

Aplastic Anemia & Myelodysplasia Association of Canada (AAMAC) Accomplishments



Annual Report July 2021 - June 2022

A MESSAGE FROM AAMAC

AAMAC is a federally incorporated and registered national not-for-profit charity guided by dedicated volunteer members of the Board of Directors and a distinguished team of medical advisors from across Canada. Our volunteer-run organization supports patients and caregivers across the country who are living with aplastic anemia, myelodysplastic syndrome (also called MDS or myelodysplasia) and paroxysmal nocturnal hemoglobinuria (PNH). AAMAC has focused on education, support, advocacy, and research for over 30 years and provides support for patients and their families across Canada.

In the past year, we and our patients continue to face many challenges as a result of the COVID-19 pandemic. We have received steadfast support from our volunteers, Board of Directors, Medical & Scientific Advisory Committee and donors, allowing us to be able to continue to drive forward our mission.

We are thankful for the support that we have received and are pleased to share with you our accomplishments over the past year.

OUR MISSION

To provide a support network for anyone dealing with AA, MDS and PNH

ACCOMPLISHMENTS (JUL 2021 - JUN 2022)



EDUCATION

- Hosted 9 webinars on topics of interest including Understanding the Drug Approval Process in Canada, INQOVI[®]: Everything you want to know about it and other MDS treatments, Understanding your MDS Risk Score, Community Supports (and how to find them), MDS Treatment - Side Effect Management, Patient-Oriented Research and Patient Engagement in Clinical Trials, Emerging Treatment Options in PNH and Research Priorities in Myelodysplastic Syndromes: A Survey of Canadian Patients, Caregivers and Clinicians. Recordings of the webinars are available on our website.
- Shipped out printed resources (including our popular Patient Trackers) as required.

ADVOCACY



- Supported Lymphoma Canada in 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.
- Supported Canadian Blood Services submission to Health Canada to eliminate the 3-month donor deferral period for men who have sex with men, and instead screen all donors for high-risk sexual behaviour.



SUPPORT

- Our transition to virtual Support Groups has been a success. Whilst we miss seeing you person, those in smaller communities across the country have been able to join. AAMAC currently offers 4 Patient & Caregiver Support Groups across Canada:
 - Western Canada - Alberta & BC
 - Central Canada - Saskatchewan, Manitoba, Ontario & Quebec
 - Atlantic Canada - Nova Scotia, New Brunswick, Newfoundland & Labrador & Prince Edward Island
 - French Speaking - all French speaking Canadian
- AAMAC's Peer Support Program continues to offer patients, their families and caregivers the opportunity to connect with another person dealing with a similar experience.
- Promotion of awareness days and AAMAC activities on Social Media offering individuals the opportunity to learn about bone marrow failure diseases.

RESEARCH

AAMAC continues to fund research focusing on bone marrow failure diseases including:

- Canadian Aplastic Anemia and Myelodysplastic Syndrome Study ("CAMS")
- Single cell profiling of blood hematopoietic stem cells in pediatric aplastic anemia



PLANNED GIVING

AAMAC is honoured to have received generous bequests. Legacy gifts can make an incredible impact on the work we do. Please consider naming AAMAC in your will with a gift from your estate. Please contact Cindy Anthony at cindyanthony@aamac.ca for more information



ONGOING AND OTHER NEWS

RESOURCES

- AAMAC continues to produce tools to help with active management of your healthcare such as the progress trackers, emergency room cards and prompt lists.
- Quarterly Newsletter
- We also have free information booklets available for download or order. Details can be found at <https://aamac.ca/resource-books-available/>.

PARTNERSHIPS



AAMAC works in partnership with many organizations supporting patients and caregivers with rare blood cancers and bone marrow failure disorders including

- The MDS Foundation
- The Aplastic Anemia and MDS International Foundation
- The MDS Alliance
- Canadian Association of PNH Patients
- Canadian Organization for Rare Disorders
- Network of Rare Blood Disorder Organizations
- Canadian Blood Services
- The Rare Anaemias International Network (RAIN)
- The Leukemia and Lymphoma Society of Canada (LLSC)
- Regroupement québécois des maladies orphelines (RQMO)

UPCOMING WEBINARS

MDS – New and Emerging Treatments
October 17, 2022

Self-Compassion for Caregivers
November 22, 2022

Please check <https://aamac.ca/meeting-events/> regularly for any new webinars

SCHOLARSHIPS

- The Marilynne Convey Aplastic Anemia and Myelodysplasia Association of Canada Scholarship in partnership with the Canadian Nurses Foundation for nurses who will be focusing their research in the field of oncology or hematology
- Liz Lemire Memorial Scholarship - a memorial tribute to the significant role that Liz Lemire played in the education of health care professionals, ensuring nurses are able to be effective advocates for their patients.
- AAMAC TEAM award - recognizing an individual or group that has contributed significantly to advocacy efforts, improved care, treatment options or improved access to care and treatment options on behalf of bone marrow failure patients.

BOARD NEWS



Hellos

- We welcome the return of Haydn Laing. Haydn originally joined the board in 2016. He left in 2021 and rejoined in January this year.
- Rohail Badami joined the board in June this year. We are looking forward to all he has to offer.

Goodbyes

- We said goodbye to Nicole Saba in March this year. Sadly, she was unable to contribute as much as she had intended due to other obligations. Nicole helped establish our French speaking group and for that we are very grateful.



THANK YOU

We acknowledge the many donors and sponsors who have generously provided support for us to continue to achieve our mission. Because of you, patients and caregivers have been able to receive much needed resources and support to learn more about their disease and to better navigate the changing landscape of their care. Thank you for continuing to use AAMAC as a resource throughout your bone marrow failure journey!



AAMAC
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Association of Canada
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