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

Newsletter - Spring 2022

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

Message from the Executive Director

> "What is the essence of life? To serve others and to do good."
> Aristotle

AAMAC was founded by a volunteer in 1989 and over the years many volunteers have ensured that AAMAC has succeeded in our mission and goals.

Every April we celebrate National Volunteer Week in Canada and in this issue we are highlighting one of our Board Members, Christine Pappas. We are so grateful for each of our Board Members who give their time to lead our organization, many of whom are living their lives with MDS, Aplastic Anemia or PNH.

There are so many other areas within AAMAC for people to volunteer. Our Peer to Peer Support Program volunteers provide such an important service to new patients in particular. We are always looking for patients to support newly diagnosed patients so if you are interested please email info@aamac.ca to learn more about this and other volunteer opportunities.

We had hoped that the spring would allow for us to offer some in person meetings across the country, however at this time we will continue to offer educational webinars and our four online support groups. Please continue to check our website for updated information on meetings.

Hoping you enjoy this issue of our newsletter and wish everyone good health for the upcoming year.

Cindy Anthony

IN THIS ISSUE

BEHAVIOUR-BASED SCREENING FOR BLOOD DONATION :

EVOLVING ELIGIBILITY CRITERIA FOR GAY, BISEXUAL AND OTHER MEN WHO HAVE SEX WITH MEN

Before the introduction of testing for human immunodeficiency virus (HIV) in the mid-1980s, thousands of Canadians were infected through tainted blood products. Being solely responsible for Canada's blood supply at that time, the Canadian Red Cross Society introduced a donor eligibility criterion that excluded all men who have had sex with a man even once since 1977. This criterion was embedded into Health Canada regulations in 1992.

In 2019, Health Canada approved Canadian Blood Services' and Héma-Québec's application to reduce the men who have sex with men waiting period from one year to three months. In other words, as long as they meet all other donor eligibility criteria, a man is now eligible to donate blood if it has been at least three months since he last had sex with a man.

CBS believes this is an important step toward being as minimally restrictive as possible while also maintaining the safety of the blood supply. This change was made after extensive review of scientific and epidemiologic evidence. Equally important was the consultation with high-interest groups, including patient groups representing heavy users of blood and blood products as well as members of lesbian, gay, bisexual, trans and queer community groups.

What's next?

Canadian Blood Services is exploring the possibility of moving toward behaviour-based screening.

Canadian Blood Services' goal is to stop asking men if they've had sex with another man and instead focus on high-risk sexual behaviour among all donors. To this end, they have made a submission recommending this change to Health Canada, their regulator, in December 2021.

The aim is to identify a long-term solution that prioritizes patient safety while minimizing the societal impact on certain groups of people.

AAMAC’s involvement

AAMAC has long held a seat at Canadian Blood Services National Liaison Committee and over the past 7 years been involved in discussions advocating for first the reduction and now the elimination of a deferral period for men who have sex with men. AAMAC supports the implementation of behaviour-based screening that supports a stronger and safer blood donation system, that identifies all potential donors engaging in high risk behaviours, that is free from discrimination based on gender or sexual identity.

For more information, please visit: https://www.blood.ca/en/blood/am-i-eligible-donate-blood/men-who-have-sex-men/eligibility-criteria-gay-bisexual-and-other

BOARD DIRECTOR - QUÉBEC

AAMAC is now looking for a **volunteer representative based in Québec** to sit on its Board of Directors with a mandate to continue 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 Quebec 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 in Québec, bilingualism and a passion for the cause are important assets.

If you are interested in this rewarding position, please apply online at **https://www.odgersberndtson.com/en/careers/17900**. For more information, contact **Dominik Legault** at the executive search firm, Odgers Berndtson.

REMEMBERING LINDA O'BRIEN

by Dolores d'Entremont & the members of the Atlantic Support Group

Linda and her mother Leona

Members of the Halifax support Group of AAMAC were saddened to learn of the passing of Linda O'Brien on November 12th 2021. Linda worked at the QEII Health Science Hematology Laboratory in Halifax (where she was diagnosed) until 2006, following her diagnosis of acute myeloid leukemia-myelodysplastic syndrome (MDS) in December 2004.

She received a Stem Cell Transplant from her brother Donnie in 2006 and subsequently a Double Lung Transplant in 2009.

At the AAMAC Patient Education Day in Halifax and Newfoundland Linda shared her journey of her MDS stem cell transplant and lung transplant. Linda's resiliency and strength were an inspiration to all who knew her. Even after moving to Antigonish both Linda and her mother Leona remained active with the AAMAC Support Group. Leona would like to thank the continuous support of the AAMAC support group which helped Linda immensely in the post transplant years.

CANADIAN CANCER SOCIETY: COMMUNITY SERVICES LOCATOR

Canadian Cancer Society

Need help finding services like support groups, wigs and prosthesis, financial help, places to stay and more...

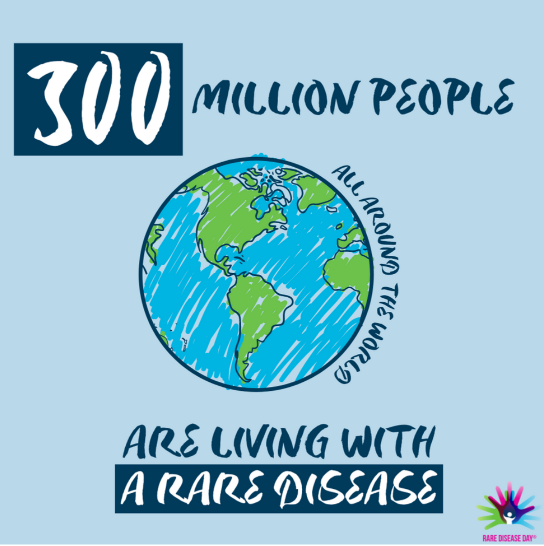
<u>What is the Community Services Locator?</u>

- a nationwide directory supported by the Canadian Cancer Society with over 4,000 services listed.
- a tool designed to help find services and programs for people living with bone marrow failure diseases and their family and friends.

www.cancer.ca/csl

RARE DISEASE DAY 2022

Canada's Rare Disease Strategy



What is Rare Disease Day?

Rare Disease Day is the globally-coordinated movement on rare diseases, working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease.

Rare Diseases in Canada

Current estimates show there are already more than **7,000** rare conditions identified, which collectively impact **one in 12 Canadians** - two-thirds of them children. However, there are no standards of care, few effective treatments for each disease and medical expertise and support services are limited and fragmented across the country.

Right now, only 60% of treatments for rare disorders make it into Canada and most get approved up to six years later than in the USA and Europe. People with rare disorders in Canada are missing out on treatments that could save or significantly improve their lives. This needs to change.

In 2015, CORD published its ***Rare Disease Strategy***, playing an instrumental role in pushing policy development in this area. Canada's Rare Disease Strategy proposes a five-point action plan that will address unnecessary delays in testing, wrong diagnoses and missed opportunities to treat.

1. Improving early detection and prevention,
2. Providing timely, equitable and evidence-informed care,
3. Enhancing community support,
4. Providing sustainable access to promising therapies and
5. Promoting innovative research

To learn more, visit ***raredisorders.ca***

VOLUNTEER SPOTLIGHT

Christine Papas - AAMAC Board Member

How long have you been volunteering at AAMAC?

I was diagnosed with MDS in 2015. My hematologist told me about AAMAC and a support group in my area. It became a lifeline for me in the early days. Bone marrow failure diseases, like MDS, Aplastic Anemia and PNH, are considered rare and like most people, I knew nothing about them. At the support group I was surrounded by supportive people who shared their experiences and who not only survived bone marrow failure diseases, but thrived. I joined the Board of Directors at AAMAC in 2018.

How did you get started volunteering with AAMAC?

Because the support group gave so much to me, I wanted to give back. I was drawn to the organization's mandate. AAMAC provides a support network for patients, family members and healthcare providers through support groups, regional patient education days, educational materials, peer-to-peer support, and funds research into the diseases. It also works with other organizations to amplify AAMAC's voice nationally in advocating on behalf of patients to ensure they have access to the treatment and care they need.

What has been the most rewarding aspect of volunteering?

I think the most rewarding aspect has been working with people who are newly diagnosed, and to see their fear and confusion turn into understanding and hope. I also find advocating for patient care has been particularly rewarding. Working with other organizations on issues like accessibility to drug trials and advocating for new and emerging treatments, such as immunotherapies, gene therapy and personalized medicine – and making them affordable -- has given us new pathways in the treatment of bone marrow failure diseases.

In your opinion, what is the most important work that this organization does?

Without a doubt, it is the support that this organization provides to patients and their families through patient information days, support groups and peer-to-peer counselling. AAMAC is also the leading funder of research into these diseases and currently is funding an important national study with SickKids in Toronto on pediatric bone marrow failure.

Finally, due to COVID-19, AAMAC has been forced to change the way it interacts with its members. And this pivot has produced some unexpected benefits. Because the support groups are now all online, it has made these meetings much more accessible than in-person meetings. People living in smaller communities are now able to join these groups and benefit from the experiences and stories of others.

THANK YOU VOLUNTEERS!

Thank you all for the immeasurably valuable work you have done for AAMAC! We cannot thank you enough, and want to let you know that your dedication is essential to the work that we do. We cannot do it without you.

Interested in volunteering with us?
Contact us at info@aamac.ca

MEETINGS & EVENTS

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

Patient Support Group Meetings

AAMAC offers monthly virtual patient support group meetings. Join us from the comfort of your home - patients and caregivers welcome!

Central Canada Patient Support Group

Date: Wednesday, March 9th
Time: 6pm ET
This meeting will be held on the second Wednesday of each month

French Speaking Patient Support Group

Date: Monday, March 14th
Time: 7PM ET
This meeting will be held on the second Monday of each month.

Atlantic Patient Support Group

Date: Thursday, March 17th
Time: 7pm AT
This meeting is held on the third Thursday of each month

Western Canada Patient Support Group

Date: Monday, March 21st
Time: 6PM PT
Future meeting dates to be decided. Dates will be posted on our website.

Webinars

MDS Treatment – Side Effect Management & “Ask a Hematologist”

Date: Thursday, March 24, 2022
Time: 2:00pm ET
Speakers: Danielle Moch, BScN, RN, MN, CON(c)., Courtney Walz, BScPharm from Cancer Care Alberta – Alberta Health Services &, Dr. Dwip Prajapati, MD, FRCPC Hematologist

Patient-Oriented Research and Patient Engagement in Clinical Trials: An Introduction

Date: Wednesday, March 30, 2022
Time: 11 AM ET
Speakers: Dr. Stuart Nicholls - Strategy for Patient Oriented Research (SPOR) Program Facilitator, Ottawa Hospital Research Institute, Alicia Hilderley - Patient at The Ottawa Hospital

Research Priorities in Myelodysplastic Syndromes:

A Survey of Canadian Patients, Caregivers and Clinicians.
Date: Tuesday, May 3, 2022
Time: 2:00PM ET
Speaker: Dr. Grace Christou, Hematologist at The Ottawa Hospital.

Emerging Treatment Options in PNH

Dr. Christopher Patriquin and Dr. Monika Oliver
April (date TBD)

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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SickKids®

National 2022 Marrow Failure and Myelodysplasia Virtual Patient and Family Conference

Saturday April 30, 2022: 12 p.m. to 6 p.m. EST

We are pleased to invite you to this interactive meeting. It is an ideal opportunity to learn, network with other families and meet experts in the field.

This meeting 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. Children and adult patients are invited.

Virtual attendance

Virtual attendance will be provided through webcasting by zoom

Conference agenda

New treatments and clinical trials, adult care, cancer risk, fertility, new transplant strategies (e.g. haploidentical), long-term effects of transplant, new MDS/leukemia-predisposition syndromes, expert centres in Canada, support groups and research

Speaker list

Physicians, scientists, research students, nurses, social workers, genetic counsellor, patient and family representatives

Examples of bone marrow failure disorders and myelodysplastic syndromes/leukemia relevant to the conference:

• Aplastic anemia • Fanconi anemia • Shwachman-Diamond syndrome • Dyskeratosis congenita • Congenital amegakaryocytic thrombocytopenia • Familial thrombocytopenia with predisposition to leukemia • GATA2-related disorders

- Diamond Blackfan anemia • Sideroblastic anemia
- Congenital neutropenia (e.g. Kostmann neutropenia) • Cyclic neutropenia • Myelokathexis
- Glycogen storage disease type Ib • Barth's syndrome
- Thrombocytopenia with absent radii • Familial or hereditary thrombocytopenia
- Myelodysplastic syndrome (familial MDS/leukemia, de novo MDS, therapy-related MDS)
- Other bone marrow failure syndromes

The conference is free! You can attend and watch the sessions from home.

For details and to register at no charge please visit our website

SCAN ME

https://cvent.me/kkd3Yo

Virtual attendance through webcasting will be provided. Early registration is recommended!

Supporters And Affiliations of the Organizing Committee Members (Preliminary list)

FA Fanconi Canada
Team Telomere
DiamondBlackfan Anemia Canada
Shwachman-Diamond Syndrome Canada Inc.
SickKids®
national neutropenia network awareness, education, research and support
AAMAC ACAAM Aplastic Anemia & Myelodysplasia Association of Canada Association canadienne de l'anémie aplasique et de la myélodysplasie
Neutropenia