AAMAC
ACAAM

Aplastic Anemia & Myelodysplasia
Association of Canada

Association canadienne de l'anémie
aplasique et de la myélodysplasie

Newsletter - Summer 2022

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

Message from the Executive Director

Happy Spring Everyone,

Depending on what part of Canada you live in, spring seemed a long time coming this year. With each newsletter we produce, I hope that we will be announcing the return of our in person meetings, however, Covid-19 always has a new plan for all of us. For the time being we will continue to offer our webinars with many planned for the next few months. We hope you are enjoying them and finding them meaningful.

In this issue every year, we highlight our Tree of Life. I thought this year I would look back at the history and I reached out to Caroline Laughlin to ask a bit about the history.

As many of you know Caroline became involved in AAMAC shortly after it was founded. Caroline attended one of the AAMDSIF conferences in the U.S. and they had two plywood boards at the meeting. One was in memory of loved ones and the other in honour of individuals. Caroline thought this was a wonderful idea and came back and proposed the idea to the Board. The decision was made to have just one board with the concept of the Tree of Life. Jennifer Johnstone was on the Board at this time and her father, David McTavish, offered to make it. Over the years AAMAC has benefitted from the funds raised by the Tree of Life when people purchase leaves to honour their family members who have passed away. It is also a wonderful way to acknowledge people who have made a difference in AAMAC's success. Thank you to those of you who have chosen to support the Tree of Life.

Over the past couple of months we have welcomed back two familiar faces to AAMAC. Haydn Liang has rejoined our Board of Directors and Fiona Lewis is back until the fall to assist in Patient Support. We are so happy to have both of them back to share their expertise with AAMAC.

We have said farewell to Kim Brunelle, Patient Support, and to Nicole Saba, Board of Directors, and thank them both for all they have done for AAMAC during their time with us. I hope you enjoy this issue of our newsletter. Take care and have a wonderful summer.

Cindy Anthony

IN THIS ISSUE

PATIENT SPOTLIGHT: PAM DUROCHER

by Fiona Lewis, AAMAC Patient Liaison

When Pam Durocher was diagnosed with hypoplastic MDS in 2018, she worried that she would not be able to continue her work as a clinical nurse educator in the emergency department. This month she is completing a graduated return to full-time work thanks to a lot of determination and a flexible, supportive employer.

We spoke to Pam to hear more about her journey and get some words of advice for others who are planning to continue working or return to work after a diagnosis of bone marrow failure disease.

Like many others with MDS, Pam went into “watch and wait” mode after her diagnosis but was subsequently diagnosed with PNH in 2019. She started immunosuppressive therapy in 2019 and continued with ATG in 2020. Pam took a short break from her demanding healthcare job in 2018 and then a longer, 2-year break in 2019 when her low platelet and neutrophil counts were impacting her energy levels.

Now she is on a graduated return to work plan which includes 4 shifts a week in the hospital and one shorter shift at home. She reports feeling exhausted much of the time but says work is important to her because of the purpose and distraction it provides: “I love what I do and I don’t want this illness to win.”

Pam credits her illness with enabling her to be better at her job:

> *Having been a patient now, I see the system from an opposite side. Now I come into my work with a different perspective. I see the improvements that are needed in our health care. I’m a bigger advocate than I was before. We need to help those who don’t know the system.*

Pam's employer and co-workers played a key role in facilitating her return to work. Her flexible, modified schedule has been essential to managing her illness while working. Her co-workers learned about her reduced immunity status and help ensure she has all the Personal Protective Equipment she requires and is not needlessly exposed to germs or viruses. Most important, however, is honesty among team members:

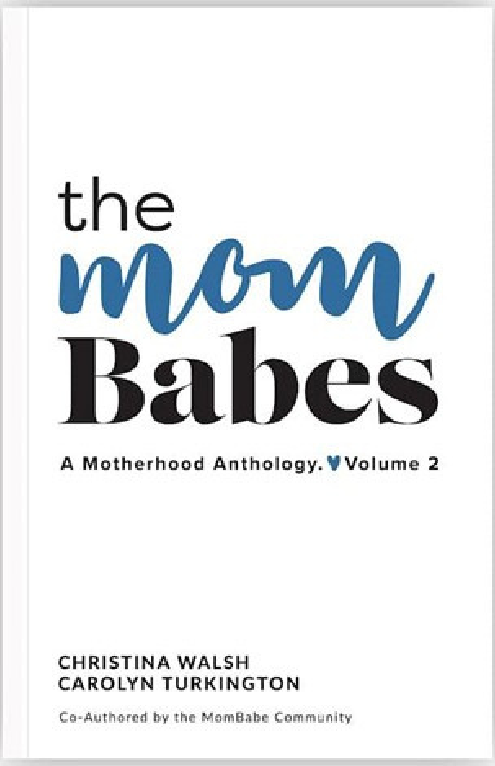
> *You need to trust a few people and communicate with them about your illness so they can support you. I rely on these trusted co-workers to make sure I take care of myself. It's easy to overdo it at work because I'm so focused on what I am doing.*

For others contemplating a return to work after diagnosis, Pam advises, "*You have to be open to give a little. If they ask me to try things, I try it. You have to be a team player*." She also stresses the need to understand your own physical limits and accept them by taking breaks when needed, eating well, staying hydrated, and being honest about how you are feeling.

Her final words of wisdom: **"Believe in yourself and stay positive. It's not easy."**

THE MOMBABES

We are pleased to announce that AAMAC board member, Ashley Oakes, is a contributor to a new book entitled The MomBabes. This motherhood anthology is a collection of stories from 18 incredible women and mothers exploring the many facets of motherhood – triumph, tragedy, grief, humour, mental health, sickness, loss, and love. In this second volume, Ashley tells her story of being diagnosed with Severe Aplastic Anemia while pregnant. She is frank about the fears and unknowns of navigating that diagnosis while being a first-time mom to a premature baby. You can order the book via Ashley's site: https://ashley-oakes.square.site/



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:

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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
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Gordon Burgess
Gordon O'Halloran
Harry Alfred Roper
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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

PATIENT-ORIENTED RESEARCH AND PATIENT ENGAGEMENT IN CLINICAL TRIALS: AN INTRODUCTION

In March, AAMAC hosted a webinar regarding patient-oriented research and patient engagement in clinical trials. We followed up with some questions of the presenters, Dr. Stuart Nicholls of the Ottawa Methods Centre and Alicia Hilderley, a research partner at The Ottawa Hospital. Their responses are below.

1. It seems that some hospitals recruit their patients from a fairly small pool of existing advisory members. Is there any way to expand that to access a more diverse group of patients?

The ways in which hospitals recruit to the Patient and Family Advisory Committees (*PFACs*) will likely vary; indeed, the location of the program that supports the PFACs likely varies between hospitals. Some programs, for example will have a home in Quality Improvement, or Volunteer Services. At The Ottawa Hospital the Patient and Family Engagement Program is based in Patient Relations, and so some of the advisors become engaged following a complaint or a positive engagement with the hospital. The Patient and Family Engagement Program at The Ottawa Hospital has over 230 patient advisors, who are engaged across many clinical and research activities. More information about the program and the Office for Patient Engagement in Research Activities (OPERA) can be found at www.ohri.ca/opera and was recently covered in a news story by the Ontario Hospital Association: https://www.oha.com/news/the-ottawa-hospital%E2%80%99s-patient-engagement-in-research-model-a-collaborative-effort

For individual research projects/programs, creating a recruitment flyer for advisors may be an alternate route to engage a more diverse group. If hospital policies allow, this flyer can be given to clinicians who can then share with potentially interested patients. The flyer can also be shared with past research participants, if continued communication with participants has been approved by ethics. This approach is most successful if the clinicians are invested in the research project as it requires clinician time and effort. Some research programs have created their

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own pool of advisors using this approach. We suggest that the flyer outline the study, role of the patient partner, time commitment and timelines.

2. Does your hospital have a guide for patients participating in trials, other than the terms of reference you referred to? Would that be useful?

We will first distinguish patients who are research participants (subjects) from patients who are research partners or advisors. Patients involved in research as a partner/advisor may or may not be research participants. Typically, patient partners/advisors are not participants in the study for which they are engaged as a patient partner/advisor. They may not be eligible to be participants, but usually have lived experience that relates to the research.

The Ottawa Hospital or Ottawa Hospital Research Institute do not provide a generic guide for patients who are participating as a subject (or participant) in a trial. Information about research participation is provided individually by the research teams. However, several organisations do offer such information. For example, Clinical Trials Ontario provides a number of resources that give information about clinical trials, have a ‘trial finder’ service, as well as a glossary of terms: https://www.ctontario.ca/patients-public/

Our work at The Ottawa Hospital and Ottawa Hospital Research Institute is to provide support and resources for patient partners/advisors who are working with researchers in the design and implementation of research (which may include trials) and so our support includes more general information regarding the research process overall. We also work with teams on an individual basis to help them develop materials for their patient partners/advisors as required. We provide templates for terms of reference that each study team can modify for their specific research.

3. How can support groups such as AAMAC provide input into the patient engagement experience? Is that feasible?

Groups such as AAMAC can absolutely provide input into the patient engagement experience. Examples could be through patient input in the peer review of funding applications, as has been done by the Ontario SPOR Support Unit as part of its EMPOWER awards (https://ossu.ca/for-researchers/work-we-support/ossu-empower-awards/). Other examples include the formation of a patient advisory group or network of Lived Experience Advisors. Examples of this approach include the Ontario

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Institute for Cancer Research (https://oicr.on.ca/community/patient-partnership/). Others, such as the Parkinson's Disease Foundation have written about their patient engagement work:

> Feeney, M., Evers, C., Agpalo, D., Cone, L., Fleisher, J., & Schroeder, K. (2020). Utilizing patient advocates in Parkinson's disease: A proposed framework for patient engagement and the modern metrics that can determine its success. Health Expect, 23(4), 722-730. doi:10.1111/hex.13064

4. How is the patient experience documented, reported, and shared throughout the trial period, and afterwards? Is there an evaluation component to your work?

For patients engaged as partners (not trial participants) we commonly conduct 'check ins' with patient partners throughout the life of a project. This can be informal emails or calls or can be more formal. For example, in one study the team is using the Public and Patient Engagement Evaluation Tool (PPEET: https://ppe.mcmaster.ca/our-products/public-patient-engagement-evaluation-tool) to check in with their patient partners, as well as doing an end-of-project evaluation. In addition to this, when patient advisors from the Patient and Family Engagement Program at The Ottawa Hospital are linked with a research study an end date is established. When this end date is reached a short evaluation form is automatically sent to both the patient partner and the lead investigator to understand their experience of the engagement within the project and identify potential areas for improved support or where activities could be enhanced.

There are an increasing number of tools for evaluation. Below are some options that we find helpful:

- SCPOR Patient-Oriented Research Level of Engagement Tool measures the degree of patient involvement [1]
- Guidance for Reporting Involvement of Patients and the Public (GRIPP2)[2] can be used as a partnership reporting checklist
- Canada's Strategy for Patient Oriented Research (SPOR) Framework[3] can be used to guide partnerships

REFERENCES

1. *Saskatchewan Centre for Patient-Oriented Research. SCPOR Patient-Oriented Research Level of Engagement Tool [Internet]. 2018. Available from: www.scpor.ca*
2. *Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S, et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. BMJ. 2017 Aug 2;358:j3453.*
3. *Canadian Institutes of Health Research. Strategy for Patient Oriented Research (SPOR) Framework. 2014.*

MDS FOUNDATION INC.

MDS Patient Features

The MDS Foundation regularly shares patient stories to those on their email list. Everyone has a different experience with Myelodysplastic Syndromes and their hope is that as they continue to share these stories, the reader is able to find relatable information that helps educate you and your loved ones. In March, one of AAMAC's regular volunteers, Rosemary was featured.

MEET ROSEMARY

Q: What was your first MDS symptom?
A: Low blood count and extreme fatigue.

Q: What is the worst symptom you've experienced?
A: Neuropathy from an immunomodulatory drug I took for more than six years.

Q: What is something you wish more people knew about MDS?
A: That it is a serious disease, and even though people with it may not look any different, their friends and family should not expect them to carry on as before.

Q: Best advice for other's living with MDS? Or a coping mechanism you've found comforting?
A: Listen to your body and rest if you need to. Don't feel guilty about sitting down with a book any time of the day.

Q: Where can we find you in your spare time?
A: Reading in winter, gardening in summer, or walking.

Are you willing to share your story?
Complete their form to be featured.

FACEBOOK FUNDRAISERS

Recently it has become popular for people to hold a birthday fundraiser for their favourite charity via Facebook. It's a great way for your friends to celebrate you and help others at the same time. AAMAC has been the grateful recipient of some of these birthday gifts with $1,165 being donated so far this year.

If you'd like to create a special occasion fundraiser for AAMAC, it is very easy to do via this link: https://www.facebook.com/fund/AAMACanada/. We'd appreciate it if you could let us about your fundraiser by emailing info@aamac.ca.

Thank you in advance!

BOARD DIRECTOR - QUEBEC

AAMAC is still looking for a volunteer representative based in **Quebec** 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 and help volunteers to increase the reach and visibility of AAMAC's services to all affected individuals. Experience in governance in Quebec, 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.

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, June 15
Time: 6pm ET
This meeting is usually held on the second Wednesday of each month but we are unable to host a meeting on June 8.

Western Canada Patient Support Group

Date: Monday, June 20
Time: 6PM PT
Future meeting dates to be decided. Dates will be posted on our website.

Atlantic Patient Support Group

Date: Thursday, June 23
Time: 7pm AT
This meeting is usually held on the third Thursday of each month but we are unable to host a meeting on June 16.

French Speaking Patient Support Group

The French speaking group will be taking a break until further notice. Please check our website regularly for updates.

Webinars

Blood Safety in Canada

Date: Tuesday May 31, 2022
Time: 6:00pm ET
Speaker: Dr. Aditi Khandelwal
NB: This will be a LIVE webinar ONLY. It will NOT be recorded.

Progression of MDS to AML

(Webcast hosted by the Leukemia & Lymphoma Society of Canada)
Date: Thursday July 14, 2022
Time: 2:00pm ET
Speaker: Dr. Kevin Brown

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

Date: Tuesday June 14, 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

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

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