

# Aplastic Anemia & Myelodysplasia Association of Canada (AAMAC) Accomplishments Annual Report July 2020 - June 2021



## A MESSAGE FROM AAMAC

AAMAC is a leading funder of research into bone marrow failure diseases in 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 VISION

Support in dealing with AA, MDS and PNH

### OUR MISSION

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

## ACCOMPLISHMENTS (JUL 2020 - JUN 2021)



### EDUCATION

- Launched a children's book **IT'S IN ME TO WIN**, written by Loretta Garbutt and illustrated by Jessica Spring, supporting children with bone-marrow diseases. The book is designed to offer a clear, easy-to-understand overview of Aplastic Anemia symptoms and treatment for children and their parents. Available to order from our website.
- Hosted 11 webinars on topics of interest including eating well to boost your energy, self compassion for caregivers, iron overload, understanding clinical trials, Q&A on COVID-19 vaccines, treatments for MDS, bone marrow transplants, drug pricing regulations in Canada, nurturing your holistic wellbeing, cytogenetics and molecular testing in MDS. Recordings of all webinars are available on our website.
- Shipped out printed resources (including our popular Patient Trackers) as required.

### 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



### SUPPORT

- Transitioned Support Groups to virtual environment. 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 Canadians
- 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.

### ADVOCACY



- Supported Lymphoma Canada's White Paper Update on Improving Access to Innovative Cancer Therapies in Canada in follow-up to the recommendations released in 2018
- Joined with other blood cancer patient groups requesting public health authorities shorten the wait times for the COVID vaccine
- Provided input for submissions to the Canadian Agency for Drugs and Technologies (CADTH) and Institut national d'excellence en santé et services sociaux (INESSS) for drug approvals to improve the lives of patients living with MDS and PNH.
- Continue to work with other patient organizations to provide input on the proposed Patented Medicine Prices Review Board guidelines.

### 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](mailto:cindyanthony@aamac.ca) for more information



## ONGOING AND OTHER NEWS

### UPCOMING WEBINARS

- ☼ MDS Foundation Toronto MDS Patient Webinar (Virtual) - **September 25, 2021**
- ☼ Understanding the Drug Approval Process in Canada (Virtual) - **October 19, 2021**
- ☼ Other webinars are in the pipe-line. Check our website for updates. In-person meetings will resume once it is safe so to do.

### REMEMBERING MARILYNNE CONVEY

Sadly, AAMAC board member, Marilynne Convey passed away on November 13, 2020. Marilynne was diagnosed with Aplastic Anemia. She was an avid spokesperson for AAMAC and volunteered much of her time to lead the nurse education program. As she depended on donated blood, she became a big proponent for others to give blood.



### 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
- PNH Global Alliance
- The Rare Anaemias International Network
- The Leukemia and Lymphoma Society of Canada (LLSC)

### 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 as well as providing other educational materials.
- ☼ Quarterly Newsletter

### 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.

# 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 during the COVID-19 pandemic. Thank you!



**AAMAC  
ACAAM**

Aplastic Anemia & Myelodysplasia  
Association of Canada  
Association canadienne de l'anémie  
aplasique et de la myélodysplasie

2201 King Road, Unit #4,  
King City, Ontario L7B 1G2

Toll free: 1-888-840-0039

General inquiries: [info@aamac.ca](mailto:info@aamac.ca)

Website: [aamac.ca](http://aamac.ca)

Charitable Registration No. 87557 2265 RR0001