

THE PULSE

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



AAMAC Newsletter - Fall 2020



In this Issue:

Meet a Nurse
Educator- 2

Advance Care
Planning- 3

Tree of Life- 4

Meetings & Events- 6

Have your say!- 7

Social Media- 8





MEET A NURSE EDUCATOR: NICOLE CRISP



Nicole Crisp is a Nurse Practitioner at the Cross Cancer Institute in Edmonton, Alberta

Many years ago, I sat next to a patient of mine in a quiet outpatient treatment room, receiving a transfusion. He was reading to his young daughter, as he often did during the many visits he had to our unit. He shared with me the struggles he was facing, but his determination in making it through the remainder of his chemotherapy. I remember feeling humbled by his bravery and strength. Knowing I had young children myself, he provided me with a treasured gift—a book of short stories, to read to them as well.

“Take advantage of every minute; soak in every second you have with them”, he told me.

Being a nurse practitioner is a constant reminder for me of what is truly important. I am so privileged to have experienced nursing over the past sixteen years. The nurse practitioner role, in particular, has given me the ability to streamline the patient’s pathway by providing necessary testing or prescriptions, and to admit directly from our unit, rather than send a patient to wait in emergency. I love being able to provide continuity and stability during times of uncertainty for patients. At present, I am working at the Cross Cancer Institute, primarily in stem cell transplant. However, I have encountered patients at many stages of their journey, and in several other countries, including New Zealand and the United Kingdom.

If you are a patient in the Edmonton area, I look forward to meeting you and your families, and to ensuring that no one fights cancer or bone marrow failure alone. I am so grateful to AAMAC for the wonderful services they provide to our patients and staff! I have been a proud recipient of the Liz Lemire memorial scholarship, and been able to host several events sponsored by AAMAC for our patients.

Thank you AAMAC!





ADVANCE CARE PLANNING

Fiona Lewis, RSW
BC/AB Patient Support Liaison

Nurse Practitioner, Reanne Booker, recently spoke on an AAMAC webinar about Medical Decision Making. You can listen to the webinar and/or review her slide show on the AAMAC website: <https://aamac.ca/wp-content/uploads/2020/07/AAMAC-Webinar-June-23.pdf>

Part of her presentation covered the area of Advance Care Planning, defined as:

“...a way to help you think about, talk about and document wishes for health care in the event that you become incapable of consenting to or refusing treatment or other care” (from Alberta Health Services). It involves conversations with your family and friends, substitute decision-makers, health care providers, legal and life planning service providers.

Advance care planning goes beyond talking about whether or not you would like to be resuscitated. It encourages you to think about what you value in life and how these values translate into decisions about future care and treatment. There are many tools available to help you think about these issues and discuss them with your loved ones.

This short video reviews the 5 steps of advance care planning:

<https://www.youtube.com/watch?v=mPtU-FpY1Kw>

PlanWell is a Canadian resource that helps you explore your care wishes not only if you are terminally ill but also if you contract a serious illness such as Covid-19. It includes a graphic tool that helps you think about what is important in your life.

Another site called *Speak Up Canada* allows you to create a plan on line, tailored to the unique legal framework of the province in which you live.

Advance care planning is a difficult topic to broach but studies show that engaging in it can bring peace of mind, to both the patient and their loved ones who may be left behind. A February 2019 study revealed that while 80% of people in Canada think it is important to do Advance Care Planning less than 1 in 5 people in Canada have an Advance Care Plan (Speak Up Canada). Take charge of your future by starting a conversation today.

“*Life is pleasant. Death is peaceful. It's the transition that's troublesome.*
-Isaac Asimov”





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 and 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:

Albert H. Stahlke
 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
 Earl J. Banford



**In Memory of:**

Ed Glazier
Elinor MacLean
Elizabeth Rose Herman
Elmer Kerbes
Erin Lawless
Gai Thomas
Geof Smith
Giovanni Arcuri
Glenn D. Schwartzendruber
Gord Sanford
Gordon Burgess
Gordon O'Halloran
Harry Alfred Roper
Heather McIntyre
Helen Robinson
Herb Sixt
James Novak
Jim Smith
Joan MacDonald
Joe Burleigh
John Maxwell Cameron
John R. Barton
Keith Curry
Kenneth Kwok Shing Mok
Kenny Wentzell
Laurel Burgess
Lauren Renaud
Marcelle Gai Thomas
Marian Elizabeth Peters
Marko Lyshak
Marnie Douglas
Megan Locke
Nastor W. Bill Gryba
Nicole Wilson
Olive Lilian Sundal

Paul Ullrich
Paul van Bolderen
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Stephanie Dawn Temple
Sterling Ruggles
Susan Laughlin
Talsa Coon
Trevor Thompson
Valdemars Jankovskis
Vern Coles
Walter Salamandyk
Wilfred Hinchey
William Slawson
William Terry McEvoy





MEETINGS & EVENTS

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

Webinar

Latest Research on MDS

Date: Friday, September 18, 2020

Time: 2pm EST

Speaker: Dr. Heather Leitch, Director Hematology/Oncology Research (SPH), Clinical Professor, St. Paul's Hospital

Webinar

Let's Talk Nutrition

Date & Time: To be announced

Stay tuned for more information about this informative nutrition talk!

Webinar

Information on Medical Cannabis

Date: Wednesday, September 30, 2020

Time: 3pm EST

Speaker: Reanne Booker, Registered Nurse

Webinar

Patient Stories - Let's Chat about AA and MDS

Date: Wednesday, October 21, 2020

Time: 1pm EST

Speaker: A panel of 3 patients

September is Blood Cancer Awareness Month

Visit KNOW-AML.com to find out how you can get involved.

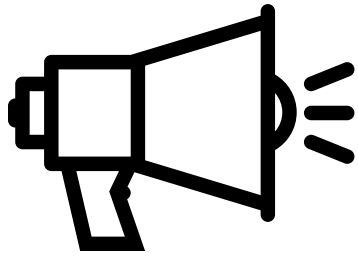
Ottawa Patient Support Group Meetings

We are going virtual! Join us every second Wednesday of each month for a FREE online Patient Support Meeting. The first meeting will take place on Wednesday, September 9th.

Annual General Meeting (AGM)

Join our virtual AGM! Everyone is welcome to participate in the virtual AGM but you must be a member to vote. To confirm you are a member or if you would like information about becoming a member, please contact info@aamac.ca or call us at 1-888-840-0039. This year's AGM will take place virtually on Saturday, October 17th @ 2pm ET. Please visit the AAMAC website for registration details.





HAVE YOUR SAY!

AAMAC is developing a submission for the pan-Canadian Oncology Drug Review (pCODR) for (orally administered/tablets) decitabine and cedazuridine (INQOVI) for the treatment of patients with Myelodysplastic Syndrome (MDS). We are specifically seeking input from patients with experience with treatments for MDS including oral decitabine (INQOVI). Your insights and experience will help guide the pan-Canadian Oncology Drug Review - an evidence-based, cancer drug review process designed to inform Canada's provinces and territories in guiding their drug funding decisions. This survey will be open until October 1st, 2020.

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

We want to reach you with information that is interesting and useful to you. Help us to create webinars that will be of interest to you and will reach you at a time and place that works best for you. When do you want webinars to be held? What topics should we cover? Tell us what you think! Complete this brief survey before August 31st, 2020.

<https://www.surveymonkey.com/r/NNX5XL5>





Aplastic Anemia & Myelodysplasia
ASSOCIATION OF CANADA
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de l'anémie aplasique et de la myélodysplasie

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Atlantic

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Cindy Anthony - info@aamac.ca



Are you on Twitter or Instagram?

Want to connect with others who have bone marrow failure disease?

Try searching these organizations:



@aamdsif
@raredisorders
@MDSFoundation
@CanadasLifeline
@caringbc
@CaregiverON
@CaregiverNS
@CaregiversAB

