



**AAMAC**  
**ACAAM**

Aplastic Anemia & Myelodysplasia  
Association of Canada

Association canadienne de l'anémie  
aplasique et de la myélodysplasie

## Newsletter - Fall 2022

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

### Message from the Executive Director

I hope everyone is having a wonderful summer. By the time you receive this newsletter it will almost be over and at AAMAC we are looking into the fall planning process.

Covid does not seem to be going anywhere soon, so for the fall we will continue with our online webinars and our monthly support groups. I have had the opportunity to join in on the groups recently and I am so happy with how you all support one another. If you have not had the opportunity to participate in one of these meetings I encourage you to do so. There is such value in meeting and supporting one another at all the different stages you experience. The French speaking group will start again in October with a new leader and you can read about Rudy in this newsletter. I really hope we may be able to have some regional meetings in 2023. We will of course be watching the news on Covid and will make plans accordingly.

Our Annual General Meeting will be held on October 22, 2022 virtually, details to register are included in this Newsletter. We welcome everyone to join and hear updates on AAMAC.

We have welcomed a new Board Member recently and you can read all about Rohail in this Newsletter as well.

Enjoy this Newsletter, thank you to both Fiona Lewis and Robyn Hodes for their continued work on putting this together for you.

Cindy Anthony

### IN THIS ISSUE

Meet our newest  
Board Member -  
Rohail Badami 2

Stem Cell Donation 4

AAMAC's role in  
clinical research 5

Suit up for Jack 6

Meet Rudy Lessard 7

Join a support  
group 8

Upcoming  
Webinars 10

Notice of the Annual  
Meeting of Members 12



## GETTING TO KNOW AAMAC'S NEWEST BOARD MEMBER: ROHAIL BADAMI

by Fiona Lewis, AAMAC Patient Liaison

**Q. I understand you were diagnosed with Aplastic Anemia (AA) last year. Can you tell us about that?**

A. In the spring of 2021, I was having lots of symptoms: fatigue, losing weight, looking pale, always cold. I fasted during Ramadan in April and did not tell anyone about my symptoms.

Shortly after that I got a tooth infection that would not go away so I told my Mom about my symptoms. My aunt, who is a doctor saw me one day and said I needed a blood test, which I had done at her clinic. I was immediately sent to the ER with my hemoglobin at 3, platelets at 17, and neutrophils at 0.01. There I was referred to a hematologist for a transfusion. I had an allergic reaction to the transfusion, became delirious and landed in the ICU for 2 days. For the next

transfusion I was premedicated to prevent a similar reaction. A bone marrow biopsy confirmed that I had severe AA. We immediately started looking for a bone marrow donor. I was told I could not do ATG because of the severity of my AA. I was in Dubai at the time, having returned there from studying in Canada, due to the pandemic. They were not yet doing transplants in the United Arab Emirates so I had to go abroad. I couldn't return to Canada because of the pandemic. The next option was the U.S. My sisters got tested but were not matches to me. The doctors were going to default to my parents, but tested my cousins also. One of my cousins was a half match to me so it was decided that he would fly to the U.S. with me. On July 6th, 2021, I went into hospital and began 7 days of chemo. July 16th was my transplant day. A blood type mismatch with my cousin caused some complications but all went ahead. After the transplant I experienced lots of fatigue, nausea, loss of appetite, fevers, and chills. My counts started to rise two weeks after the infusion. I was discharged on transplant day plus 22. I remained in Baltimore 100 days post-transplant. I was very lucky that my extended family was able to be with me in the U.S. I went to the clinic frequently for checkups.



*continued....*



My doctor in Dubai was able to manage my care once I returned home. I developed Acute Graft Versus Host Disease of the skin after the 100 days. I had to go on steroids, which worked after a couple of weeks. I had to be extra cautious due to the pandemic, even around my family, but was able to attend my sister's wedding 6 months post-transplant. Finally, my stamina built up enough that I could dance at her wedding.

I had to defer one term of school. I thought I could take two courses on-line during the period of the transplant, but this turned out to be really difficult due to my fatigue. I had to ask one my cousins to help with the work. In May of this year, I was able to come back to Canada and attend classes part-time. I'm still careful and wear a mask indoors all the time.

I'm doing really well now. I feel completely back to normal although my counts are still on the lower side due to immune suppressants and other drugs. My hair grew back a totally different texture; a new head of hair! Another impact is that my blood type is now changing to that of my donor. As a student who plans to go into medicine, I found the whole process quite fascinating. It was also very eye-opening for me to become a patient in this way.

**Q. How did you hear about AAMAC?**

A. I felt isolated as a patient, as I was the oldest in the pediatric program. I started looking to connect with others who had the disease. I also wanted to provide support to others who were in a similar situation. I just did research on Google. I found the AAMAC website and followed the organization on social media. I joined first as a peer support volunteer, then offered to lead support groups and applied to join the board.

**Q. Why did you decide to become a board member?**

A. I want to support others and be part of an organization that would help me as well as others.

**Q. You are also going to be facilitating our central Canada support group. What has motivated you to do that?**

A. I started out as a peer support person in the U.S. I joined the meetings and

*continued....*

realized how beneficial it was to hear other people's stories and ask questions. It was like therapy for me. I wanted to be more involved in this process.

It's super important to understand the patient perspective. Surrounding myself with other patients will also help me with my plans for the future.

**Q. What would you like to achieve as a board member?**

A. Outreach is super important to me. More people should be aware of what AAMAC has to offer. I want to use social media to reach people but also target hematology clinics. Different strategies are needed to reach people who have a rare disease. I also want to be more involved in helping patients on a broader scale by advocating for funding of the drugs we need.

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## STEM CELL DONATION

As many of our readers are aware, for those diagnosed with aplastic anemia, MDS or PNH, the only hope for a cure is a bone marrow transplant. The search for a donor usually starts with family members, but in Canada, less than 25% of patients find a family match and must rely on volunteer donors from a registry.

You can spread the word about the need for stem cell donors in Canada by talking to your family, friends, and acquaintances. People who are in good health and between the ages of 17-35 are encouraged to visit the website of [Canadian Blood Services](#) or [Héma-Québec](#) to find out more.





## RESEARCH

We recently talked with AAMAC's Executive Director, Cindy Anthony, about AAMAC's role in clinical research.



**1. You were recently cited as an author in a published study about *Patient Preferences for Benefits, Risks, and Administration Route of Hypomethylating Agents in Myelodysplastic Syndromes*. What was your role in this study?**

I provided input on the survey questions for patients and then once the survey was complete, I was part of a team that analysed the data from the responses.

**2. Has AAMAC been involved in a similar way in previous studies?**

Yes, AAMAC is often involved in Patient Advisory Boards for the pharmaceutical companies. Patients, caregivers and patient advocates are invited to participate. It is very valuable for the companies to hear the patient's voice.

**3. What are the benefits to patients when AAMAC gets involved in the design of clinical studies?**

One of the biggest drawbacks for patients and caregivers are the side effects of any treatment. It is important right from the beginning to acknowledge how these reactions impacts the quality of life for the patient and their family. Patients unable to cope will not complete the study and this of course has negative impact on the study itself. By addressing some of these concerns prior to the start of the trial, the hope is to have a successful clinical trial so the companies have the data necessary to move forward with the treatment.

**4. How would you describe the relationship between patient advocacy groups and pharmaceutical companies?**

AAMAC is extremely fortunate to deal with pharmaceutical companies that truly value the patient voice. AAMAC has a good relationship with these companies and values the opportunities to ensure that patients and caregivers are given space to share their experience. The financial support from the companies is one of the areas of support that AAMAC relies on to offer the patient support programs.

*continued....*



## 5. Are there any similar studies planned in the future? What are you currently working on?

I am currently working on 2 other projects. One involves Research Priorities in Myelodysplastic Syndromes. The other is a study to better understand the priorities and the needs of patient advocacy groups in supporting patients and their caregivers with PNH.

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## SUIT UP FOR JACK


June 14th was World Blood Donor Day. Blood transfusions are one of the first lines of treatment for aplastic anemia, MDS and PNH patients. Like Jack, the need for blood is constant, not just one day in the year!


A year ago, Jack a London, ON youth, launched Suit Up For Jack, a cosplay-themed blood donation campaign which is now in five countries. Jack's campaign was reported on CBC in July

<https://www.cbc.ca/news/canada/london/suit-up-for-jack-cosplay-blood-donations-1.6510343>.

You can learn more at <https://www.suitupforjack.com>, or follow the campaign on Social Media:

 @SuitUpForJack

 @suitupforjack

 @suitupforjack

If you are able, please book an appointment to give blood with [Canadian Blood Services](#) or [Héma-Québec](#).

THE NEED FOR BLOOD IS CONSTANT.





## **FRENCH SPEAKING SUPPORT GROUP:**

### **MEET RUDY LESSARD**

Rudy Lessard has recently joined AAMAC to provide support to our French-speaking patient support group. We checked in with him to find out a bit more about him and his interest in this role.

**1. I understand that you have MDS. Can you tell our readers a bit about your experience with the disease so far?**

Hello! Currently, my condition is stable and I am in remission despite some side effects. I was diagnosed with MDS in 2016. Because of my deteriorating health since 2016, I had to have a bone marrow transplant in 2019. I had intensive chemotherapy for 5 weeks, full-time in a hospital room unable to leave. That's when the transplant was performed. I had 1 transplant rejection. Subsequently, I had to undergo another stem cell transplant. Following the infusions, I still had very serious complications. All this happened in 2020. Now the worst is behind me and I can look to the future with better feelings.



**2. What are the important hobbies or activities in your life?**

My family, the outdoors, eating well, being physically active, reading and listening to music. I have a background in Reiki (energy massage). I also practice meditation since my illness.

**3. What made you interested in the role of the patient support group?**

I wish I had some support during my illness, just to talk and exchange information. I almost died twice in 2020 because of this disease. So, I have a concrete experience of what we feel and the fears that inhabit us in these difficult times. I wish I had had someone who listened to me and told me about his/her experience



when I was fighting the disease. So, I want to offer my experience to those who are fighting the disease right now. For those who need to talk about their illness, I am able to listen to them.

#### **4. Why do you think patient support groups are important?**

They break the isolation. We feel understood when we talk to people who have experienced or are going through a similar ordeal. This allows us to quiet a lot of fears. Just talking about it with other people helps us a lot. The support of the group can help a person go through this ordeal. We can also share tips and information with that person. I learned a few things during the illness and would like to share my experience with others who are currently battling the disease.

#### **5. What would you say to someone considering joining a patient support group for the first time?**

Try it once and afterwards you will see if it suits you. But you have to give yourself the chance to try it once. You don't have to talk. Everyone is free. So, there is no pressure to share. Silence and listening have their place in a support group.

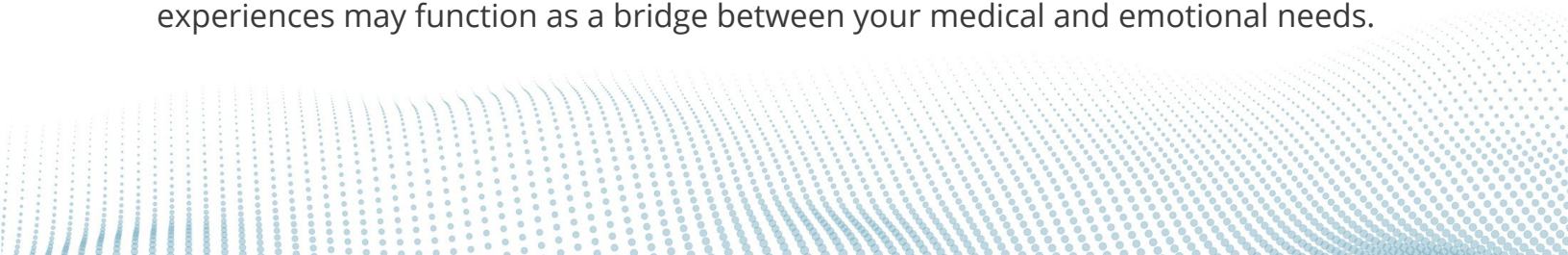
#### **6. Is there anything else you'd like to share?**

We must continue to hope and remain resilient in the face of this disease. Treating the disease requires a multitude of different tools. It doesn't just come down to one doctor or one person. Yes, the doctor is paramount. But, in addition, we must also take the time to choose lifestyle habits that will promote our healing. If I hadn't cleaned up my life and my lifestyle habits, I wouldn't be here today. To facilitate healing, it is important to use all possible means at one's disposal. Do not stay alone with your illness. Asking different people for help is already a step in the right direction.



## **PATIENT SUPPORT GROUP MEETINGS**

Join us at a Patient Support Group Meeting. You may find that it 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 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](mailto:info@aamac.ca). Patients and caregivers are welcome!

**Central Canada Patient  
Support Group -  
Saskatchewan, Manitoba,  
Ontario & Quebec**

The second Wednesday of each  
month at 6PM ET

Next meeting:  
Wednesday, September 14

**Atlantic Provinces Patient  
Support Group - Nova Scotia,  
New Brunswick,  
Newfoundland & Labrador &  
Prince Edward Island**

The third Thursday of each  
month at 7PM AT

Next Meeting:  
Thursday, September 15

**Western Canada Patient  
Support Group - Alberta &  
British Columbia**

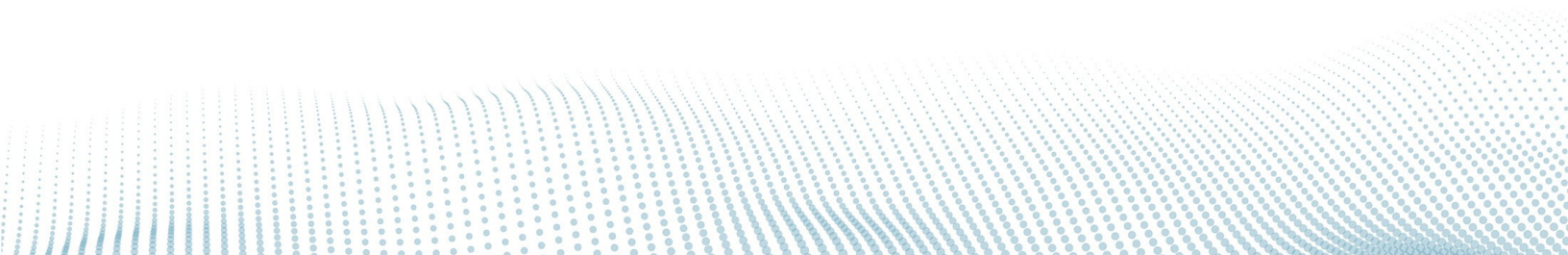
The third Monday of each month  
at 6PM PT | 7PM MT

Next meeting:  
Monday, September 19

**French Speaking Patient  
Support Group - All French  
Speaking Canadians**

The first Wednesday of each  
month at 7PM ET

Next meeting:  
Wednesday, October 5





## MEETINGS & EVENTS

Visit [AAMAC.CA](https://aamac.ca) for all meeting and event details and registration

### Webinars

#### Transitioning from Pediatric to Adult Care – Inherited Bone Marrow Failure Syndromes

Date: Thursday September 8, 2022

Time: 7:00pm ET

Speaker: Dr. Yves Pastore

#### Managing Day to Day with AA

Date: Tuesday September 20, 2022

Time: 2:00pm ET

Speaker: Dr. Grace Christou

#### Psychosocial Aspects of Care Amidst a Pandemic (Carers and Patients)

Date: Tuesday September 27, 2022

Time: 2:00 PM ET

Speaker: Jocelyn Lepage, Clinical Nurse Expert

Is there a topic you would like discussed on a webinar?

Please share your ideas with us at [info@aamac.ca](mailto:info@aamac.ca)



AGM  
—  
AGA  
2022

**Saturday, October 22, 2022**

**2:00PM ET**

The 2022 Annual General meeting will take place virtually. Anyone is welcome to join.

You will have the right to vote at the meeting if you are a member of AAMAC at the close of business on Friday, October 7, 2022. If you are interested in becoming a member please email [info@aamac.ca](mailto: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 donations. 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](http://CanadaHelps.org)

## AAMAC NATIONAL OFFICE

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\* preferred email for contact

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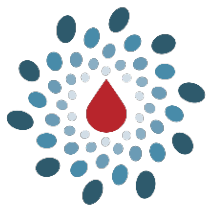
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**APLASTIC ANEMIA AND MYELODYSPLASIA ASSOCIATION OF CANADA  
(the "Corporation")**

**NOTICE OF THE ANNUAL MEETING OF THE MEMBERS**

**NOTICE** is given that the Annual Meeting of the Members of the Corporation is called for and will be held electronically, using a virtual meeting platform on October 22, 2022, at 2 p.m. Eastern Time, for the following purposes:

1. To receive the financial statements of AAMAC for the year ended June 30, 2022, together with the report of the auditors and treasurer;
2. To appoint the auditors of AAMAC;
3. To elect the Board of Directors of AAMAC;
4. Annual AAMAC report/update.
5. To transact such other business as may properly be brought before the meeting or any adjournments.

**You have the right to vote:**

You are entitled to receive notice of and vote at the Meeting if you are a member of AAMAC at the close of business on Friday, October 7, 2022.

*In accordance with AAMAC's by-laws, there is no proxy voting at the annual meeting.*

**DATED** as of the 14<sup>th</sup> of June 2022

*Video conference arrangements will be provided to each Member prior to the meeting.*

**BY ORDER OF BOARD OF DIRECTORS**

Per: *Jesse Prager*  
Name: Jesse Prager  
Title: Chair