



AAMAC
ACAAM

Aplastic Anemia & Myelodysplasia
Association of Canada

Association canadienne de l'anémie
aplasique et de la myélodysplasie

Newsletter - Summer 2021

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

Welcome to the summer issue of the AAMAC newsletter. This edition focuses on wellness, self-care and self-advocacy, all critical components of well-being. The Covid-19 pandemic has put additional stress on many families and patients living with bone marrow failure. In her article about the 7 Dimensions of Well-Being, social worker Nikki Stiver discusses how to take a holistic viewpoint of your overall wellness and assess where you can make adjustments to improve your wellness. We provide some links to mental health resources that are geared to the difficult times we are living through. This month's patient perspective is provided by Derek Caine whom we interviewed to learn about his successes in advocating for himself.

The pandemic has also put added stress on caregivers. This newsletter features AAMAC TEAM award winner Chris Meyer who not only cared for her husband but contributed so much to the growth of AAMAC. We also share news of a recent research report about the needs of caregivers.

We hope each of you finds some valuable takeaways from this month's newsletter. As always, we welcome your feedback or any ideas for future editions at info@aamac.ca

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ADVOCATING FOR YOUR HEALTH: A PATIENT'S PERSPECTIVE

An Interview with Derek Caine

Derek Caine was diagnosed with Chronic Lymphocytic Leukemia (CLL) in 2004. During his experience with CLL and in the years that followed throughout his remission, he became a devoted patient advocate through his dynamic blues harmonica music and the role he played as a board member of the CLL



Patient Advocacy Group. Fourteen months ago, Derek was diagnosed with aggressive MDS. His treatment for the past 12 months has involved Azacitidine and Inquovi[®]. AAMAC Regional Support Liaison, Kimberly Brunelle, asked Derek to share his thoughts about patient advocacy. This is their interview.

What advice do you have for others when they are starting out managing their disease?

To me, the most important action is to record everything that is happening to you. All blood counts, etc. Obtain copies of all tests wherever possible. The World Wide Web certainly has a plethora of information but just remember MDS is so personal and many of us, even with similar diagnoses, will react in different ways. So number one is record keeping.

What advice would you have about using the Internet for information, given the wide range of information available?

The more information you can obtain will provide you with a better understanding of the challenges you are facing. It is important however to only select credible sites that reflect ongoing and historic proven medical information. There is so much on the web that is from unproven sources that can drive you crazy trying to sort it all out. Remember you can trust information from those hospitals specializing in MDS as well as groups formed for MDS patients, caregivers etc.



What sources of information have you found to be the most useful?

Obviously, yourselves at AAMAC as well as the MDS Foundation. I have also spoken with a clinical nurse about the treatments I am receiving. Now here is another key for information and that is to try and find another person or persons with similar diagnostics who are travelling the same road you are on and are on the same treatment plan.

How do you combine self-care with advocacy so that the advocacy doesn't exhaust you?

Self-care to me is advocacy and the two go hand in hand. My brain, while obviously stressed, is helped by knowing what is happening in the world of MDS. The big challenge is the combination of a challenged immune system with the current Covid restrictions. Sitting home, other than a walk whenever possible, is NOT conducive to a stress-free environment.

Was there ever a time when you really had to push a healthcare professional to do what you wanted? If yes, how did you go about this?

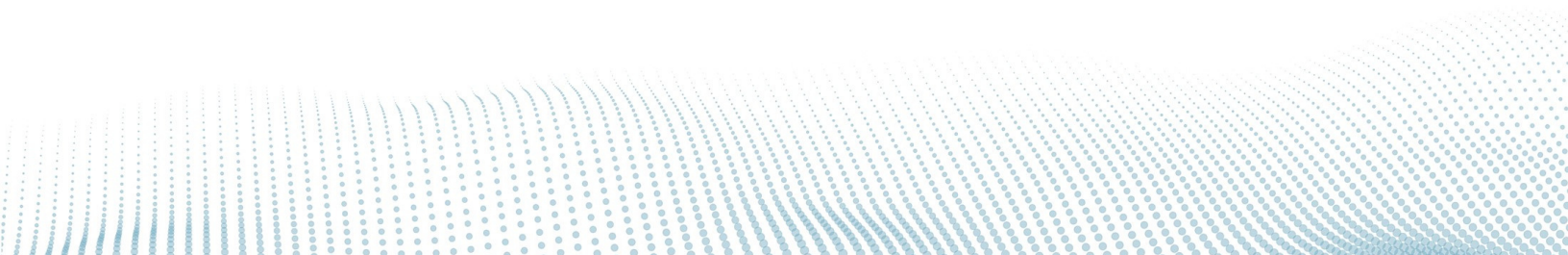
YES YES YES YES!! So once over the shock of the diagnosis, it is vital that you have a complete understanding of what is planned for you. The hospital visit under the Canadian health care system is usually a rushed affair and you need to try to slow it down. I always have a list of questions and make sure they are answered. My research showed another option for treatment other than the Azacitidine injections and my continual questions led me to Inquovi which my hematologist got compassionately for me. Now it seems as my blood counts collapsed due to this pill I need to look further so I will be pursuing this at my next visit.

To learn more about Derek's story or to listen to his music, visit:

<https://youtu.be/6Wdxf2rjYXo>

<https://youtu.be/LuI-QBR5SSM>

<https://youtu.be/NMx09xMZKlQ>



ADVOCACY TIP #1 - WRITE EVERYTHING DOWN!

We have got you covered! See the AAMAC tools below that will help you to stay organized and keep track of your important health information.



My Progress Tracker

2021

My Progress Tracker has been developed to help you be an active partner in your health care. It will help you keep track of your important contact information, appointments, test results and any treatments you receive.

2021 Progress Tracker

This booklet encourages you to be an active partner in your health care. It will help you keep track of your important contact information, appointments, test results and any treatments you have.

Order your copy here:

aamac.ca/resource-books-available/



EMERGENCY ROOM INFORMATION

Myelodysplasia (MDS)

Name: _____

Date of diagnosis: _____

Blood type: _____

Known antibodies: _____

Drug allergies: _____

Doctor: _____

Hospital: _____

Emergency Room Cards

These cards allow you to quickly share information about your condition if you need to go to Emergency. They are available for AA, MDS & PNH patients at aamac.ca/emergency-room-cards/

If completed online you will get an email confirmation. For a hard copy, please email us at info@aamac.ca or call us on 1-888-840-0039 and one will be mailed to you.



Making the most of your consultation PNH Question Prompt List

This is a helpful list of questions, which you can use at any point in your PNH journey - from diagnosis to various forms of treatment, including clinical trials.

Frequently, patients do not think of specific questions until after the consultation is over or until they read specific information booklets. This is perfectly normal as consultations are time-stress, where you need to go home. Using such a list may help to cover all topics you need to be aware of.

Most of this list was compiled by patient groups, working in conjunction with researchers, to help PNH patients gain greater control over the flow of information in consultations.

We adapted the list for Canada and added a few comments - to facilitate the discussion with your hematologist.

Just diagnosed with PNH

- How sure are you about the diagnosis of PNH?
- Can you explain what PNH is?
- Do I need any other tests before we can decide on treatment?
- Can you explain the stages of treatment to diagnose PNH?
- Do I need to do any other type of blood test?
- Are there factors that could affect my outlook or treatment?
- Can I have a print-out of my blood results?
- What are the typical blood counts that are associated with PNH?
- Are there other disorders/conditions that are associated with PNH?
- How many people a year are diagnosed with PNH?
- Is it contagious? (Should this concern me or those around me?)
- Am I able to travel safely, both within Canada and internationally?

When deciding on a treatment plan
Support groups and PNH experts do recommend an additional opinion when it comes to treatment. However, this is not all that hematologists can do for you. This can also be helpful to gain access to a wider range of blood tests.

- How much experience do you have treating PNH?
- Should I get a second opinion before starting treatment?
- Can you suggest a doctor or Centre of Excellence?
- What is the best time to start treatment?
- Does my need to start the PNH right away?
- Which treatment if any do you recommend, and why?
- What should I do to be ready for treatment?
- Is there a self-treatment that I should be aware of that there will be a doctor?
- What are the risks or side effects of the treatment that you recommend? How long are they likely to last?
- Will treatment affect my daily activities?
- What is the outlook for my survival?
- What do most people choose as treatment?
- How many people have passed away from PNH?

- At what percentage does the medical community recommend being treated?
- Are there any requirements for being treated with Subcut?

Clinical Trials

- Are there any clinical trials I might be aware of before deciding on a clinical treatment?
- What is the benefit of being in a clinical trial?
- Will I be treated any differently if I enroll in a trial?
- What are the top research hospitals/centres for PNH trials?
- Are there any benefits or risks associated with enrolling in a clinical trial?
- Will you still continue to monitor my case if I do enroll in a clinical trial?

During and after treatment

Once treatment begins, you want to know when to report and what to look for. Not all of these questions may apply to you, but getting answers to the ones that do may be helpful.

- How will we know if the treatment is working?
- How long does it typically take for treatment to start working?
- What symptoms or side effects should I tell you about right away?
- Do I need to change what I eat during treatment?
- Are there any foods I should not eat?
- Should I exercise? What should I do, and how often?
- What is the best way to manage my symptoms?
- Is there anything I can do to increase the chances of treatment working?

Other support

Can you suggest a mental health professional I can use if I am very stressed or have trouble sleeping, or depression?

Where can I find more information and support? (AAMAC website is a good first step for support for diagnosis/treatment.)

Top tips

- Take a pen and paper and write your questions down.

With the permission of your physician, you can sometimes electronically record the consultation, if you find you cannot take all the information down.

We recommend you attend most consultations with a family member or friend, and a car to drive home after the visit.

Find a person who has been diagnosed with PNH and understand what you are going through. Ask your doctor or search online for groups to connect with.

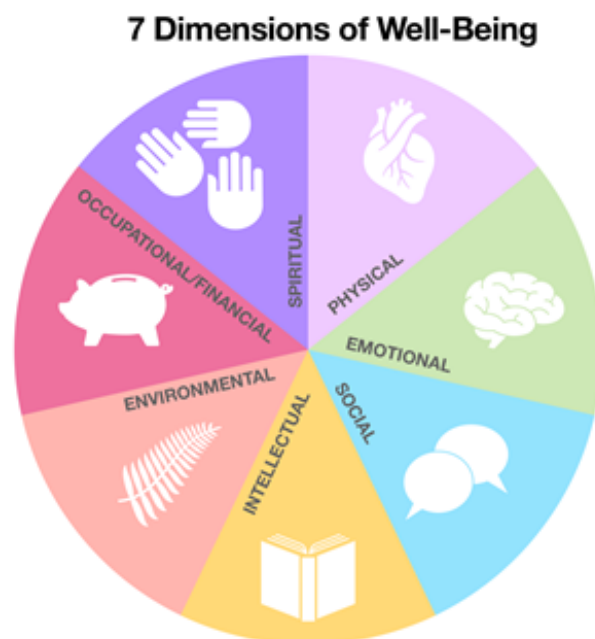
Prompt Lists

These helpful lists of questions can be used when talking with health professionals at any point in your journey. Available for download for AA, MDS & PNH patients at aamac.ca/resources under the Educational Materials tab.

THE 7 DIMENSIONS OF WELL-BEING

NIKKI STIVER, MSW, RSW

When people think about the impacts of living with a chronic illness, they often think solely of the physical impacts. However, the impacts go beyond one's physical well-being. Wellness is a harmonious integration of seven dimensions of well-being: physical, emotional, social, spiritual, occupational/financial, intellectual, and environmental. While each dimension listed below is discussed individually, it's important to know that each dimension is interconnected, meaning they continually affect and overlap with one another.



1) Physical Dimension

Physical wellness encompasses a variety of healthy behaviours to avoid harmful habits and practice activities that support the health and safety of your physical body. It includes choices around physical activity, healthy eating, sleeping, safer sex, getting medical care, using personal protective equipment (ex. Face masks) and avoiding misusing drugs and alcohol. There is no question that a chronic illness diagnosis impacts one's physical health. The specific impacts vary dependent on the type, subtype, and/or classification of the diagnosis, length and intensity of treatment, side effects from medications and pre-existing health conditions. Such physical health impacts can include fatigue, muscle and nerve problems, pain, general discomfort, and susceptibility to infection.

2) Emotional Dimension

Emotional wellness encompasses a variety of healthy behaviours to build an understanding around your own feelings and practice activities that support the health and safety of your emotional or psychological self. It includes the ability to manage stress and anxiety, cope with life's challenges and practice self-compassion. Emotional reactions to the diagnosis, its causes, its consequences, and treatment vary in type, intensity, and frequency. Common emotional reactions include stress, fear, anxiety, grief (ex. Loss of function, ability, and /or identify), anger, depression, and self-criticism.

3) Social Dimension

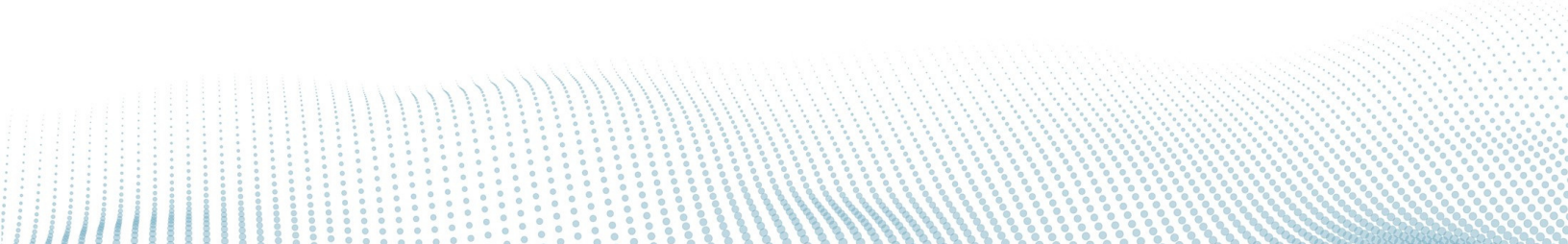
Social or relationship wellness encompasses how well we interact with others and the quality of such relationships. Others may include our partner/spouse, children, family, friends, medical treatment team, colleagues, community and anyone else around us. It includes building supportive relationships, dealing with conflict and communicating effectively, setting flexible boundaries, and making time to socialize (in-person or virtually). Chronic illnesses can often shift the balance within relationships. For example, if you are receiving care from your spouse or partner, you can feel more like a patient than a partner. For some, more time and energy may be directed to other dimensions of well-being and their social well-being takes a backseat. For others, their diagnosis strengthens their relationships.

4) Spiritual Dimension

Spiritual or cultural wellness encompasses the level of faith, hope and commitment to your individual beliefs and values that provide you with a sense of meaning and purpose. It includes morals, beliefs, values, and harmony between what lies within yourself and the forces outside. Chronic illness comes with a lifestyle change, and with this change, there can be a shift in beliefs and values. For some, it strengthens or reconnects them with their core beliefs and values, including their faith. For others, it challenges their faith and has them questioning the cause of their chronic illness.

5) Occupational/Financial Dimension

Occupational or financial wellness encompasses the level of fulfillment from your work and/or study, making use of your gifts and talents in order to gain a sense of purpose, and building a healthy relationship between your goals and your financial obligations. It involves goal setting, skill building, and budgeting. This dimension is frequently experienced by those living with a chronic illness. Most require some time off from work due to feeling unwell, to attend medical appointments, or to relocate to another city to receive intensive treatment. In some instances, this requires individuals to stop working entirely. Insurance and disability programs may be available for those eligible, which can provide some financial support. Oftentimes, this change in working hours and source of income can negatively impact one's financial well-being.





6) Intellectual Dimension

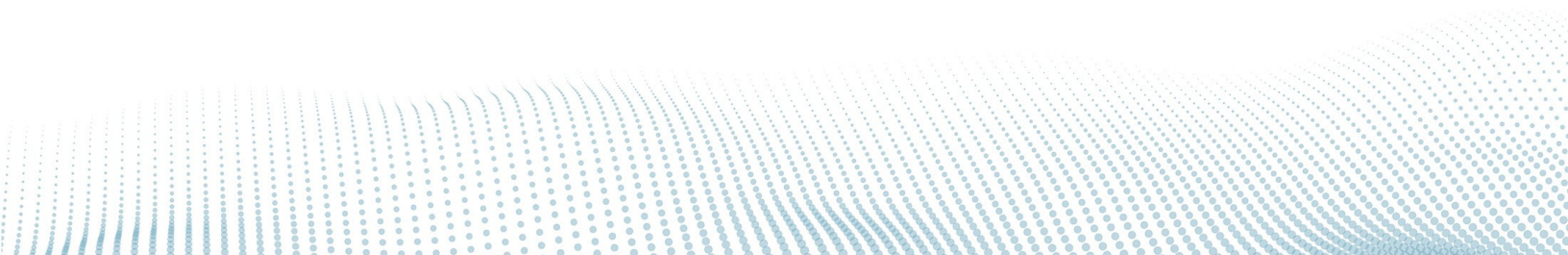
Intellectual wellness encompasses ways in which you engage in mentally stimulating activities and expanding your knowledge. This can be nurtured through formal academic pursuits, artistic- or skill-based learning. When initially diagnosed with a chronic illness, there comes a steep learning curve. There are terminologies, treatments, medications, and guidelines that one is continuously educated on throughout treatment, and therefore intellectual well-being can be enhanced. However, this same intellectual well-being can also be negatively impacted as some physical and emotional impacts of the chronic illness may make it challenging to engage in mentally stimulating activities such as reading and participating in educational sessions.

7) Environmental Dimension

Environmental wellness involves the awareness of the health and safety of the environments in which you live, work and play in. You can't always choose the environment yourself, but you can take small, controllable steps to make these environments safer. It includes keeping a healthy home environment, recognizing the need to have people and things around you that inspire and comfort you, and being aware of risks in various settings. This dimension is one of the least recognized in terms of our personal well-being, but it's so important for those living with a chronic illness, such as aplastic anemia, MDS or PNH. Due to immunocompromised health statuses, it is encouraged that personal environments are regularly cleaned and vacuumed, and air purification filters changed. For some, their environmental well-being may have been positively impacted by their chronic illness. In some instances, individuals may need to relocate to another city to receive treatment. This change in environment can bring feelings of discomfort and stress, negatively impacting environmental well-being.

The specific ways in which these dimensions are impacted by chronic illnesses are unique to the person themselves. Below are some approaches you can take to self-assess and self-manage your holistic well-being:

I) Build awareness of each dimension: Reflect over your day-to-day (what behaviours/thoughts/feelings are in support or not in support of these dimensions?)





II) Reflect on your satisfaction with each dimension: On a scale of 0-10 (0 being not satisfied at all, and 10 being extremely satisfied) what would you score each dimension?

•Of those dimensions that you are not completely satisfied with, ask yourself, “What can I control”?

What actions can you take to either improve or maintain your well-being in this dimension? Follow through with these actions and reflect on your satisfaction once again. If you have identified that there is nothing within your control to improve your well-being in this dimension, ask yourself: “Can I accept the status of this well-being as it is, for right now, until there is something that I can do to improve it?”

III) Advocate for yourself in the healthcare system: Once you have identified your holistic health needs, connect with a member of your medical team. By describing your symptoms and concerns to your healthcare provider, nurse, social worker, occupational therapist, physiotherapist, or any other member of your medical team, you can maximize choice and control over your own holistic well-being.

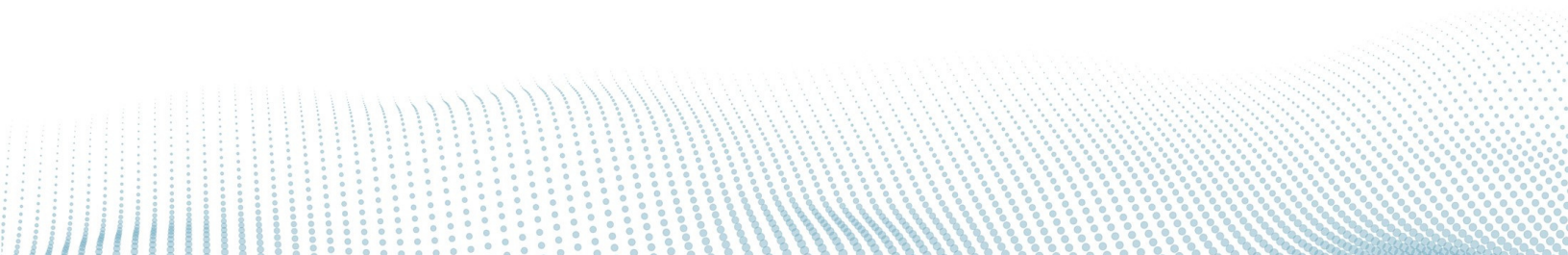
References:

Grand Rapids Community College (n.d.), *Seven Dimensions of Wellness*. Retrieved from <https://www.grcc.edu/faculty-staff/human-resources/professional-development/wellness/seven-dimensions-wellness>.



If you are looking for extra support to deal with the impact of the pandemic, you may find the following links to be useful.

Crisis Services Canada Local Support
Anxiety Canada: Coping with Covid-19
CAMH – Mental Health and the Covid-19 pandemic
Mental Health Commission of Canada – Resource Hub
Canadian Mental Health Association – Covid 19 and Mental Health

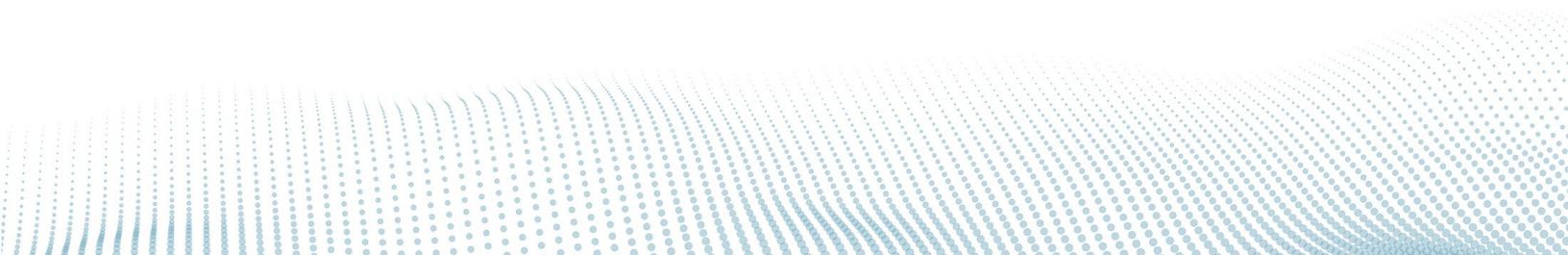




AAMAC TEAM AWARD

The Excellence in Advocacy Medal's purpose is to recognize 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. The award is a plaque usually given out at an AAMAC event but due to COVID19 restrictions, the presentation to this year's recipient of the TEAM Award, Chris Meyer was virtual.

It is unclear when Chris first became involved with AAMAC but it was certainly before June, 2004, when her partner, Rod, and she ran the Ontario Chapter of AAMAC. They, together with other Ontario members, were very involved in organizing the Spring Swing, an Ontario Fundraiser. At the time, Chris also did a lot of work with Canadian Blood Services in raising awareness of the need for blood donations, very much needed after the Krever Report and the tainted blood scandal. Chris became involved with AAMAC because Rod had been diagnosed with MDS. Sadly, by 2005 his MDS had progressed and he needed a stem cell transplant. Very sadly, he contracted an infection during the transplant which proved fatal. Chris did not drop her AAMAC contacts but, rather, became even more involved and joined the Board in 2006. Being a Board Member living in Toronto in 2006 in many ways required a lot more work than it does today. AAMAC's only employee was a part-time Office Assistant and the local Board members were expected to help out and they did. There was also an incredible amount of work involving advocacy and Chris, despite having full-time employment, was always there to participate. In 2010, Chris became AAMAC's President and was adamant that AAMAC had become too large to continue without an Executive Director. She was instrumental in finding our current Executive Director, Cindy Anthony, for us. Chris, we can't thank you enough for this! Chris left the Board in 2012 but didn't leave AAMAC. She continued as the Newsletter Editor until 2019. Despite her departure those of us who know her, know we can give her a call any time should we need her help or have a question. Chris, you're missed but your contributions to AAMAC are still so very much appreciated.





RESEARCH REPORT: EXPERIENCES AND SUPPORT NEEDS OF CAREGIVERS OF PATIENTS WITH HIGHER-RISK MDS

Higher-risk MDS patients and caregivers face many challenges in the course of disease management. Patients with advanced cancer and their caregivers can experience physical, emotional, social, financial, and functional issues. Research on the burden of caring for advanced cancer patients suggests that there is insufficient support for caregivers, likely due to the lack of knowledge about their needs and burdens. The overall experience of caregivers for MDS patients has not been evaluated to date.

Recently, Cindy Anthony, AAMAC's Executive Director was involved in a research project identifying these challenges.

The findings highlight a significant impact and burden on caregivers of patients with higher-risk MDS, which varies depending on the stage of the disease, the choice (or lack of choice) of treatments, and the personal situation of the caregiver. For example, although the caregiver role for more recently diagnosed patients is perceived as minimal effort, their role increases significantly if a stem cell transplant occurs, and/or if there are changes in the patient's health status (eg, infection, medication change, managing side effects). Emotional stress is pervasive, especially at diagnosis and prognosis stage, and when told to “watch and wait.” This is amplified when Health Care Professionals are perceived to lack knowledge/expertise about MDS, resulting in additional burden to patients and caregivers as they seek more appropriate care. There is a strong need for mental health support for both patient and caregiver. The extent required depends on the personal situation and dynamics of the patient and caregiver. Additional stress factors include the uncertainty of employment and financial burden; the time burden when balancing other commitments; and the impact on their own health, particularly if they have their own health issues to manage. Most caregivers can manage the physical and functional aspects of care; however, many state that the bigger unmet need for both patient and





caregiver is emotional support, which has not typically been part of the standard of care provided to MDS patients. There is thus an opportunity for healthcare systems to provide better support in these areas of emotional burden.

This study has been published and Cindy Anthony has been recognized as one of the authors on the study for the work she completed during the study. AAMAC strives to look for ways to support both patients and caregivers in the many needs that surface after a diagnosis.

If you are a caregiver looking for support, we offer monthly support group meetings for patients and caregivers. Please contact us for details.



BOARD DIRECTOR - WESTERN CANADA

The association is now looking for a volunteer representative based in Western Canada to sit on its Board of Directors with a mandate to establish 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 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, community building and a legal background will be considered important assets.

Applications are encouraged immediately and should be submitted online at <https://www.odgersberndtson.com/en/careers/17215>.

For more information, please contact Dominik Legault of Odgers Berndtson or Cindy Anthony cindyanthony@aamac.ca. We thank all those who express an interest, however only those chosen for further development will be contacted.





GRAFT VERSUS HOST DISEASE (GVHD)

AAMAC has recently been working with other patient groups to explore the needs of transplant recipients who experience Graft versus Host Disease (GvHD). GvHD is an immune system response that can occur after a stem cell transplant. GvHD is not yet fully understood and it's difficult to predict who will get it and who won't. You can find out more about this disease from a charity called *Anthony Nolan*.

Over the next few months, a drug called ruxolitinib (Jakavi[®]), will be the subject of an evaluation as part of the CADTH Common Drug Review (CDR). INESSS is also considering funding it as a new treatment for patients with graft-versus-host disease (GvHD) aged 12 years and older who have inadequate response to corticosteroids or other systemic therapies.

AAMAC invites all patients who have received an allogeneic stem cell transplant to share their experience regarding graft-versus-host disease (GvHD) via this survey:

https://www.surveymonkey.com/r/EN_Ruxolitinib_Jakavi

https://fr.surveymonkey.com/r/Jakavi_fr

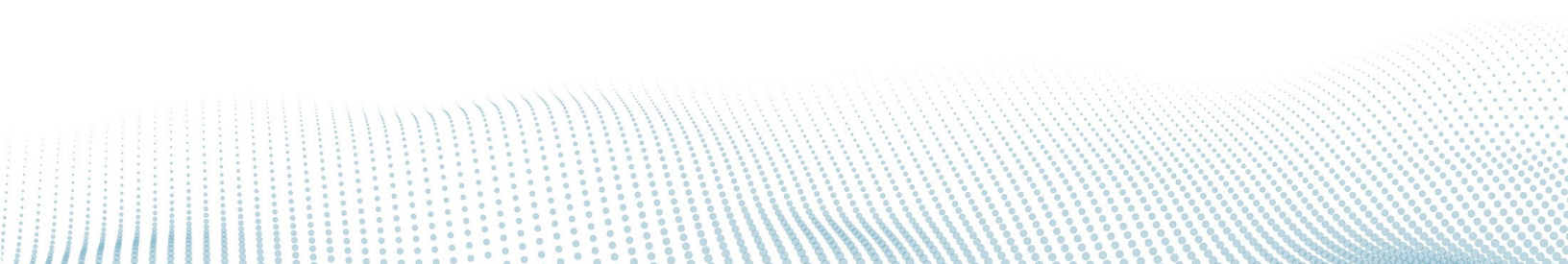
This survey should only take approximately 25 minutes of your time. The survey completion deadline has been extended to June 1, 2021. We will share patients' input with the review committee to ensure our community's voice is being heard and our needs considered. Thank you for your participation.



Saturday, October 23, 2021
2:00PM ET

AGM 2021

Due to the uncertainty resulting from the COVID-19 pandemic, the 2021 Annual General meeting will take place virtually. To register for the meeting, please email info@aamac.ca.



MEETINGS & EVENTS

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

Webinars

Introduction to Cytogenetics & Molecular Testing in MDS

Date: Saturday, May 29th

Time: 1:00pm ET

Speaker: Dr. Cyrus Hsia,
Hematologist, London Health
Sciences Centre and the London
Regional Cancer Program.

Toronto MDS Patient Webinar

Date: Saturday, September 25th

Time: 12:00pm - 2:00pm ET

FREE WEBINAR WITH LIVE Q&A SEGMENT

12 PM–2 PM ET

SEPTEMBER 25, 2021

TORONTO
MDS PATIENT WEBINAR



REGISTER NOW
[www.mds-foundation.org/
upcoming-2021-webinars-for-mds-patients-caregivers/](http://www.mds-foundation.org/upcoming-2021-webinars-for-mds-patients-caregivers/)

HELD IN CONJUNCTION WITH OUR
**16TH INTERNATIONAL
MDS VIRTUAL CONGRESS**
23-26 SEPTEMBER, 2021



**UPDATES FROM EHA 2021:
PROMISING TREATMENT
ADVANCES FOR MDS AND AML**

Heather Leitch, MD, St. Paul's Hospital, Vancouver, Canada



**THE ROLE OF ALLOGENEIC STEM
CELL TRANSPLANT IN MDS**

**Bart Scott, MD, Fred Hutchinson Cancer Research Center,
Seattle, Washington**



**APLASTIC ANEMIA AND
MYELODYSPLASIA ASSOCIATION
OF CANADA**

Cindy Anthony, Executive Director



the myelodysplastic syndromes foundation, inc.



Association of Canada
Association canadienne de la leucémie
et du sang

Patient Support Group Meetings

AAMAC is now offering a monthly virtual patient support group meeting. Join us from the comfort of your home - patients and caregivers welcome!

Atlantic Patient Support Group

Date: Thursday, June 17th

Time: 7:00pm AT

This meeting will be held on the third Thursday of each month

Ottawa Patient Support Group

Date: Wednesday, June 9th

Time: 6:00pm ET

This meeting will be held on the second Wednesday of each month

Western Canada Patient Support Group

Date: Wednesday, June 30th

Time: 6:30pm PT

Future meeting dates to be decided. Dates will be posted on our website.

**Interested in joining
a support group?**

Contact us at
info@aamac.ca to
register for a group

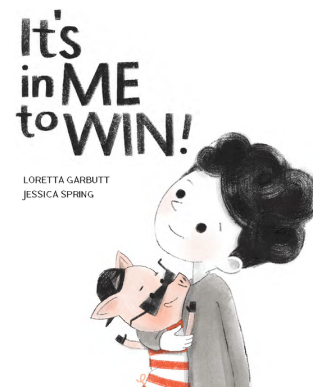


Author, Loretta Garbutt

New Children's Resource

AAMAC is thrilled to announce the release of a new children's book written by author, Loretta Garbutt called "It's in Me to Win". This is a story about a child's journey from diagnosis of Aplastic Anemia through treatment and recovery. You can order your free copy through the AAMAC office. The book is available digitally and by hard copy.

<https://aamac.ca/resource-books-available/>



Provincial Support Groups & Regional Support Liaisons

British Columbia

Fiona Lewis - bcsupport@aamac.ca

Alberta

Fiona Lewis - albertasupport@aamac.ca

Ontario

Kim Brunelle - ontariosupport@aamac.ca

Atlantic

Kim Brunelle - atlanticsupport@aamac.ca

Other Provinces

Cindy Anthony - info@aamac.ca

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Email: info@aamac.ca

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- Email info@aamac.ca or call 1-888-840-0039

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