



TORONTO & DISTRICT MULTIPLE MYELOMA SUPPORT GROUP NEWSLETTER

Website: www.myelomatoronto.ca

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Newsletter # 159

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My Myeloma Journey

--*Ferdinand Gill*

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- Dave and Erika's CAR T-Cell Therapy Experience
Dave McMullen, Co-Chair Emeritus, Toronto & District Multiple Myeloma Support Group

Hello Fellow Members and Friends,

Next In-Person Meeting: Saturday, April 6, 2024

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

Speaker: Dr. Martha Louzada, MD, MSc., Hematologist, London Regional Cancer Program; Associate Professor Oncology, Western University. Dr. Louzada is a leading myeloma researcher and is tremendously appreciated by her patients.

Topic: CAR T-cell and Other T-cell Therapies.

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 be an in-person meeting. There will be no Zoom access. A summary of the talk will be in the next newsletter.

Since many in-person attendees will have weakened immune systems, participants are welcome to wear masks and observe social distancing while indoors.

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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Patrick Taylor, 416-522-8538, pdmtaylor@gmail.com

Last In-Person Meeting: February 3, 2024

- Topics:**
- 1) *Brief Highlights of 2023 American Society of Hematology (ASH) Conference*
 - 2) *Share and Care Group Discussion*

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

Announcements

1) Upcoming In-Person Meetings with Guest Speakers

June 1, 2024: Dr. Peter Anglin, Physician Lead, Stronach Regional Cancer Centre, Newmarket

Myeloma 101

August 10, 2024: Chantel Wicks, Regional Community Engagement and Development Manager – Ontario, Myeloma Canada

Being a VIP – a Very Informed Patient: How to Advocate for Yourself

October 5, 2024: Dr. Roger Smith, MD, MB ChB, Interventional Neuroradiology, University Health Network, Toronto

Kyphoplasty and Related Treatments

2) Upcoming Virtual Share and Care Meetings

Thursday, May 2, 2024, 7:00-8:30 p.m., Virtual Zoom Meeting

Share and Care Zoom meetings are normally held on the first Thursday of 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) Walk & Talk: MM Walking Groups

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



The High Park group has been walking through the winter, with good turn-outs as the weather warms and spring arrives. The Earl Bales group is starting up again on April 2 just as the spring buds are beginning to open.



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

Earl Bales: Every second Tuesday at 10:30 AM
Contact: Suzanne Jordan - suzannejordan@hotmail.com (416 709-4418)

High Park: Every Second Thursday at 11:00 AM
Contacts: Rosa Bergman - rbergman@rogers.com (416 662-5671)
Patrick Taylor - pdmtaylor@gmail.com (416 522-8538)

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).

4) Social Outings

In past years the support group has organized many social outings, including picnics in parks, lunches in homes and restaurants, and boat tours of Toronto harbour. The Steering Committee will be organizing more outings this year. Stay tuned! If you have ideas for a particular group activity, feel free to discuss it with any member of the Steering Committee.

5) Myeloma Awareness Month!

What the 🚫 is myeloma? Myeloma Canada's national campaign for Myeloma Awareness Month is well underway, with support groups and individuals around the country speaking out about myeloma and sharing their experience throughout March. You can learn more about these initiatives and read amazing stories by patients about how they found out they had myeloma on the [Multiple Myeloma Awareness Month](#) page on the Myeloma Canada website.

6) Celebrating Jocelyn Kervin

We were all saddened to hear that Jocelyn Kervin passed away peacefully on February 5th. A leading light on the support group's Steering Committee, her lively spirit always enhanced our meetings and activities. Jocelyn had a gift for energetically promoting awareness of multiple myeloma and was featured frequently in our newsletters. So dedicated was she that when members of the support group joined Myeloma Canada to advocate for increased research funding at Queen's Park last October, she left her treatment bed at Princess Margaret Cancer Centre to join the team at Queen's Park.



she left her treatment bed at Princess Margaret Cancer Centre to join the team at Queen's Park. Never one to be shy about sharing her own story, Jocelyn organized an amazing Celebration of Life, her life, which she lived to the fullest every day.

Jocelyn's life will always remain an inspiration to myeloma patients. Among the many tributes to her, the following are from fellow Steering Committee members.

I will remember Jocelyn with a big smile, wearing red, and tirelessly advocating for multiple myeloma: standing in front of the red Toronto sign at City Hall, holding the Toronto proclamation declaring that March was Myeloma Awareness Month; standing below the CN tower, lit red to raise awareness about myeloma; being interviewed on national TV and on podcasts, doing so much more for our community. Jocelyn was my friend and colleague in this journey, and I learnt so much from her about raising awareness, being bold and clear, and not being afraid or hesitating to ask questions. I already miss her at our group meetings, or our private chats over coffee or lunch, laughing and having a great time together. Jocelyn, you left us, but your spirit and legacy will stay with us forever. – *Rinat Avitzur*

Jocelyn was an outstanding example of immeasurable courage and caring about us – in spite of the immense challenges she faced with her own disease. She was a most supportive friend to all those she knew in the myeloma community. She tirelessly advocated for our causes and promoted awareness of myeloma. As her disease progressed in recent months, Jocelyn remained amazingly cheerful and positive, and so appreciative of her very many friends and most devoted family. We will always miss and fondly remember Jocelyn. – *Dave McMullen*

Jocelyn was such a fighter for Multiple Myeloma, and I doubt the word 'no' was in her vocabulary. Whether it was attending meetings at Queen's Park between treatments or making sure that the Toronto sign was lit up in red, she was always doing something to help fellow patients or caregivers. When COVID became a thing, that didn't stop her either! Although the Myeloma Walk in Newmarket in 2020 was virtual, she was determined to do the walk in person. There we were, her team and me, by ourselves

doing the walk. She loved music and I would always send her videos of a very special young lady in my life who is currently in her first year in Music at York. She loved to hear them. Jocelyn was a warrior while she was with us. She now has her Angel's Wings. She will be truly missed, yet never forgotten. – *Bob McCaw*

Jocelyn's Obituary

7) Myeloma Canada Patient and Caregiver Conference Held in Toronto

Myeloma Canada hosted a national conference in Toronto on March 22 for patients and caregivers. Presenters included hematologists Dr. Philip Kuruville (Brampton Civic Hospital) and Dr Urvi A. Shah (Memorial Sloan Kettering Cancer Centre); physiotherapist Alan Richter (Revive Physio); clinical research coordinators Olga Levina and Naomi Kimbriel (Princess Margaret Cancer Centre). There was also a panel of Patient Support Program (PSP) representatives with Alan Birch (Sentrex), Chris Dalseg (BioScript), Jana Gallagher (Janssen), and Alison Oliver (Cencora, Innomar Strategies), moderated by Chantel Wicks (Myeloma Canada). Michelle Oana presented updates from Myeloma Canada. The presenters drew on their wealth of experience addressing issues related to multiple myeloma and covered topics such as research and treatment, managing side effects, clinical trials, nutrition, exercise, and PSPs. Participants from the Greater Toronto Region and across the country listened attentively as presenters discussed topics of direct relevance to their care and quality of life.

There was ample time for questions, and presenters were happy to mingle with and speak to participants informally. Patients and caregivers also enjoyed meeting and learning from each other and speaking to Myeloma Canada personnel. The conference was upbeat and reassuring, especially for newly diagnosed patients. Attendance was excellent and most participants stayed to the end, even as a heavy spring snowfall threatened to bring downtown Toronto traffic to a halt!

Myeloma Canada regularly hosts conferences for patients and caregivers in different parts of the country and they are always very informative, well organized, and worth attending.

8) Support Group Survey

The January edition of the support group newsletter summarized the results of our recent support group survey. At its upcoming annual planning meeting, the steering committee will review these results and draw from them as it plans the upcoming year. Thanks to everyone for responding and contributing their ideas.

9) Travel Insurance Update – New Insurers Found!

Jan Wleugel, whose helpful advice on travel insurance has been featured in previous newsletters, has received information about another travel insurance provider who may cover myeloma patients. As previously indicated, Medi-Quote (www.mediquote.ca), may provide travel coverage to myeloma patients with a seven-day stability period. Travel Guardian (travelguardian.ca) has also provided coverage to myeloma patients subject to a seven-day stability period. We have now heard from several myeloma patients who have received coverage with short stability periods with these insurers.

A shorter stability period is better, as it represents the amount of time before a claim is made that the insured must be medically "stable" for coverage to apply. The pre-existing condition exclusion will not apply if the traveller is "stable" prior to travel for the stability period, so that a myeloma-related claim would not be excluded for this reason. Stability is carefully defined, and an applicant should read the policy wording carefully.

For further information on travel insurance, see Jan's detailed overview of travel insurance on the first page of the support group website: www.myelomatoronto.ca. Please let Jan know by contacting him at janwleugel@gmail.com if other travel insurance providers are found so that the information can be shared with other myeloma patients.

10) American Society of Hematology (ASH) Annual Meeting 2023

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. Some of this research will be covered by our support group speakers in the coming year (see, for example, the summary of Dave McMullen's very helpful ASH overview at the end of this newsletter). There are, in addition, useful presentations online, including the following IMF presentations linked here:

[IMWG Conference Series ASH 2023, "Making Sense of Treatment,"](#) Dr. Brian G. M. Durie, International Myeloma Foundation (IMF) Chief Scientific Officer; Dr. María V. Mateos, University of Salamanca; Dr. Thomas Martin, University of California, San Francisco, Dec. 14, 2023.

["Top Myeloma Research at ASH 2023 from a Patient Perspective,"](#) Dr. Brian G. M. Durie with patient advocates, Jessie Daw and Michael Tuohy, January 4, 2024.

11) Canadian Myeloma Research Group (CMRG) Patient Education Series

Patient Education Seminar Series

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



This excellent patient webinar series is presented jointly by Dr. Donna Reece, CMRG Chief Medical Officer, and Suzanne Rowland, an experienced Princess Margaret Cancer Centre nurse practitioner.

For a full list of webinars, see the CMRG website, linked here: [patient-webinars](#).



Upcoming Webinars:

- Seminar 6: New Myeloma Treatments — CAR-T, BiTE, and New Drugs in Canada
April 25, 2:00 p.m. [REGISTER](#)
- Seminar 7: Myeloma Symptom Management
May 16, 2:00 p.m. [REGISTER](#)
- Seminar 8: End of Life Care and MAID (Medical Assistance in Dying in Canada)
June 20, 2:00 p.m. [REGISTER](#)

Past presentations can be viewed on YouTube at the links below:

- Seminar 1: [Myeloma 101](#)
- Seminar 2: [Lab Results and Imaging Studies: Pt I](#)
- Seminar 3: [Lab Results and Imaging Studies: Pt II](#)
- Seminar 4: [Living with Myeloma, Striving for Excellent Quality of Life](#)

Seminar 5: Current Myeloma Treatment Landscape, and Stem Cell Transplants (to be posted on YouTube)

12) How Your Gut Health Can Affect Your Blood Cancer Treatment and Quality of Life



Webinar presented by Dr. Bertrand Routy, Scientific Director of the University of Montreal's Microbiome Centre

Our July 2023 newsletter contained an article on gut health, "G.I. Hacks and Other Remedies for Myeloma Survivors" by Jan Wleugel, that many readers found useful. This upcoming webinar, hosted by the Leukemia & Lymphoma Society of Canada, promises to be equally useful for myeloma patients. >> [Register](#)

13) Myeloma Canada News

Myeloma Canada Lounge

Myeloma Canada has launched MC Lounge, a new online community platform for Canadians. MC Lounge provides a private and secure social platform that includes online patient and caregiver support groups, the latest myeloma news, upcoming educational events, the Myeloma Canada resource library, and the Myeloma Canada YouTube channel. MS Lounge also allows you to privately message individual members and Myeloma Canada staff, and to find volunteer opportunities. You can sign up to MC Lounge on the Myeloma Canada website: [Join MC Lounge](#)



New Myeloma Canada Website: www.myelomacanada.ca

Myeloma Canada has launched its new, patient-friendly website, the go-to source of information for Canadian patients and caregivers who need material relevant to the Canadian healthcare context. The website has excellent, accessible information on multiple myeloma, including information for newly diagnosed patients and persons living with myeloma and their caregivers. In addition to links to support groups—including virtual support groups—there is a comprehensive resource library with digital tools, information sheets and guidebooks that can be downloaded, and links to educational webinars and videos. There is also a helpful myeloma glossary along with many other useful resources.

>> Access the new [myeloma resource library](#)

New Educational Resource: Managing Myeloma in Rural and Remote Areas

This new InfoGuide provides useful insights and strategies for people living with myeloma in remote areas. These include accessing specialized care and fostering a support network within the community. The aim of the guide is to empower patients and caregivers to take charge of their myeloma journey.

>> Download InfoGuide: [Managing Myeloma in Rural and Remote Areas](#)

14) Myeloma Canada Resources

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 Myeloma Canada webinars, along with webinars hosted by our support group, are posted on the [Myeloma Canada channel on YouTube](#). Some of these are listed here:

- The Role of Palliative and Supportive Care after a Myeloma Diagnosis – [view recording](#)
- Navigating through a Cancer Diagnosis and Employment – [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](#)

Myeloma Canada Peer Support Program

Myeloma peer support volunteers help individuals with myeloma and their caregivers better understand, manage, and cope with myeloma. They come from within the myeloma community and have first-hand experience living with myeloma. Understanding what you are going through, they can listen to your concerns and provide helpful perspectives, ideas, and insights. Volunteers are trained to provide confidential, one-on-one peer support at no cost to participants.

- Peer support information: [Peer Support Program](#)
- Signup for peer support: contact@myeloma.ca (indicate Myeloma Peer Support in the subject line)

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 through the Myeloma Canada website at the following link: [Myeloma Canada News](#).

15) Respiratory Infections

Respiratory infections continue to be a major concern for immunocompromised persons, including most people with myeloma. These include COVID-19 variants, influenza, respiratory syncytial virus (RSV) and other respiratory infections such as measles. Hematologists have recommended that myeloma patients get an updated COVID-19 vaccine, the RSV vaccine, and the annual flu shot. If you have had a stem cell transplant or CAR-T therapy, your hematologist may also recommend updating your MMR childhood vaccinations one or two years after treatment, depending on your condition, to protect you from the rising incidence of measles.

In addition to keeping their vaccinations up-to-date, myeloma patients should always assess their risk in determining when they should mask and/or avoid crowds and indoor spaces.

Updated COVID-19 vaccines are available as mRNA vaccines (Pfizer and Moderna) and a non-mRNA vaccine (Novavax). Although vaccinated persons can become infected with

COVID-19, they are at a significantly lower risk of hospitalization and death. Close family members and caregivers should also be up-to-date with their COVID vaccinations. COVID vaccines can be booked online at Government of Ontario COVID-19 booking portal (covid-19.ontario.ca), by calling the Provincial Vaccine Contact Centre at 1-833-943-3900, or by contacting participating hospitals, clinics, and pharmacies.

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.

RSV vaccines require a prescription from a medical practitioner and can be booked at participating hospitals and pharmacies. 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. Although RSV is not yet fully funded, the Government of Ontario has recently approved funding RSV vaccines for high-risk adults aged 60 or older, including people who have had a stem-cell transplant (see: <https://www.ontario.ca/page/respiratory-syncytial-virus-rsv-prevention-programs>). If you have not yet received an RSV vaccine, speak to your hematologist to find out if you qualify for a free vaccine and where you can get one.

MMR vaccinations are provided by medical practitioners. The MMR vaccine is a live vaccine and is recommended for some post-transplant myeloma patients one or two years after transplant. Your hematologist may recommend that you do a titration test to determine if you have antibodies before recommending that you get the vaccine.

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>.

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>.

Online Resources

Canada's National Advisory Committee on Immunization (NACI):

[NACI Statements and Publications](#)

[Immunization of Immunocompromised Persons](#)

International Myeloma Foundation:

Dr. Brian Durie's Blog, March 7, 2024, "[Whatever Happened to COVID-19?](#)"

16) Your Toronto Group

Support Group Brochure

Our brochures, along with our website and by 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 you have a topic that you would like included in future meetings or newsletters, or have any other suggestions or requests, please contact a member of the Steering Committee.

My Myeloma Journey

Ferdinand Gill

Early Challenges

My challenges started long before I recognized what was happening to my body. The journey was fraught with one challenge after another, some of which were daunting and extremely stressful. However, I survived to tell my story.

In 2005, I was based in Florida at the office of the Consulate General of Barbados and whenever I drove for long distances, I would encounter severe pains in my legs and hips. On occasion I would have to stop and relax in rest areas before completing my journey. In 2009, I was transferred from Florida to work in our Toronto office. In 2010, I was introduced to a young lady, and we started dating. One night, while I was about to leave her home, I tripped on her stairs and injured my right hip. Initially I thought it was clumsiness on my part. With chiropractic treatment and pain killers, the pains temporarily subsided.



In the summer of 2012, while attending a conference in Barbados, I tripped in the bathroom of the hotel and reinjured the same hip. Upon returning to Canada, I sought the assistance of a physiotherapist, an acupuncturist, a chiropractor, and any form of treatment which I figured should offer some form of relief. During this period, my mobility was significantly impaired, and I relied on the assistance of a walking cane. Nothing or no one offered any long-term relief. After several months of treatment, my chiropractor, Dr. Bruce Comstock, drafted a note for me to take to my family doctor, suggesting that he schedule me for x-rays on my hips.

When my physician called and informed me that he had the results of the x-rays, I was anxious but tried to remain calm. Accompanied by Sherry, my girlfriend at the time who later became my wife, I went to his office. He informed me that the x-rays highlighted some lesions on my hips, and inquired if I was familiar with the term "myeloma." He informed me that I could have multiple myeloma and he would get his office to schedule an appointment for me with a hematologist. Weeks and months passed, and the pains grew worse.

Initial Treatment

With the kind assistance of a Barbadian nurse, I eventually secured an appointment at Toronto East General Hospital (now Michael Garron), where Dr. Patricia Disperati readily accepted me as a new patient. A biopsy of my hip, several x-rays and bone scans revealed that my condition was stage 3 multiple myeloma. Dr. Disperati suggested we commence treatment forthwith. My initial treatment consisted of sixteen sessions of chemotherapy and then six sessions of radiation. However, treatment did not go smoothly. As a diplomat, I had no legal status in Canada and the costs of the combination of drugs and doctor visits were exorbitant. My Toronto office had group medical insurance for the staff but there was no consideration for the treatment of multiple myeloma. After much consultation with Dr. Disperati and with the assistance of the nurses in the oncology ward of Michael Garron Hospital, the insurance company agreed to cover such drugs as would normally be covered by OHIP.

Treatment began in earnest in January 2013. After the fifth session of chemo and related combination of drugs, Dr. Disperati became alarmed at the significant reduction of some proteins in my blood. I said to her that I was a God-fearing man and lots of prayers were being offered on my behalf. My treatment continued according to the doctor's plan during which time I lost all my body hair, my appetite, sense of smell and taste. Eventually, Dr Disperati informed

me that I was a prime candidate for a stem cell transplant, and she would be referring me to Princess Margaret Hospital.

Barbados' Medical Aid Scheme

Paying for a stem cell transplant proved to be a major challenge as my insurance company advised that our coverage did not include stem cell transplants.

I was interviewed by Dr. Suzanne Trudel, Dr. Donna Reece, other clinical associates, and nurses who walked me through the transplant process and highlighted some of the expectations and outcomes. It was when accounting got involved that my status in Canada, or lack of it, was again questioned. Initially I was classified as an "International Patient" and told the cost of the transplant, CAD \$375,000, would have to be guaranteed before undergoing any treatment. I was then burdened with the task of proving that I was not an international patient sent from Barbados for treatment but instead worked for the Government of Barbados in Canada and as such should be considered a "Self-Paying Patient" instead.

University Health Network, of which Princess Margaret is an affiliate, accepted my latter status and agreed that once the transplant physician had confirmed my eligibility and I had agreed to undergo this type of procedure, the applicable fee of CAD \$160,000 would apply, and I would have to meet the financial requirements before I was accepted as a patient.

My stress level soared when it seemed like the transplant which could save my life was out of my reach financially. Sherry, however, refused to accept that situation as the final hurdle. She insisted that we had to secure funding at all costs even if it meant selling or remortgaging her condo. I became very depressed and was unable to think clearly. Sherry reminded me that she remembered me mentioning my communication with the Social Works Department of Barbados on behalf of Barbadian patients who were transferred to Canada for medical treatment and advised that I should reach out to that department.

I outlined my case to the Senior Medical Social Worker, Social Works Department, Ministry of Health, Barbados, who advised that she was prepared to recommend my case for consideration. However, she needed to have my request in writing, supported by the Ministry of Foreign Affairs confirming my posting to the mission in Toronto. My request was favourably considered, and the requisite funds were provided to University Health Network through Barbados' Medical Aid Scheme.

Autologous Stem Cell Transplant



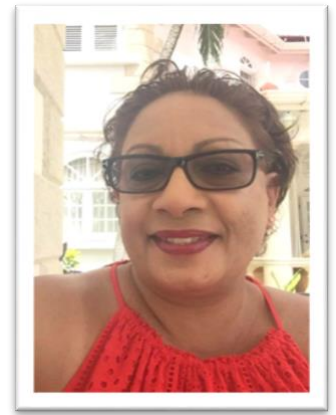
My stem cell transplant took place in May 2013. After my stem cells were harvested and all my medicals were brought up to date, I received a very high dose of chemo designed to kill the cancer cells in my body, but which also kills healthy blood cells. My stem cells were then reinfused. I remained in Princess Margaret Hospital for two and a half weeks during which I was closely monitored. While I was in Princess Margaret Hospital Sherry was my main support person. She spent every waking hour by my bedside. She communicated with the doctors and nurses on my behalf and informed them of any concerns which arose. The actual transplant went smoothly, and the care coordinators were very happy with my progress. However, Sherry discovered that I kept having conversations with family members who were not physically present! When she discussed this issue with the doctor, she was informed that it occurs more often than documented but was nothing to be alarmed about. At this juncture, I want to emphasize that the need for support persons during illness should never be understated or taken for granted.

Immediately after my discharge from the Hospital, Dr Disperati recommended a regimen consisting of Revlimid as a maintenance drug. However, Revlimid caused my entire body to break out with a rash. She tried reducing the dosage without any success. Eventually she had to discontinue the Revlimid and for ten years I went without medication. I should also mention that the cost of Revlimid for me as a non-resident was CAD\$10,000 per month. Canadians should be justly proud of their health care system: the Ontario Drug Benefit Program now covers lenalidomide (Revlimid) for patients 65 years and older and there are options available for younger patients who do not have private insurance.

My challenges resurfaced in January 2023 and my treatment was to consist of daratumumab in combination with Revlimid and dexamethasone. However, I am still unable to take Revlimid. After several months of treatment with daratumumab and dexamethasone, Dr Disperati is very happy with my progress, and I am happy to report that I am once again in remission.

Gratitude

I want to thank Almighty God for the amplitude of his blessings which he continues to bestow upon me. Special thanks also to the doctors, nurses, and all the health care workers at Michael Garron and Princess Margaret Hospitals, not only for the professional and compassionate way they discharged their duty of care, but also for recognizing the challenges I encountered and the willingness with which they offered solutions and remedies which assisted in my overall treatment and well-being. I want to thank Sherry for the role she played in my recovery and for being my advocate when my voice was silent. I would also like to thank the members of the Toronto & District Multiple Myeloma Support Group for embracing me as a member and their readiness to address my several concerns.



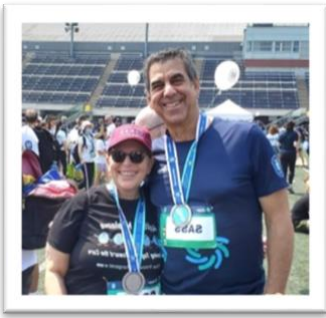
By virtue of marriage, I am now a permanent resident of Canada and the cost of various combinations of drugs is significantly reduced. I continue to receive monthly treatment at Michael Garron Hospital, and I can say unequivocally that from the time I was accepted as a patient in 2013 to this very day, Dr Disperati, the nurses, pharmacists, and the staff of Michael Garron have always treated me more like family than a patient. I recently saw a note on the wall of the hospital which read: "This isn't just a hospital, it's the heart of the east." The staff of Michael Garron Hospital have exemplified this mantra.

Annual Events

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

Registration is well underway for this year's event MM5K Walk or Run in support of the excellent Bloom Chair in Multiple Myeloma Research at Princess Margaret Cancer Centre. Every year, many members of our support group participate in this festive event. Thousands of walkers and runners meet at Varsity Stadium and then weave their way around Queen's Park and down past the Princess Margaret Cancer Centre to the cheers of onlookers and supporters, before returning to a fun-filled Varsity stadium. Members of the support group, family and friends, co-workers, caregivers, doctors, and nurses, all march through downtown Toronto to raise funds to improve the lives of multiple myeloma patients. Some supporters





also participate virtually. Last year over \$350,000 was raised to support ongoing and new research that is already contributing to very significant improvements in treatment options and outcomes for myeloma patients. The event is always enjoyable and festive, with a spirit of celebration and hope in the air.

View a lively promotion video for this year's walk featuring, among others, our very own Munira Premji, three times "cancer warrior," at the following link: [Cancer Warrior](#).



This year's event takes place on **June 16, 2024**. You can register and or/support your fellow walkers at the following link. Be sure to select the MM5K group: [Journey to Conquer Cancer 2024](#).

You can view great photos from last year's event on the MM5K Facebook page: <https://www.facebook.com/mm5Kwalk>

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. Myeloma Canada's [Multiple Myeloma March Mini Mag](#) contains full details of the walks, including fund-sharing research partnership arrangements in 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 – February 3, 2024



Some Brief Highlights of 2023 American Society of Hematology (ASH) Meeting

Dave McMullen

Co-Chair Emeritus

Toronto & District Multiple Myeloma Support Group

What is the ASH Meeting?

- Largest hematology meeting in the world, held annually, now 65th year. This year 28,000 in-person + 4000 virtual.
- Largest myeloma research meeting in the world.
- Normally in a different US city every year, in December. This year in San Diego.
- >1000 myeloma presentations (>136 oral and > 850 poster presentations).
- "Never so much advancement as this year – renewed hope."



MGUS and Smouldering Multiple Myeloma (SMM)

- iStopMM study in Iceland – 75,000 enrolled:
 - 5% of people over 50 have MGUS.
 - Screening greatly reduces damage when MM diagnosed.
 - Physical and psychological impacts evaluated.
- Treating high risk SMM:
 - Many trials looking at starting treatment, particularly for high-risk patients.
 - One trial used teclistamab – a bispecific antibody.

Updates on Front-Line Therapy

- Stem cell transplant (SCT) still recommended as standard of care for many patients.
- Use of 4 drugs, "quadruplet" (better than 3?) sometimes used in the US.
 - Daratumumab – Revlimid Velcade dexamethasone (D – RVd): "PERCEUS" Trial in Europe with SCT. Overall survival slightly better after 4 years.
 - Isatuximab – Kyprolis Revlimid dexamethasone: "IsKia" Trial in Europe. Effective, but more side effects/toxicity and cost.
- Daratumumab and other drugs are being added to or included more and more in front-line therapy.
- Clear benefit from DRd induction for transplant ineligible patients, compared to RVd.

T-Cell Engagers (TCEs)

- Sometimes called bispecific antibodies or “BiTEs.”
- A special monoclonal antibody cell is used to link a T-cell in the immune system with a myeloma cell.
- Most trials still in early phases (usually Phase I or II).
- Results so far are encouraging.
 - High response rates
 - Side effects moderate
- Lower cost than CAR-T, and “off the shelf.”
- Some discussion about reducing burden to patients and health care system.
- Side effects – infections can be common.
- Looking at intermittent or limited duration use of TCEs.
- There is much interest in research about sequencing strategies for various CAR T treatments and other T-cell directed therapies.
- Leading TCEs:
 - Janssen teclistamab
 - Pfizer elranatamab
 - Regeneron REGN5458
 - Abbvie ABB-383
 - BMS alnuctamab
 - Janssen talquetamab
 - Hoffman-LaRoche RG6234
 - Genentech cevostamab
 - Trispecific antibodies HPN217, JNJ5322
- Looking at reducing side effects and infections.
- Looking at reducing burden to health care system, including home observation.
- Perusing out-patient treatment more.
- Tremendous promise.

CAR T-cell

- Many studies in progress.
- Becoming safer, high response rate, good depth of response.
- Duration still not very long (cilta-cel had median remission about 3 years; ide-cel much less).
- Significant side effects and recovery period.
- Significant progress being made and anticipated.
- Currently used more in lymphoma and leukemia – sometimes curative, but majority still relapse.
- Not considered curative in MM.
- May replace transplants in future?
- Examining using CAR T earlier in disease, including for front-line therapy.
- Costs so far are very high. Still not publicly funded in most countries.
- Long term side effects being observed and evaluated – still early.
- Inflammation markers: ferritin and fibrinogen being examined.
- Perusing out-patient CAR T more.
- Leading candidates:
 - BMS “ide-cel”
 - Janssen “cilta-cel.” Now in trials for front-line therapy.
 - CARsgen “zevor-cel”
 - Innovent/IASO Bio CT103A
 - Gracell FasTCAR (now owned by AstraZeneca)

- Allogene ALLO-715
- BMS 986393 (targets GPRC5D)
- Several others, including with dual targets.

Other Therapies Similar to CAR T

- Work on made-in-Canada and point-of-care, or small manufacturing of CAR T-cells:
 - Myeloma Canada with others
 - TAC T-cell
 - CAR NK cell
 - Gamma–delta T-cell

Minimal Residual Disease (MRD) Testing and Liquid Biopsies

- Increasingly, MRD testing recommended in clinic – can be used to help guide and adapt therapy.
- Being considered as an “end point” for clinical trials.
- Blood test to supplement, reduce need, or replace bone marrow biopsy.
- Response-based therapy using various types of liquid testing being evaluated.

Real World Data (RWD)

- MMRF compass study.
- Teclistamab – compare with trial data, and results after of BCMA directed therapies (e.g., CAR T, Belamaf).
- Canadian Myeloma Research Group (CMRG) data base used.

Health Equity and Access

- IMF Empower Program for African Americans.
- Whole world is becoming more attuned to health equity.

Other Noteworthy Topics

- CELMoDs (CC-220 iberdomide, CC-92480, mezigdomide).
- Selinexor, alone and in combination.
- Venetoclax and belantamab mafodotin.
- Many other agents and combinations being researched.
- Studies in immune system microenvironment health.
- Quality of life – increasing importance.
- Considering reducing dexamethasone dosing.
- Diet – increasing interest.

Clinical Trials

- Ask your doctor about whether a clinical trial might be beneficial for you.
- For information about clinical trials in general, see the Myeloma Canada website, under “Research.” Lots of information here: [Clinical Trials](#).
- Also has “Find Clinical Trials.”
- Myeloma Canada InfoGuide on Clinical Trials.
- Trials at Princess Margaret can be available to patients at other centres.
- Informative websites: clinicaltrials.gov and itstartswithme.ca.