



TORONTO & DISTRICT MULTIPLE MYELOMA SUPPORT GROUP NEWSLETTER

Website: www.myelomatoronto.ca

November 2023

Newsletter # 157

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- Clinical Trials - What's Involved from the Patient's Point of View, *Dr. Giovanni Piza, Princess Margaret Cancer Centre*

Hello Fellow Members and Friends,

Next In-Person Meeting: Saturday, December 2, 2023

Open to patients, family members, caregivers, and any other interested people.

Speaker: Dave McMullen, Co-Chair Emeritus, Toronto & District Myeloma Support Group

Topic: *CAR T-Cell Therapy: A Patient Perspective*

Meeting Time: 2:00 – 4:00 p.m.

Location: Jubilee United Church
40 Underhill Drive
Toronto, Ontario (see directions below)

PLEASE NOTE:

The meeting starts at 2:00 p.m., but you are welcome to arrive any time after 1:30 p.m. to meet others and help with setup.

This will NOT be a hybrid meeting. A summary of the talk will be in the next newsletter and a video will be posted online for anyone who cannot attend in person.

As has been our tradition in the past, treats and refreshments will be available to celebrate the season.



How to Get There: Driving Directions:

Take the Don Valley Parkway, exit east on Lawrence Avenue, and then immediately turn left at the first intersection, Underhill Drive, continuing north two blocks to the church. Because traffic is often heavy on the Don Valley Parkway, some drivers prefer to use Leslie Street or Don Mills, exiting east at Lawrence.

There is plenty of available parking. Enter by the north door.

How to Get There: Public Transportation:

1. Take the Lawrence Ave. East bus (Route#54) from the Yonge and Eglinton subway station. Exit the bus at Underhill Drive and walk two blocks north to the church.
2. Take the Woodbine 91C bus from the Woodbine Station on the Bloor-Danforth subway line. This bus goes up Underhill Drive past the church.

Google Maps Link: <https://goo.gl/maps/WkNhDr6kGVy>

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Jocelyn Kervin, 416-873-4610, jkervs@gmail.com

Last In-Person Meeting: October 14, 2023

Topic: *Clinical Trials - What's Involved from the Patient's Point of View*

Speaker: Dr. Giovanni Piza, Clinical Research Manager, Multiple Myeloma and Related Diseases, Princess Margaret Cancer Centre

A detailed summary of Dr. Piza's very informative presentation can be found at the end of this newsletter. A full recording of the presentation is available on Myeloma Canada's website (under Educational Videos) and on YouTube, linked here:

<https://www.youtube.com/watch?v=bTyvosigOTo>

Announcements

1) Upcoming In-Person Meetings with Guest Speakers

February 3, 2024: 1) Brief Highlights of 2023 ASH Conference

2) Share and Care Group Discussion

April 6, 2024: Dr. Guido Lancman, Clinical Associate, Myeloma Program, Princess Margaret Cancer Centre; Adjunct Assistant Professor, Department of Medicine, Temerty Faculty of Medicine, University of Toronto

News in Myeloma Treatment and Research

2) Upcoming Virtual Share and Care Meetings

Thursday, January 4, 2024, 7:00-8:30 p.m., Virtual Zoom Meeting

Share and Care Zoom meetings are normally held on Thursday nights, every second month. The login link to Zoom is sent by email prior to meetings. The meetings provide a great opportunity to welcome new participants, meet fellow myeloma patients and caregivers, and raise questions and learn from each other in a caring and supportive environment. One attractive aspect of the Zoom sessions is that people who would not be able to attend in-person meetings can do so easily.

3) Dave McMullen Receives Canadian Cancer Research Alliance Award



Dave McMullen, co-chair emeritus of the Toronto and District Multiple Myeloma Support Group, is the recipient of one of this year's Exceptional Leadership in Patient Involvement in Cancer Research Awards! CCRA biennial awards recognize and celebrate outstanding contributions to cancer research and patient involvement in cancer research in Canada. The other distinguished recipients of this year's CCRA awards were Dr. Tak Wah Mak, Princess Margaret

Cancer Centre, Toronto; Dr. Stephen M. Robbins, Jewish General Hospital, Montreal; Dr. Mandana Vahabi, Toronto Metropolitan University; and Dr. Harvey Max Chochinov, CancerCare Manitoba Research Institute.

Announcing this year's awards, the Canadian Cancer Research Alliance (CCRA) stated: "David McMullen, passionate and very active in many leadership and advisory roles in Myeloma Canada and Canadian Myeloma Research Group, and a Canadian Cancer Trials Group Patient Representative, is the recipient of the Exceptional Leadership in Patient Involvement in Cancer Research award for his long-term involvement in promoting and participating in patient engagement in cancer clinical trials and other research, and his extensive work developing and conducting support programs for patients with multiple myeloma."

Be sure to listen to the interview with Dave linked here: [CCRA 2023 Awardee David McMullen](#). You can access the interviews with all five awardees on the CCRA Awards website: [CCRA 2023 Awardee Interviews](#).

Congratulations, Dave, what a fabulous achievement, and so well deserved!

4) Toronto & District Multiple Myeloma Support Group Survey

A special thanks to everyone who has already submitted the survey. Your results have been registered and are being prepared for consideration by the steering committee. If you have not yet had a chance to complete the survey, please consider doing so now by clicking on the link below. The survey is short, with ten multiple choice questions, and takes 5-10 minutes to complete, at most. For technical reasons, please use the link indicated below, not the link distributed on November 14. The survey will close on December 4, 2023.

[Toronto & District Multiple Myeloma Support Group Survey](#)

If you have questions about the survey or have any trouble completing it, please contact Patrick Taylor (pdmtaylor@gmail.com) for assistance. Thanks for working with the steering committee to ensure we offer the best support we can to myeloma patients and caregivers.

5) Travel Insurance Update: Insurer Providing Coverage Found

Jan Wleugel

Be Careful if you buy Travel Insurance as a Cancer Patient, and Practice Personal Risk Management if you Travel!

Travel Insurance can reimburse you for that portion of a claim not covered by OHIP or your provincial health plan for out of country Emergency Medical Services, Transportation Home, and the costs arising from the Trip Interruption. These uncovered costs can run into hundreds of thousands of dollars, particularly if they involve US healthcare.

However, these policies generally have a "pre-existing condition exclusion." This means that they will not cover you if the claim arose from a condition that existed prior to the inception of the policy – such as multiple myeloma.

NEW: We have now found an insurer that may provide Travel coverage to myeloma patients with a 7-day stability period, meaning that the pre-existing condition exclusion will not apply if the traveller is "stable" for at least 7 days prior to travel. Stability is carefully defined, and an applicant should read the policy wording provided. The insurer is Medi-Quote, www.mediquote.ca.

Do not expect an "off the shelf" policy wording such as those available with some premium credit cards to provide coverage. Contact your agent or broker and seek their assistance in tailoring the correct policy. You can also Google "Canadian accident insurance for cancer patients" for links to those insurers specializing in insurance for cancer patients.

Note that many employer-sponsored group insurance programs include Travel Medical Insurance coverage, and if one joined the program before the diagnosis of myeloma, the pre-existing conditions exclusion may not apply.

Another consideration is whether to go ahead and buy the coverage anyway, as it may provide coverage for other risks while travelling. You may also want to consider paying a bit extra for flexible airline tickets or accommodations in case you need to delay or change your departure dates.

In any event, consider augmenting your Travel First Aid Kit with antibiotics for respiratory and gastro-intestinal infections, a topical antibiotic cream and even antibiotic eye drops, especially if you are immuno-compromised. Knowing when the next flight home is may also be prudent, as in some cases one can fly home at the first signs of illness instead of using foreign medical services.

It would be appreciated if you could contact Jan Wleugel, a member of the Toronto and District Multiple Myeloma Support Group Steering Committee: janwleugel@gmail.com, if you are successful in obtaining this coverage without the "pre-existing conditions" exclusion with an insurer other than Medi-Quote. Please provide the name of the insurer, the name of the broker or agent, and ideally a copy of the insurance policy. We will not share your name with the group, but we may assist people by sharing the name of the insurer and/or broker and contact information.

6) Social Outing at Taylor's Landing Restaurant

The support group hosted a luncheon at Taylor's Landing restaurant on Saturday, November 18. This spacious and uncrowded restaurant provided a great opportunity to chat over a pleasant meal. The casual environment made it possible to move around and get to know each other and share ideas and information. The Steering Committee will be organizing more social outings in the future. If you have ideas for a group activity, feel free to discuss it with any member of the Steering Committee.



7) Walk & Talk: Let's Get Moving TOGETHER – MM Walking Group



Walking is a fun way to connect outside of meetings to both socialize and get some exercise! Walking is a terrific way to improve overall wellbeing by strengthening our bodies, increasing energy levels, enhancing mental health, helping with sleep, and reducing stress.

*We currently have two Walk & Talk groups. * The first meets every second week at **Earl Bales Park on Tuesdays**. This group has been enjoying walks throughout the summer and will continue into the fall. A second group meets every second week at **High Park on Thursdays**. This group stopped for the summer but resumed in September and will be walking through the fall and winter.*

High Park and Earl Bales have flat, paved walking paths as well as hilly, paved and unpaved walking paths. Walks are geared to accommodate people of differing levels of physical ability and are most often on flat areas though some walkers may want to explore more varied terrain. In all cases, you should ensure your own safety and comfort by wearing appropriate shoes and outerwear and using hiking poles or other walking aids as needed. As myeloma patients we have good days and not so good days, so deciding to wait for the next walk is sometimes a good decision.



For further information and to confirm dates and times please contact one of the following:

Earl Bales: Suzanne Jordan - suzannejordan@hotmail.com (416 709-4418)

High Park: Rosa Bergman - rbergman@rogers.com (416 662-5671)

Patrick Taylor - pdmTaylor@gmail.com (416 522-8538)



Whether it's one other walker or a whole group, this is a great opportunity to socialize and move together! 😊

**If you are interested in participating in a walk and talk group for myeloma patients and caregivers on a different day or in a different location, please contact Patrick Taylor (pdmTaylor@gmail.com).*



8) American Society of Hematology (ASH) Annual Meeting

The American Society of Hematology meets every year in the late fall to discuss the latest research in hematology. Many of our myeloma doctors participate in the meeting. The research presented at the meeting is of great interest to myeloma patients and caregivers as an indicator of current and future myeloma treatments. Although some of this research will be covered for our support group by our speakers in the coming year, there will be useful presentations online in the coming months, including the following panel hosted by the International Myeloma Foundation:


IMWG Conference Series: "Making Sense of Treatment," Dr. Brian G.M. Durie, International Myeloma Foundation Chief Scientific Officer, Los Angeles, CA; Dr. María V. Mateos, University of Salamanca—Salamanca, Spain; Dr. Thomas Martin, University of California, San Francisco—San Francisco, CA.

Dec 14, 2023, 02:00 PM ET >> [Register](#)

9) Canadian Myeloma Research Group (CMRG) Webinar Series

Patient Education Seminar Series

Join us in real-time for our live engaging seminars!






Dr. Donna Reece
Chief Medical Officer

Introducing the list of topics for our series of research-focused presentations tailored to myeloma stakeholders:

- [SEMINAR 1: MYELOMA 101-UNDERSTANDING MYELOMA](#)
- [SEMINAR 2: LAB RESULTS AND IMAGING STUDIES](#)
- [SEMINAR 3: DEALING WITH A MYELOMA DIAGNOSIS](#)
- [SEMINAR 4: TREATMENT OPTIONS; CLASSES OF DRUGS; STANDARDS OF CARE](#)
- [SEMINAR 5: SELF-CARE TIPS FROM A NURSE PRACTITIONER AND PHYSIOTHERAPIST](#)
- [SEMINAR 6: EXPLORING CLINICAL TRIALS AND PATIENT CARE FOR ADVANCED MYELOMA](#)
- [SEMINAR 7: TOXICITY AND SYMPTOM MANAGEMENT](#)
- [SEMINAR 8: ACCESS TO NEW TREATMENTS IN CANADA](#)



Suzanne Rowland
Nurse Practitioner

 Stay tuned for forthcoming announcements as we finalize the dates for the upcoming seminars.

In September 2023, the CMRG launched a new webinar series for patients and caregivers under the direction of Dr. Donna Reece, CMRG Chief Medical Officer, with the assistance of Suzanne Rowland, an experienced Princess Margaret Cancer Centre nurse practitioner, and Ledia Mataj, CMRG administrator and physiotherapist. To register for the upcoming webinar, click on the link below:

- Seminar 3: Lab Results and Imaging Studies: Part II
Dr. Donna Reece and Suzanne Rowland, NP
Thursday, November 30, 5.00 PM-6.30 PM [Register for Seminar 3](#)
- Seminar 4: Living with Myeloma/Striving for an Excellent Quality of Life
Suzanne Rowland, NP
Thursday, January 25, 5.00PM-6.30 PM [Register for Seminar 4](#)

Past presentations can be viewed on YouTube:

Seminar 1: Myeloma 101 - [Watch](#)

Seminar 2: Lab Results and Imaging Studies: Pt I - [Watch](#)

10) Myeloma Canada Webinars

Myeloma Canada webinars provide important, timely information on multiple myeloma. For an up-to-date list of webinars and videos of past webinars, see the following link:

<https://www.myelomacanada.ca/en/news-events/infosessions-and-meetings/webinars>

Past webinars are posted on the [Myeloma Canada Channel on YouTube](#). Some of these are listed here:

- Allogeneic Transplant and GvHD - [view recording](#)
- Living Solo with Myeloma - [View recording](#)
- Multiple Myeloma and Immunotherapy Made Simple – [view recording](#)
- Sexual and Gender Diversity in Cancer Care – [view recording](#)
- Myeloma Physiotherapy Consensus Recommendations: What Patients and Caregivers Need to Know – [view recording](#)
- Empowering Yourself on the Myeloma Journey - [view recording](#)
- Following & Understanding Your Serum Free Light Chain Test Results - [view recording](#)

11) Myeloma Canada News

Ontario Legislative Action at Queen's Park

On October 17, representatives of the Toronto and District Multiple Myeloma Support Group joined other Myeloma patients and caregivers from around Ontario and representatives from Myeloma Canada to advocate on behalf of myeloma patients at Queen's Park. The full-day event was organized by Myeloma Canada as part of a Canada-wide initiative to address the needs of the myeloma community. The primary focus of the Ontario advocacy day was funding for home-grown research into the causes,



diagnosis, and treatment of multiple myeloma. Increased funding for research on CAR-T treatment in Canada, for example, could enable Ontario to develop the research infrastructure and capacity to treat myeloma patients more efficiently at a much cheaper cost compared to current CAR-T treatments. Greater access to CAR-T therapy, at an earlier date, could also save lives and reduce costs for hospitalization and high-cost drug therapies. Furthermore, development of Ontario's research infrastructure and ability to provide home-grown treatments would strengthen university research capacity in Ontario and lead to further employment opportunities in health and other sectors.

To share our experience living with myeloma and promote these ideas, participants met with MPPs and policy advisors from all parties, particularly those that had an interest in health, education, and economic development. Although there were formal appointments to meet most officials in small groups in their Queen's Park offices, one highlight of the day was the buffet breakfast to which MPPs and other Queen's Park staff were invited to meet with us informally. Among those who turned up, most were very sympathetic, one influential MPP even sharing his own cancer story. Some MPPs listened to us attentively at the informal breakfast and still spent another half-hour at a formal meeting with a group of us later in the day. During Question Period, several MPPs formally acknowledged our presence in the legislature. The group felt welcomed and listened to at Queen's Park, and the hope is that provincial policy makers and

legislators will have a better understanding of myeloma and a stronger commitment to funding new research and treatments.

17th Annual Support Group Leaders Summit



On November 10-12, members of the steering committee of the Toronto Support Group joined other support group leaders from across Canada at Myeloma Canada's 17th Annual Support Group Leader's Summit in Niagara Falls. Highlights of the conference included presentations by leading myeloma hematologists and researchers, Dr. Hira Mian, Juravinski Cancer Centre, and Dr. Joe Michael, Chief Medical Officer, International Myeloma Foundation. Two comedians, Daniel Stolfi and Robert Hawke,

both cancer survivors, showed that, yes you can laugh through cancer, and you can listen to others and move ideas forward. ("Yes, and," we learned, is a wonderful technique used in improv comedy.) Veteran patient leaders from the International Myeloma Foundation emphasized the value of patient and caregiver support groups and the importance of addressing the needs of patients and caregivers throughout their journey with cancer. They observed that patients who belong to support groups tend to do better!

Representatives from Myeloma Canada and Myeloma Canada's Patient Advisory Council (PAC) presented updates on Myeloma Canada's research strategies, fundraising campaigns, awareness and advocacy initiatives, and other Myeloma Canada activities and plans. The presentation by Chantel Wicks, Myeloma Canada's Regional Community Engagement and Development Manager for Ontario, had a special message for patients. Chantel discussed the importance of being a VIP, a "very informed patient," and emphasized a patient's right to be fully informed, to be entitled to a second opinion, and to have access to medical records, among other rights (see the Patient's Bill of Rights in the *Myeloma Canada Advocacy Handbook*, available for download in the Advocacy and Resources section of the [Myeloma Canada website](#).)

There were many opportunities for support group leaders to renew friendships, meet new leaders, and learn from each other. Although most participants attended the conference in person, some attended virtually, and most presentations were delivered in hybrid format. Overall, the conference was a great success, thanks to the enthusiasm of the presenters and the tremendous work of Myeloma Canada personnel and their patient advisors.



Myeloma Canada / Patient Advisory Council Survey

Myeloma Canada and the Patient Advisory Council is inviting persons living with myeloma and their caregivers to complete a confidential survey about their experiences, needs, and opinions on subjects relevant to the myeloma community. Please consider participating in this survey as it will help Myeloma Canada design and direct its programs and resources to create the greatest possible impact. As a thank you for participating and sharing their perspectives, participants can enter a draw to win 1 of 10 gift cards for \$50 at the end of the survey. You can find the survey at the following link: [Myeloma Canada/PAC Survey](#).

12) Myeloma Canada Resources

Myeloma Canada Website: www.myelomacanada.ca

Myeloma Canada has excellent information on multiple myeloma on its website, including virtual support groups, educational webinars and videos, information sheets (InfoSheets), detailed information guides (InfoGuides), a myeloma glossary and many other useful resources. It is highly recommended as the go-to source of information for Canadian patients and caregivers, who need material relevant to the Canadian healthcare context. InfoSheets and InfoGuides can be downloaded from the [Myeloma Canada website](http://www.myeloma.ca), under the [resources tab](#).

Myeloma Canada Peer Support Program

Myeloma Canada's Peer Support Program, created in collaboration with Wellspring (wellspring.ca), helps patients and caregivers better understand, manage and cope with what they are going through. Selected carefully from across Canada, myeloma peer support volunteers are trained by experienced Wellspring peer counselling facilitators and have first-hand experience living with myeloma or caring for someone with myeloma. Wellspring is a network of community-based centres that offer programs and services to all Canadians, at no charge and without referral, to anyone, with any type of cancer, at any stage in their journey. Wellspring has extensive experience in creating, managing, and executing peer support programs. For further information or to request peer support, see the following link: <https://www.myeloma.ca/en/find-support/myeloma-peer-support-program>.

Myeloma Canada Newsletter Mailing List

We recommend that anyone affected by myeloma consider joining the Myeloma Canada newsletter and email mailing list. This way, you can keep up to date on any bulletins, notices, newsletters, and other information emailed from Myeloma Canada. You can sign-up for the newsletter through the Myeloma Canada website, on the "Find Support" tab, and then "Join Our Community" at: <http://www.myeloma.ca/>.

13) COVID-19 Update – New Vaccines!

New COVID variants are spreading quickly and cases are expected to increase over the winter. Hematologists have recommended that myeloma patients get one of the new COVID vaccines as well as the flu shot and new RSV vaccine. (Respiratory syncytial virus or RSV is a common respiratory virus that typically causes mild, cold-like symptoms, in most people, but can lead to severe illness in infants and older or immunocompromised individuals.) Close family and caregivers should also be fully vaccinated. Although vaccinated persons can become infected, they are at a significantly lower risk of hospitalization and death. Myeloma patients should also monitor the COVID situation as it changes to determine if they should mask and/or avoid crowds and indoor spaces.

If a person with myeloma contracts COVID, regardless of the severity of the symptoms, they should contact their health care providers as soon as possible after the onset of symptoms to determine if they are eligible to receive one of several available treatments. If administered within five to seven days of onset, depending on the treatment, they provide significant protection from severe outcomes.

Booking the New COVID Vaccine: The new COVID vaccines can be booked online at Government of Ontario COVID-19 booking portal (<https://covid-19.ontario.ca>), by calling the Provincial Vaccine Contact Centre at 1-833-943-3900, or by contacting participating hospitals, clinics, and pharmacies.

Timing Vaccinations: Myeloma patients should contact their hematologist, oncologist, or health provider for advice on the timing of vaccinations in relation to their current treatment regimen and risk profile.

VaxFacts: VaxFacts is a service offered by Scarborough Health Network to provide timely, accurate information about vaccinations. To make an appointment to speak to a doctor by phone see the VaxFax website at <https://www.shn.ca/vaxfacts>.

COVID Antibody Tests: COVID-19 vaccines are generally not as effective for myeloma patients as they are for the wider population, and, in addition, are less effective over time. Myeloma patients may therefore wish to consider taking the COVID-19 spike protein test (SARS-COV-2 Antibody Panel) available at Dynacare Labs at a cost of \$80. You will need a requisition signed by your oncologist or family doctor. The test indicates if you have antibodies to COVID-19 because of previous exposure to vaccines or to COVID-19. It does not indicate the actual ability of your immune system to resist infection. For further information and to download the requisition form see the Dynacare website: <https://www.dynacare.ca/covid19-antibody-test.aspx>.

COVID Online Resources

Canada's National Advisory Committee on Immunization (NACI): [Statements and Publications](#)

Myeloma Canada: <https://www.myeloma.ca/en/news-events/covid-19>

International Myeloma Foundation: [Dr. Durie's Blog, Sept 21, 2023](#)

14) Your Toronto Group

Support Group Brochure

Our brochures, along with our website and word of mouth, are the main ways in which newly diagnosed patients and their caregivers find out about the support group. The brochures are being distributed to all oncology centres in the GTA as well as to clinics and cancer support organizations. If you know of any place where brochures are needed, or if you would like some to give to people who might be interested in the group, you may contact any member of the steering committee or pick up copies at our next in-person meeting. Pdf copies are also available on the home page of the support group website: myelomatoronto.ca.

Support Group Website

Our website, myelomatoronto.ca, includes a "Useful Links" page, which provides links to organizations that provide information and resources for myeloma patients. It also contains current and past newsletters, as well as information on upcoming meetings and events.

Support Group Facebook Page

Our Facebook page, www.facebook.com/Toronto-and-District-Multiple-Myeloma-Support-Group, provides information about the support group for Facebook users or others who may not have found our regular website. The Facebook page is passive and refers Facebook users to our website. The support group relies principally on its website, newsletters, and emails when communicating with support group members and the public. Anyone interested in active Facebook engagement with other patients and caregivers is encouraged to join one of Myeloma Canada's virtual support groups on Facebook, linked here: <https://myelomacanada.ca/en/find-support/virtual-support-groups>.

Volunteering for the Support Group

The work of the Toronto and District Multiple Myeloma Support Group is sustained by the many dedicated patients and caregivers who provide peer support, attend meetings, set up the

meeting room equipment and Zoom meetings, greet new members, organize the kitchen and refreshments, assist with secretarial work, and participate on the Steering Committee. Your assistance in all these areas is greatly appreciated by all support group members. Please contact Rinat Avitzur or any member of the steering committee if you are interested in volunteering in any way. Special thanks to those who have indicated their interest in volunteering or who already contribute on a regular basis.

Videos from Previous Support Group Presentations

Videos from previous presentations at our support group meetings are posted on Myeloma Canada's YouTube channel, linked to the Myeloma Canada website: <http://www.myeloma.ca>, under Resources/Educational Videos/Videos. Our videos have a red gerbera daisy flower on the title page. We will no longer be providing DVDs for distribution or loan because the presentations are readily available on the website and DVDs are too costly to produce. If you are interested in having one of our older DVDs to keep, and would like to make a modest donation, please speak to Bob McCaw at the next support group meeting at the resource table or contact Bob by email at robert.mccaw038@sympatico.ca.

Suggestions or Requests

If anyone has any topics or items you would like included in future meetings or newsletters, or other suggestions or requests, please contact anyone on the Steering Committee.

My Myeloma Journey

Suzanne Angel Jordan

My myeloma journey and the pandemic are so intertwined I often wonder what life would have been like if they hadn't appeared simultaneously.

In 2015 at the age of 50, my GP referred me to a hematologist as blood tests revealed abnormal protein levels in my blood. I was casually advised I had MGUS. No treatment was required and the risk of it progressing into blood cancer was relatively low, 1% a year. Annual appointments were stressful, but in true 'me' form I was able to compartmentalize my concerns and hope it would not progress into something more serious. I had no classic multiple myeloma symptoms, although I have had anemia as far back as I can remember. I led a healthy, active, busy life.



The unfolding events in March 2020, with the world grappling with so many unknowns and the province declaring a state of emergency, marked a significant turning point. It was then that I received a diagnosis of smouldering myeloma. My hematologist informed me virtually that there was a spike in my protein markers which required further investigation. A bone marrow biopsy confirmed the diagnosis.

I was advised that it would probably be a while before I required active treatment. This was fine with me as my plate was already full. My high school and university kids had pivoted to virtual learning and my husband was now working from home. My eldest, who had been living abroad for years, returned home. The pandemic was in full swing – I had no time for cancer! I had left my occasional teaching job when schools closed and decided not to return to the classroom until the world had returned to normal . . . little did I know!

We held off telling our three young-adult children about my diagnosis until we had more information on timelines and treatment. There was no need to worry them further in a world already fraught with uncertainty and fear. I also needed time to fully process what I had just been told, do my own research, and figure out what the future held. I clung to my doctor's words that people often go years with smouldering myeloma before any progression occurs. Regular monitoring and blood tests seemed just fine with me.

In August 2020, just five months after my initial smouldering myeloma diagnosis, I received another virtual call (yes, still virtual!). I was informed that things had progressed quickly, and I now had full-blown multiple myeloma. Immediate treatment was required. Between quarantining, bubbling, distancing, and sanitizing I had been preoccupied with the global pandemic and not with my health.

I often reflect on that day and the conversation with my doctor. Thank goodness I had my husband by my side, and we had taken some time to learn about multiple myeloma. The conversation was very clinical. Lots of information was exchanged, including terms we had never heard of and drug names that we couldn't spell. It all felt very surreal. I have cancer.

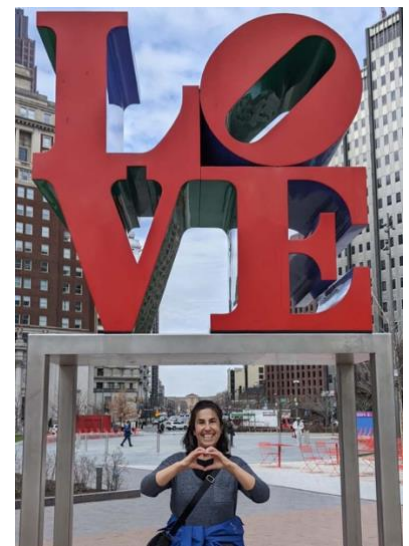
I remember thinking, will I see my daughter graduate from high school? My sons from university? I want to be around to see my kids get married and experience the joy of being a grandmother one day. Will my husband be OK? How exactly do we tell the kids? Do we focus on new treatments and skim over the fact that it's an incurable cancer? What if they google "multiple myeloma life expectancy" as I had done too many times?

As heartbreaking as it was to share this news with my family, I felt relieved. I have come to realize that my children are much more resilient than I ever imagined. Yes, there were tears, but there were also lots of hugs, treasured time together, and a healthy dose of humour. The outpouring of love, generosity, and support from my family and friends was incredible, especially given everyone was isolated and struggling with their own pandemic uncertainty.

And so, my treatment journey began. There were five months of CyborD (cyclophosphamide, bortezomib, and dexamethasone) and its adverse side effects. Looking back, I faced my cancer head on, as did my husband. Although he was not allowed to accompany me to my hospital visits or the chemo clinic, he provided a wonderful valet service for all my appointments. I didn't miss a beat on the home front, which I realize now is not necessarily a good thing. I'm still learning that it's 'OK' to not be 'OK,' and it is important to acknowledge vulnerability and accept help. I guess I am a work in progress.

Walking became my daily therapy. It was my way of socializing, maintaining my health, preserving my sanity, staying away from COVID updates, enjoying the outdoors, and cultivating gratitude.

On Valentine's Day, 2021, while the city was under its second state of emergency and stay at home orders in full effect, I checked into Princess Margaret Cancer Centre as an inpatient for an autologous stem cell transplant. The hospital was eerily quiet and visits over the next three weeks were severely limited. Most of my time preparing for the transplant was ensuring the fridge and freezer at home were fully stocked; the kitchen was littered with Post-It notes and instructions. The stem cell transplant (SCT) was no walk in the park – it was brutal, to say the least – but I knew I was in excellent hands. The books, magazines, downloaded movies, and treats that accompanied me to the hospital did not leave my bag. I joked that



I had packed for a spa holiday and not a transplant. GI issues complicated my recovery as did my stubborn neutrophils. Overall, I kept a positive outlook, walked laps around the hospital floor when I could, and counted the days until I returned home to my family.

My recovery pace post-transplant was slower than what I would have liked, and I found myself learning to adjust to this unpredictability. As someone who was used to being in control, I attempted to loosen my grip and let things unfold naturally. The significance of being immunocompromised was now widely understood due to the pandemic, leading everyone in my circle to understand the importance of keeping me safe. My oncologist recommended I get a wig as many find hair loss following a SCT to be distressing. I got one but never wore it. I felt unfazed, confidently embracing my baldness and at ease with the changes cancer brought. By early spring, I had reintegrated a walking routine, albeit at a different pace, prepared for my baby vaccines, and celebrated the rollout of the first COVID vaccines – particularly significant as transplant patients were given priority!

I've been on maintenance therapy for over two years now, gradually adjusting to my new normal. Initially, the fear of relapsing terrified me, and monthly blood tests were triggering. However, I've come to realize that this mindset isn't conducive to managing my illness in a healthy way. My ability to fight infection continues to be compromised so I limit my whereabouts to minimize the risk of getting sick. I've had fractured ribs, prolonged hospital stays due to infections, osteoporosis, neuropathy, GI issues, chronic diarrhea, wonky light chains, and decreased physical strength. Despite these challenges, I consider myself fortunate that my multiple myeloma has remained in remission. I am dedicated to keeping cancer from taking over my life, and for the most part, it doesn't. I cherish the days when I feel strong and healthy, making a conscious effort to savour each moment without taking anything for granted. And I walk, yes, I walk.

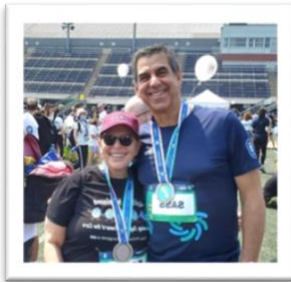
Discovering the Myeloma Canada website and accessing their resources proved to be remarkably beneficial during the initial stages of my diagnosis and continues to be my go-to place for information. Educating myself on what to expect has significantly helped me in navigating this complex journey. Connecting with the Toronto Support Group has been invaluable right from the start. This community, made up of extraordinary individuals, is welcoming, open, supportive, knowledgeable, and social. Finding a wonderful circle of myeloma warriors and friends has been a lifeline. The Walk & Talks have been a terrific way to connect in person with group members, share stories, enjoy the outdoors, and move together. For this and so much more, I am grateful.



Looking back, I often think about the early days of the pandemic when our family was all together at home, my myeloma was in its infancy, and life felt simpler. My kids are now out in the world doing their thing and I know that's the way it should be. It is crazy to think that while I write this, I am just days away from receiving my 7th COVID vaccine while diligently maintaining indoor masking. The passage of the last three years has felt incredibly swift, but instead of merely marking off the years that remain, I look forward with great anticipation to what the next twenty plus years will bring!

Annual Events

MM5K Walk or Run in Support of Bloom Chair, Princess Margaret Cancer Centre



On June 18, 2023, many members of our support group participated in the MM5K Walk or Run in support of the excellent work of the Molly and David Bloom Chair in Multiple Myeloma Research. Marking the 10th anniversary of Journey to Conquer Cancer, the walk this year began and ended at Varsity Stadium. Thousands of walkers and runners wove their way around Queen's Park and down past the Princess Margaret Cancer Centre to the cheers of onlookers and supporters, returning to a fun-filled Varsity stadium. Members of the support group, family and friends, co-workers, caregivers, doctors, and nurses, were all marching through downtown Toronto to raise funds to improve the lives of multiple myeloma patients. Some supporters also participated virtually. Nearly \$350,000 was raised this year for ongoing and new research that is already contributing to very significant improvements in treatment options and outcomes for myeloma patients. This was an enjoyable and festive event, celebrating hope and our myeloma community.

See great photos of the event see the MM5K Facebook page:

<https://www.facebook.com/mm5Kwalk>

Next year's event will take place on **June 16, 2024**. You can register early at the following link:

[Journey to Conquer Cancer 2024](#)

Myeloma Canada Multiple Myeloma March



Mississauga Multiple Myeloma March

Myeloma Canada's Multiple Myeloma March takes place every fall in more than 30 communities across Canada to build awareness and raise funds for clinical research and accelerated, equitable access to new, life-changing therapies, treatments, and programs for Canadians living with myeloma. Locations around the Greater Toronto Area attract a lot of support and participation from Toronto Support Group members and other interested persons. Like the Princess Margaret walk, these are opportunities for family and friends to get together, meet

new friends and have fun supporting research and building awareness for a cause that is of the utmost importance to so many of us.

In 2023, in honour of the 15th anniversary of the Multiple Myeloma March, Myeloma Canada initiated a special Research Fund-Sharing Partnership Program. Myeloma researchers and associated myeloma treatment and research centers could apply to partner with their nearest Myeloma Canada Multiple Myeloma March and be awarded a research grant of up to 50% of the net march proceeds. The march was very successful across Canada, with nearly \$800,000 raised. Further information is available on the [Multiple Myeloma March website](#), linked here. See also Myeloma Canada's [Multiple Myeloma March Mini Mag](#) with full details of the various walks, including fund-sharing research partnership arrangements for the 2023 march.

Fabulous photos of the 2023 March from across Canada can be viewed at the following link: <https://www.flickr.com/photos/135746311@N08/albums>.

Fundraising

If you are interested in making charitable contributions to organizations dedicated to Multiple Myeloma, the following are noteworthy.

Myeloma Canada

Myeloma Canada is the only Canadian national organization dedicated solely to the benefit of Canadians affected by myeloma, through education and support, research, promoting access to new therapies, and public awareness. Myeloma Canada has charitable status and donations will be deductible for tax purposes. Donations can be made online at www.myeloma.ca.

Myeloma Canada

1255 TransCanada Hwy., Suite 160

Dorval, QC H9P 2V4

Email: info@myeloma.ca

Website: <http://www.myeloma.ca>

Telephone: 1-888-798-5771

Princess Margaret Cancer Foundation – Myeloma Research Fund (Bloom Chair)

The Princess Margaret Cancer Foundation

610 University Avenue, Toronto, ON M5G 2M9

Email: info@thepmcf.ca

Telephone: 1-866-224-6560

Please make sure to specify the Myeloma Research Fund in the memo area of the cheque, as the funds will otherwise go into the hospital's general cancer research fund. The Princess Margaret Cancer Foundation, c/o Myeloma Research Fund, has charitable status for tax deduction purposes.

Donations may be made online through the Princess Margaret Cancer Foundation, at: <http://www.thepmcf.ca/Ways-to-Give/Donate-Now>. Select the "Myeloma Research Fund."

International Myeloma Foundation (IMF)

Dedicated to improving the quality of life of myeloma patients while working toward a cure.

International Myeloma Foundation

4400 Coldwater Canyon Ave, Suite 300

Studio City, CA 91604, USA

Tel: 800-452-CURE

Donations may be made online at <https://www.myeloma.org>. Unfortunately, the IMF does not have Canada Revenue Agency recognition for tax deduction purposes.

SPECIAL THANKS TO MYELOMA CANADA FOR THEIR FINANCIAL SUPPORT OF THE TORONTO AND DISTRICT MULTIPLE MYELOMA SUPPORT GROUP

Highlights of Presentation at Support Group Meeting – October 14, 2023



Clinical Trials

What's Involved from the Patient's Point of View

**Dr. Giovanni Piza,
Clinical Research Manager, Multiple Myeloma and Related Diseases
Princess Margaret Cancer Centre**

Dr. Piza's full presentation may be viewed on Myeloma Canada's website (under Educational Videos) and on YouTube linked here: <https://www.youtube.com/watch?v=bTyvosigOTo>

Dr. Piza noted his discussion would focus on what questions to ask when you are considering participation in a clinical trial. He will review basic clinical research technology and definitions, help patients navigate their clinical trial journey, cover different key components and steps in clinical trial participation, and address any questions the group might have on clinical trials.



Dr. Piza stated there are basically three steps in getting new drugs or treatments to patients: discovery, development (or clinical trials), and delivery. In the discovery phase, ideas are developed through basic research that shows a drug's potential impact on myeloma cells. Viable ideas move forward to in-vitro testing, animal testing and, finally, clinical trials which involve testing on humans. There are three phases of clinical trials. It can take many years before a drug progresses to regulatory approval and delivery to patients.

Phase I, Phase II, and Phase III Trials

Phase I trials look at the safety profile of a new treatment. These trials usually take place at one centre, last a few months, and involve 20 to 40 patients. Phase II trials take place at more than one centre, involve 40 to 100 patients and last for one to two years. Once the research identifies the treatment is safe, it proceeds to Phase III clinical trials which compare the new treatment to the current standard of care. Phase III trials take place at multiple centres with randomized groups, often in blind or double-blind trials. At a minimum, this will take two years.

How can you get on a clinical trial?

Ask your myeloma team. Eligibility can be selective so do not be discouraged if you are not selected. You should review the study with your doctor and the study coordinator to determine if you are interested in participating. And finally, if you are selected and agree to participate, review the consent forms in detail with your family and friends. Know what to expect and don't be afraid to ask questions.

Clinical trials in Canada are guided by the Tri-Council Policy Statement (TCPS), which is a joint policy of three federal research agencies: the Canadian Institutes of Health Research (CIHR),

the Natural Sciences and Engineering Research Council of Canada (NSERC), and the Social Sciences and Humanities Research Council of Canada (SSHRC). This promotes the ethical conduct of research involving humans according to the highest ethical standards.

What is a clinical trial?

A clinical trial is an investigation involving participants that evaluates the effects of one or more health related interventions on health outcomes. Interventions are planned treatments given to patients. So, a clinical trial is a scientific investigation to explore the safety and efficacy of an intervention. Interventional trials are those which investigate the efficacy and safety of drug treatments. Non-interventional trials look at a patient's quality of life, frailty assessments, and correlative studies.

Industry sponsored trials are those led by pharmaceutical companies. Network led studies are those led by groups such as the Canadian Myeloma Research Group (CMRG). There are also Investigator Initiated Trials (IITs), which are led by clinical investigators. It is important to know the objectives and goals of any clinical trial in which you may participate. What is hoped to be achieved? How will outcomes be measured?

Why do we do clinical trials?

Basically, clinical trials are performed to evaluate interventions by comparing two or more approaches. The intent is to hopefully bridge some gaps and have access to new drugs or therapies. It is important to note that there may not be any direct benefit to participating in a clinical trial, but the trial may have benefits for other patients later on.

How can you participate in a clinical trial?

You should begin with your attending physician, oncologist, hematologist, or clinical care team and find out what trials are being conducted at your treatment site. Patient support groups are good sources of types of treatments available and what is involved. Regulatory agency websites, such as Health Canada's [clinical trials database](#), usually have information about clinical trials and how to participate. Trial registries such as [clinicaltrials.gov](#) list clinical trials, including trials based in Canada, and regularly update the information on their status. Advertisements and media announcements also provide information on which clinical trials are looking for participants and their requirements. As well, pharmaceutical companies that are leading clinical trials will list those on their websites.

At PMH, there is a dedicated group of myeloma clinical researchers, including clinical research nurses. Additionally, there are data management teams and coordinators to support the clinical trials. Twenty-one years ago, there were only two people involved in the program; now it has grown to a group of over 40 and continues to grow.

In 2022, PMH had 70 open and active interventional and non-interventional projects in progress. 300 new participants were enrolled, which brought the total number of active participants to 970.

What is informed consent?

This is when someone has voluntarily agreed to participate in a particular trial, after being informed of all aspects of the trial. It is documented by a written, signed and dated consent form. Consent means free (i.e., voluntary), informed, and ongoing. You have the right to withdraw your consent at any time.

What should you ask during the consent process?

- What is the study title? This should tell you what type of trial it is (Phase I, II, or III), and if everyone will receive the medication.
- Who is the lead investigator/doctor? This will tell you where the research is being done and the investigator and investigator's research background.
- What is the contact information? This will be in the consent form.
- Who is the sponsor of the trial? Is it an investigator-initiated trial, a network, or a pharmaceutical trial?

You should ask:

- What type of investigation is being conducted?
- Is it a new drug study?
- Is it oral or intravenous?
- Do you have to be on site?
- What is the schedule of the trial?
- Where are the visits going to happen? What type of visit is it?
- Are there any costs associated with the trial?
- What are the time commitments and inconveniences?
- Are there any extra burdens for patients?
- Is there any need for hospital visits; can I take the medication at home?
- How often will I need to see my team?
- How long is the trial?
- Is there any benefit for me or myeloma patients in the future?
- What are the potential risks or side effects?

Screening and Eligibility

The screening process involves assessments, procedures, and tests prior to enrolment to confirm the trial is right for you. This can involve a chart review and a discussion with your attending physician. The inclusion and exclusion criteria are thoroughly considered. This process can take one visit or multiple visits. Once eligibility is confirmed, the next step is to enrol the participant in the trial. The trial can be randomized to reduce any potential bias.

Receiving Treatment

Once you are enrolled, you may be moved into a specific arm of the trial based on your health condition. You will undergo a baseline assessment of the status of your myeloma disease and other health conditions. This will help to ensure safety, assess side effects, and establish the disease's response to treatment.

After the baseline visit, you will begin to receive the treatment. It is important to participate in monitoring and follow-up visits to ensure you are in compliance with the trial protocol and that the trial is successful. Make sure you have a calendar with appointments, daily pill intake, tests, etc. Keep a journal of any side effects or positive events to discuss with your treatment team. Keep your consent form handy; it contains lots of information that will be useful as you go through the clinical trial.

There are other aspects of trials you need to be aware of, and some require extra effort from patients. For instance, the collection of 24-hour urine samples can be key to have data to prove the efficacy of the trial.

Scenarios that will End Participation in a Trial

There are three scenarios that will end your participation in a clinical trial. First, the clinical trial has completed the number of treatment cycles as per the written protocol. The participants will be followed for a period of time after which their participation will end.

Secondly, there can be an early termination by the trial sponsor or regulatory agency. This could be because the objectives were met earlier than expected. This could be good in that the results are so overwhelmingly positive that approval is accelerated. Alternatively, the results were not as expected, and the participants could not be kept safely on the treatment.

The third scenario is when you decide to end your participation in the study for whatever reason. Of course, you have the right to withdraw, but the researchers will want to know your reasoning to try and avoid this from happening in the future.

Follow-up after a Trial

Once you have been released from the trial, for any reason, it is important for you as a patient to inquire what will happen with your treatment. Do you have the option to continue with the study medication if you have received some benefit?

Rollover studies are studies that continue once you have completed the clinical trial. They provide an opportunity for those who benefited from the trial to continue on the drug. Or, if you were on the standard of care arm of the study, you may be allowed to receive the trial drug. These happen usually during Phase II studies.

There is also a Special (Compassionate) Access Program which fast tracks access to approved drugs awaiting provincial funding approval. Talk to your clinicians about this.

Lastly, there is an Expanded Access Program for drugs which are required to have more safety or efficacy information. In this case, Health Canada will provide drugs to patients to allow researchers to collect more data in a real-world setting. This could be done through Phase IV trials or post-marketing trials.

Of course, there are reporting responsibilities. Interim reporting provides updates on safety and efficacy. So, if we see concerns, we update the consent form to advise participants. As well, a decision may need to be made on whether the treatment is safe to continue. The final report is for publication and addresses whether the objectives were reached and what was learned from the research. This is a very technical document, so it is not shared with participants. However, at Princess Margaret, we have begun to summarize the final report into a two-page document in layman's terms.

To summarize, talk to your care provider and support group about clinical trials. Do not be afraid to ask questions during the information and consent process. Remember your participation is voluntary and you may withdraw your participation at any time. Involve your family, friends, and other treating physicians to discuss your participation. Use tools such as a calendar and diary. Your commitment is important for successful participation in the trial. Remember, you may have no direct benefit from the trial, but others will in the future.

Questions and Answers

Q. When you screen a person, doesn't that add bias into the process?

A. Technically, yes, but as researchers' experience evolves, they learn to eliminate those biases.

Q. What is standard of care treatment? Is that like a placebo?

A. No, it is the current treatment protocol for your stage of myeloma.

Q. Do you get to choose which arm of the clinical trial you go through, the standard of care or the new treatment?

A. In Phase III trials, the decision of who gets the standard of care or new treatment is randomized. In Phase II trials, everyone will get the new treatment, but how they receive it may be randomized. For example, someone may just get the new drug while others will have the new drug added to their standard of care protocol. In Phase I trials, everyone gets the new drug, but at different levels as we are trying to determine the safe dosage.

Q. Are there recent studies that you have received approval for?

A. Not currently in my group. However, we have participated in trials that have led to the approval of drugs in the past.

Q. What percentage of trials are funded by industry?

A. I would say approximately 70% are industry funded.

Q. On the point of therapeutic misinformation, how do you help us to work through that?

A. We have to emphasize you may not benefit from the trial. We have to be mindful to stress that what will occur is we will gain knowledge about how to help others in the future.

Q. Isn't it true that most of the Canadian studies and trials have already been done in the US?

A. To a certain point. Health Canada will require Phase III trials in Canada before it provides approval. We participate in Phase III trials that are led in Europe and the US.

Q. You said that Phase III trials are randomized. Do you tell the participants what treatment they are receiving?

A. It depends on the study. Sometimes the participants don't know what they are receiving, sometimes both the participant and the researcher don't know what they are receiving, and sometimes everyone knows what they are receiving.

Q. How do you see AI affecting clinical trials?

A. We are trying to figure out ways for it to help, but also not negatively impact clinical trials. It could be used to keep participants informed, help them through the processes, such as the consent process. It could also be used as a tool to remind participants of their commitments and what is required. As well, it could be used to translate the study results into lay terms.