC funding mean to you?

Funding for research and trainees has become much more limited and competitive over time. While there are many funding opportunities rightfully open for cancer research, there are relatively few that apply to rare disorders and/or non-malignant blood disorders. As such, receiving this funding from AAMAC is very important to researchers like myself who are interested in meaningfully moving the needle in translational research for bone marrow failure. In this study, AAMAC's support has been matched with a seed grant from B.C. Children's Hospital Foundation, so we are excited to embark on this work and will look forward to delivering on our findings in the future.

Derek Chan, MD, PhD, is a Pediatrics Resident at B.C. Children's Hospital and Research Institute, part of the Department of Pediatrics in the Faculty of Medicine at the University of British Columbia.



Interested in getting involved with PNH research?

The **Global PNH Patient Registry** is an online registry for patients with PNH. It is a collaborative effort between the Aplastic Anemia and MDS International Foundation (**AAMDSIF**) and the National Organization for Rare Disorders (**NORD**®), along with the support of industry partners, Apellis Pharmaceuticals, Inc., Genentech, Inc., and BioCryst Pharmaceuticals, Inc. The registry will collect information from participants, who are affected by PNH.

The primary aim of the Global Paroxysmal Nocturnal Hemoglobinuria (PNH) Patient Registry is to conduct a prospectively-planned and efficient natural history study that will result in a more comprehensive understanding of the disease and its course and pace over time. To register or for additional information, please visit <https://pnh.iamrare.org>.



ARE PATIENT SUPPORT GROUPS RIGHT FOR YOU?

During the past year, the move to virtual meetings has allowed AAMAC to offer more patient support group meetings than ever before. If you have been thinking about attending one, you may be interested to read what some current participants say about the meetings:

Q. What led you to join these meetings?

A.

"I wanted to listen to others who have MDS and understand how they related to their disorder. I'm interested in hearing from people who are 'cured' or don't need transfusions."

"My husband was searching on the internet for information on MDS in August 2018 after my diagnosis and found the AAMAC website. We were sent a package of information on MDS and right away we felt we found the right place to be. We knew that being a part of this community could allow us to learn more about the disease, progression, treatments and get the support we needed."

"My husband was a patient with quite advanced MDS and of course we were shocked because we had never heard of MDS. We searched for information everywhere we could find it and found others like us who were also dealing with a rare blood disorder and needed support."

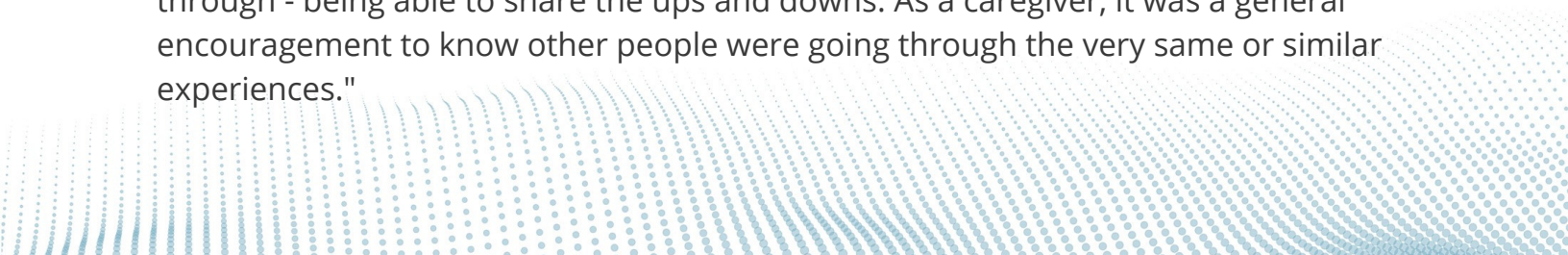
Q. What do you like about attending the meetings?

A.

"I like meeting new people and learning about new medications, especially related to iron overload and MDS."

"The meetings can give you a sense of courage and hope. Everyone has a different story as not all MDS and AA patients are the same. I like hearing the stories of the other patients and seeing their progress during treatments. I like having a safe place to talk and knowing that a group of people know exactly how I feel."

"To meet other people with a similar illness and to hear what they were going through - being able to share the ups and downs. As a caregiver, it was a general encouragement to know other people were going through the very same or similar experiences."





Q. *How have you benefited from attending?*

A.

"Just knowing that other people have the same blood-related disorders. Even when I go for transfusions, I don't meet people who experience MDS like I do. I feel comfortable knowing that there are others I can talk to and get suggestions from."

"The one thing I have taken away from attending the meetings is to advocate for yourself. If something does not feel right then ask questions. The diagnosis is scary so you need have a medical team that you feel you can trust. In the discussions with the group you learn more questions that you should ask your medical team. You also receive access to new trials information and more educational opportunities to attend and learn."

"I learned that even though they all had something in common, they were all dealing with things in a different way. Every single person is different and everyone reacts differently to medication and treatments - that lesson was such a big part of the support group process."

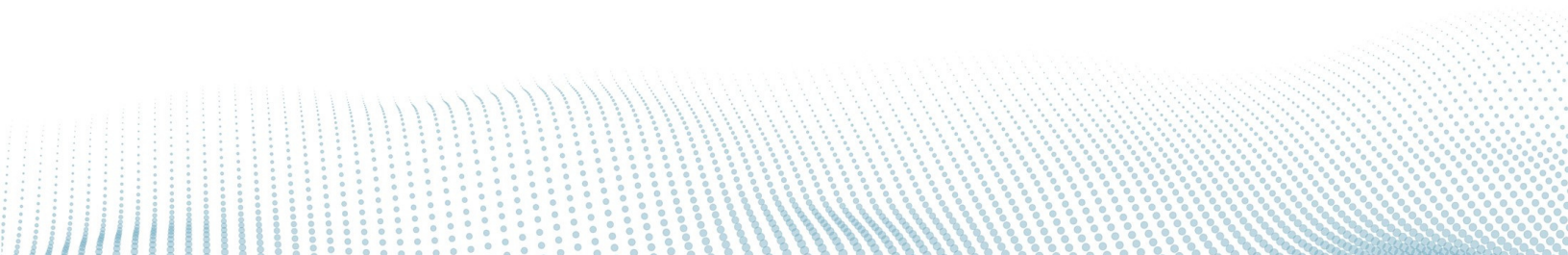
Q. *What would you say to someone considering attending a meeting?*

A.

"I would suggest that they attend, especially if they can meet someone with a similar condition. Tune in and listen and share your own experience, too. I would say that is it also very useful for your care partner to attend the meetings."

"I highly recommend patients and caregivers to join a support group meeting. You will benefit from hearing from other patients who truly understand what you are facing. You have the option to tell your story or just listen to other stories. You will learn what is new and what future education opportunities are coming. I advocate for all patients and caregivers that knowledge is power the more you know the more you have can take on this disease. Bring a pen and paper!"

"Support groups sometimes get a bad vibe, but they are really about fun, encouragement and friendship. Our little group started in 2006 and over the years, many of us are still friends. Just join!"





In summary, you may find that one of AAMAC's patient support groups can fill a gap between medical treatment and the need for emotional support. Your relationship with a doctor or other medical personnel may not provide adequate emotional support, and you may find that family and friends may not understand the impact of your disease or treatment. A support group among people with shared experiences may function as a bridge between your medical and emotional needs.

We currently offer 4 **Patient & Caregiver Support Groups** across Canada. All of our support groups meet virtually on a monthly basis. To register or for more information, please visit our website or email us at info@aamac.ca

Western Canada

Alberta & BC

Next Meeting:
September 15th, 2021

Central Canada

Saskatchewan, Manitoba,
Ontario & Quebec

Next Meeting:
September 8th, 2021

Atlantic Canada

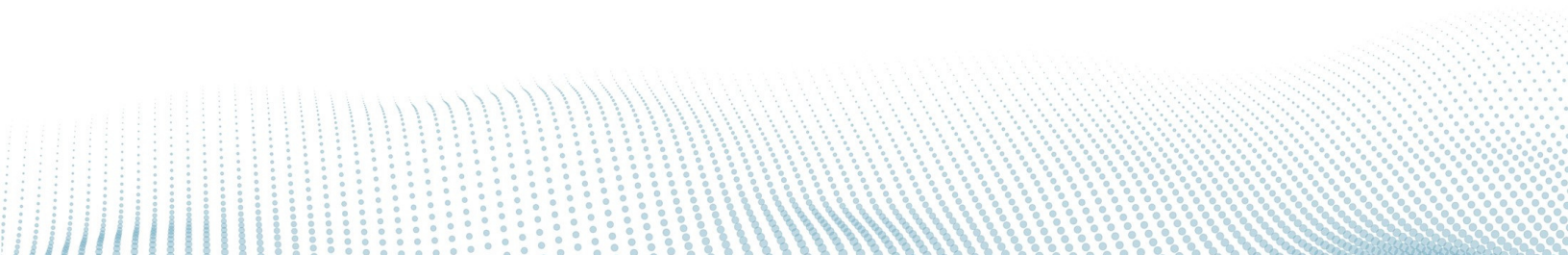
Nova Scotia, New Brunswick,
Newfoundland & Labrador
& Prince Edward Island

Next Meeting:
September 16th, 2021

French Speaking

All French speaking
Canadians

Next Meeting:
September 13th, 2021



MEETINGS & EVENTS

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

Webinars

Aplastic Anemia & Paroxysmal Nocturnal Hemoglobinuria (PNH): An Overview

Date: Tuesday, September 28th, 2021
Time: 6:00pm ET

Understanding the Drug Approval Process in Canada

Date: Tuesday, October 19, 2021
Time: 3:00pm ET
Speaker: Mr. Anil Kaul - Associate Director, Patient Access, Sobi

Is there a topic you would like to see discussed at an upcoming webinar?
Email us at info@aamac.ca

Toronto MDS Patient Webinar

Date: Saturday, September 25th
Time: 12:00pm - 2:00pm ET

FREE WEBINAR WITH LIVE Q&A SEGMENT

12 PM - 2 PM ET

SEPTEMBER 25, 2021

**TORONTO
MDS PATIENT WEBINAR**

HELD IN CONJUNCTION WITH OUR
16TH INTERNATIONAL
MDS VIRTUAL CONGRESS
23-26 SEPTEMBER, 2021



REGISTER NOW

[www.mds-foundation.org/
upcoming-2021-webinars-for-mds-patients-caregivers/](http://www.mds-foundation.org/upcoming-2021-webinars-for-mds-patients-caregivers/)



**UPDATES FROM EHA 2021:
PROMISING TREATMENT
ADVANCES FOR MDS AND AML**

Heather Leitch, MD, St. Paul's Hospital, Vancouver, Canada



**THE ROLE OF ALLOGENEIC STEM
CELL TRANSPLANT IN MDS**

Bart Scott, MD, Fred Hutchinson Cancer Research Center, Seattle, Washington



**APLASTIC ANEMIA AND
MYELODYSPLASIA ASSOCIATION
OF CANADA**

Cindy Anthony, Executive Director



AGM 2021

**Saturday, October 23, 2021
2:00PM ET**

Due to the uncertainty resulting from the COVID-19 pandemic, the 2021 Annual General meeting will take place virtually. To register for the meeting, please email info@aamac.ca.



DONATE

You can help someone living with AA, MDS & PNH by making a donation. Patient support meetings, resources and programs are made possible by your thoughtful and generous donation. Thank you.

There are many ways to donate to AAMAC:



Call the National Office to donate by phone.



Click the 'Donate Now' button on our website



Visit CanadaHelps.org

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Email: info@aamac.ca

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Kimberly Brunelle
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Atlantic Canada:

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Western Canada:

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