



TORONTO & DISTRICT MULTIPLE MYELOMA SUPPORT GROUP NEWSLETTER

Website: www.myelomatoronto.ca

January 2024

Newsletter # 158

In This Issue

Next In-Person Meeting Details

Last In-Person Meeting

Announcements

- Upcoming In-Person Meetings with Guest Speakers
- Upcoming Virtual Share and Care Meetings
- Toronto & District Multiple Myeloma Support Group Survey
- Travel Insurance Update – New Insurers Found!
- Walk & Talk
- American Society of Hematology (ASH) Annual Meeting 2023
- Canadian Myeloma Research Group (CMRG) Webinars
- Myeloma Canada News
- --New Myeloma Canada Website
- --New Educational Resources
- --Imagine Canada Accreditation
- Myeloma Canada Resources
- COVID-19 and RSV
- Your Toronto Group

My Forest Bathing Experience
--*Patricia Gostick*

Annual Events

- MM5K Walk or Run, Princess Margaret Cancer Centre
- Myeloma Canada Multiple Myeloma March

Fundraising

Highlights of Presentation at Support Group Meeting, December 2, 2023

- 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, February 3, 2024

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

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

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

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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Last In-Person Meeting: December 2, 2023

Topic: *Dave and Erika's CAR T-Cell Therapy Experience*

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

A detailed summary of Dave McMullen'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 YouTube site, linked here: <https://www.youtube.com/watch?v=VWOeie0CN1c>.

Announcements

1) Upcoming In-Person Meetings with Guest Speakers

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

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

Kyphoplasty and Related Treatments

2) Upcoming Virtual Share and Care Meetings

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

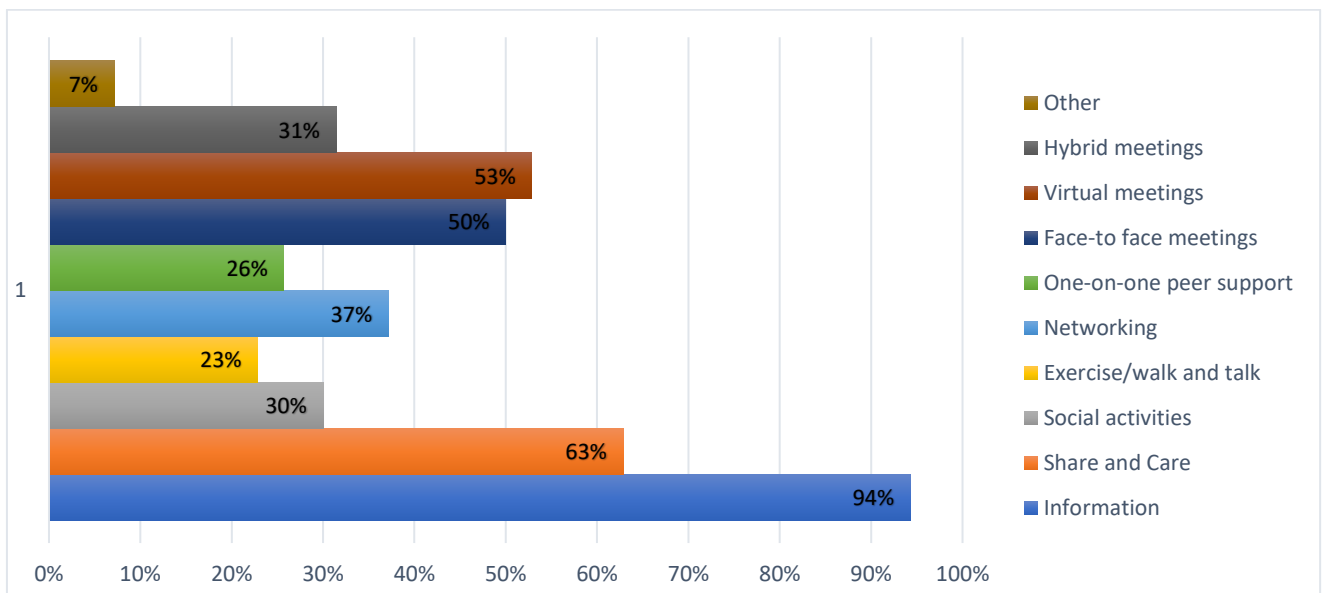
Share and Care Zoom meetings are normally held on the first Thursday of every second month. The login link to Zoom is sent by email prior to meetings. The meetings provide a great opportunity to welcome new participants, meet fellow myeloma patients and caregivers, and raise questions and learn from 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) Toronto & District Multiple Myeloma Support Group Survey

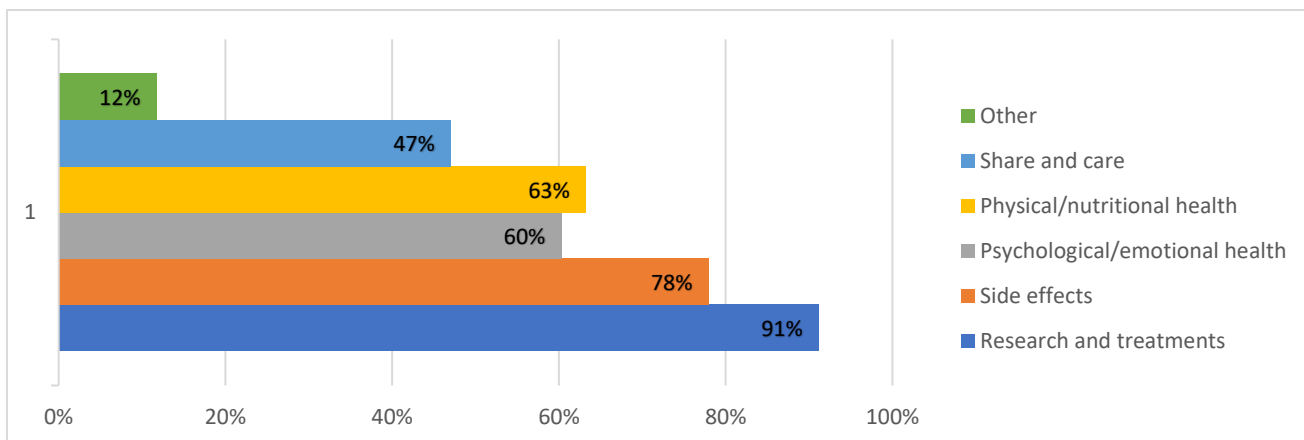
The steering committee was delighted with the response to the recent member survey and would like to thank support group members for contributing their ideas. The survey was distributed in mid-November and the response rate was so high that we had to open a second (duplicate) survey one week later. In total, seventy-one people completed the survey online, an excellent response, especially when compared to the last online survey in 2021 (thirty responses) and earlier paper surveys. The survey will provide the steering committee with very useful information about member opinions and needs and will assist in future planning. Thank you very much to everyone who participated.

Highlights of the survey:

- The vast majority of respondents believe that the support group is successful or very successful in meeting its goals as a support group.
- As the graph below demonstrates, most respondents indicated that what they need from the support group is information, while the second greatest need was share and care sessions. About half of respondents indicated that they valued both face-to-face and virtual meetings, with some choosing hybrid meetings because of difficulties attending in-person meetings. A significant minority of members expressed the need for networking, social activities, exercise/walk and talk, and one-on-one peer support.



- Research and treatment information was the most popular meeting topic, though side effects, emotional/psychological health, and physical health/nutrition were also of interest to most respondents, while share and care was of significant interest to many, as demonstrated by the graph below:



- Virtually all respondents were satisfied with our speakers, newsletters, and websites, and further suggestions were provided for each of these.
- Of the respondents who were interested in social outings, a majority selected picnics or gatherings in a park and meeting for coffee.
- Many respondents volunteered to assist in the activities of the support group, especially at in-person meetings. There was also a lot of interest in assisting with peer support. Half of the respondents indicated that for health or personal reasons they were unable to volunteer at this time.
- Many respondents added very useful comments, suggestions, and expressions of appreciation for the work of the support group.

4) 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 placed 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.

5) Walk & Talk: MM Walking Groups

We currently have two Walk & Talk groups.* The first meets every second week at **Earl Bales Park on Tuesdays**. This group enjoyed walks throughout the summer and fall but has stopped for the winter months. A second group meets every second week at **High Park on Thursdays**. This group continues to walk through the winter, provided weather is accommodating.



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.

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)

**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).*

6) 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. Although some of this research will be covered for our support group by our speakers in the coming year, there are already 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.

For more detailed reports on presentations at ASH 2023, see the daily blogs posted by the Multiple Myeloma Research Foundation (MMRF), as summarized below by the MMRF with links to each day:

[Day one](#) highlights included real-world data on the use of the bispecific antibody Tecvayli, health-related quality of life findings with the CAR T-cell therapy Abecma, iberdomide maintenance therapy, and updates on the treatment of high-risk newly diagnosed disease and smouldering myeloma.

Day two included a real-world comparison of quadruplet versus triplet regimens in newly diagnosed multiple myeloma and an assessment of the real-world utilization of autologous stem cell transplantation in newly diagnosed patients.


Day three featured updates on CAR T-cell therapy, bispecific antibodies, the impact of age on transplant outcomes, and novel therapies in early phase clinical trials.

Day four featured an important late-breaking abstract on Darzalex Faspro in combination with the standard care regimen of Velcade, Revlimid, and dexamethasone (VRd) in newly diagnosed patients with multiple myeloma who were eligible for an autologous stem cell transplant.

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

Patient Education Seminar Series

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



CMRG
Canadian Myeloma
RESEARCH GROUP
Transforming Myeloma Research



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. For further information contact info@cmrg.ca.

Seminar 4: Living with Myeloma/Striving for an Excellent Quality of Life
Suzanne Rowland, NP
Thursday, January 25, 5.00PM-6.30 PM

Some of CMRG's past presentations can be viewed on YouTube:

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

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

8) Myeloma Canada News

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 those already 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.

New Educational Resources

1. Understanding Relapsed/Refractory Myeloma

Most myeloma patients will encounter the terms “refractory” and “relapse” as they negotiate their myeloma journey. Knowing that treatment is not working or that the disease is coming back is physically and emotionally difficult. This useful InfoSheet explains how these terms are used, discusses the types of treatment options that are available following relapse, and provides helpful coping strategies.

InfoSheet: [Understanding Relapsed/Refractory Myeloma](#)

2. Understanding Graft-versus-host Disease (GvHD)

GvHD is a complication that can happen following an allogeneic stem cell transplant. It does not occur with the more commonly performed autologous stem cell transplants. Myeloma Canada has prepared a new information sheet on this topic that can be downloaded at the link below. As well, there is new webinar and shorter video that can be viewed at the links below.

InfoSheet: [Allogeneic Transplant & Graft-versus-host Disease](#)

InfoWebinar: [Allogeneic Transplant in Myeloma & Graft-versus-host Disease](#)

InfoVideo: [What is Graft-versus-host Disease and How Can the Complication Affect People with Multiple Myeloma?](#)

3. Demystifying Palliative and Supportive Care

While palliative care was once associated with end-of-life, it is now offered during treatment to better manage multiple myeloma, help control pain and symptoms, and maintain the best possible quality of life. Myeloma Canada has developed an InfoSheet and InfoWebinar to provide information on palliative care needs and the resources available to support patients and caregivers. Click on the links below:

InfoSheet: [Palliative Care InfoSheet](#)

InfoWebinar: [The Role of Palliative and Supportive Care after a Myeloma Diagnosis](#)

Imagine Canada Accreditation

On November 9, 2023, Myeloma Canada achieved accreditation through the Imagine Canada Standards Program for its excellent service to the myeloma community. Accreditation is testimony to Myeloma Canada’s commitment to excellence, transparency, equity, and continuous improvement. It confers official recognition that the organization’s governance and practices are exemplary and that it is trusted, reputable, forward thinking, and accountable to its community of stakeholders. Imagine Canada is a national charitable organization dedicated to building excellence within Canada’s charities and non-profit organizations and strengthening confidence in the sector through common standards of practice in such areas as governance, financial accountability and transparency, fundraising, staff management, and volunteer involvement.

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

10) COVID-19 and RSV

Respiratory infections are on the rise this winter, including COVID-19 variants, influenza, respiratory syncytial virus (RSV) and other respiratory infections. Hematologists have recommended that myeloma patients get an updated COVID-19 vaccine, the RSV vaccine, and the annual flu shot.

Updated COVID-19 vaccines are available as mRNA vaccines (Pfizer and Moderna) and a non-mRNA vaccine (Novavax). Although vaccinated persons can become infected from 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 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. RSV vaccines require a prescription from a medical practitioner and can be booked at participating hospitals and pharmacies. **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.

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

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>.

Online Resources

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

Myeloma Canada: [COVID-19 Overview](#)

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

11) 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 you would like included in future meetings or newsletters, or have any other suggestions or requests, please contact anyone on the Steering Committee.

My Forest Bathing Experience

Patricia Gostick

I first heard about forest bathing earlier this summer.

The Toronto Botanical Garden proposed a forest bathing outing as part of its offerings of nature experiences. When I read about this experience, I thought, “How New Age! What a throwback to hippie culture!” I didn’t think anymore about this outing until I saw “Forest Bathing” advertised in the Wellspring Westerkirk House listings about two months later. I read the description of this forest walk, described as a “wellness walk,” and it sounded very appealing.

I have participated in Wellspring programs in the past, such as Reiki, easy yoga, and chair yoga and always found them to be helpful. Although there are 6 locations in southern Ontario and online programs, Westerkirk House is near my home. It is a warm and inviting centre on the Sunnybrook Hospital campus. Wellspring (wellspring.ca) is a charitable organization funded solely through the generosity of donors, and its programs and services are offered free of charge. Wellspring describes itself as “your source for cancer support,” and I don’t think that you could find a more comprehensive, generous support system anywhere.



I signed up for the walk. It was to take place on September 12, but rain caused it to be delayed until October 3. We benefited from the summer-like weather that we enjoyed at that time. Our leader, a very gentle man, guided the group of six women through the ravine near the old Sunnybrook stables. En route, we stopped to listen to birdsong, trying to identify which birds made the sounds. We touched the bark on trees, feeling the roughness and grooves in the wood. We observed the interdependence of nature, seeing mushrooms growing from the base of the trees and flowers growing out of cracks. We sat on the bank of a stream listening to the brook babble as it hurried over rocks. We drank a small cup of herbal tea that our leader had boiled from cedar bark with added cinnamon and maple syrup. The highlight of the experience was walking into a stand of the oldest trees in the forest. They were tall and majestic, filtering the warmth of our blue-sky day. We were asked to each choose a tree that somehow spoke to us. We were encouraged to hug it, to feel its strength and solidity. I had never hugged a tree before, and I felt a real connection with the natural world through this tree. I felt that Mother Nature was a support in my life that I hadn’t fully appreciated before.

After we had finished hugging our chosen tree, we were invited to share how we felt about the experience. I imagine that we were all cancer patients, as this was a Wellspring program. I was diagnosed with smouldering myeloma in 2012 and had a stem cell transplant in March 2017. Participants could have been diagnosed with any of the many cancers that are prevalent today. Of those who spoke, everyone said that they felt more at peace, less worried about things that were bothering them earlier in the day.

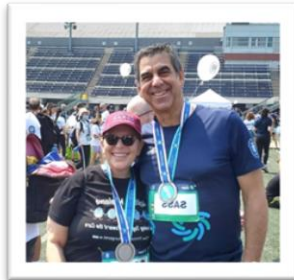
Our leader told us that forest bathing was developed by the Japanese. I thought that I should investigate its history a bit further. Japan is one of the smallest, most densely populated countries, with 338 people per km squared (compared to 4 per km squared in Canada.) However, approximately 68.5 % of Japan’s land is covered by trees, making it one of the world’s most forested countries. As a result, the Japanese have a very special relationship with trees. Sacred trees, or shrine trees, are planted at Shinto shrines to mark a sacred site. The veneration of ancient trees is still practised by modern Japanese citizens today.

Dr. Qing Li, Chairman of the Japanese Society of Forest Medicine, is credited with developing forest bathing, or Shinrin Yoku, in the 1980s. In his 2018 book, *Into The Forest: How Trees Can Help You Find Health and Happiness*, Qing states: “This is not exercise or hiking or jogging. It is simply being in nature, connecting with it through our sense of sight, hearing, taste, smell and touch.” (p. 12)

I would encourage everyone to try forest bathing. It’s not only for old hippies!

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. 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

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

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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 – December 2, 2023



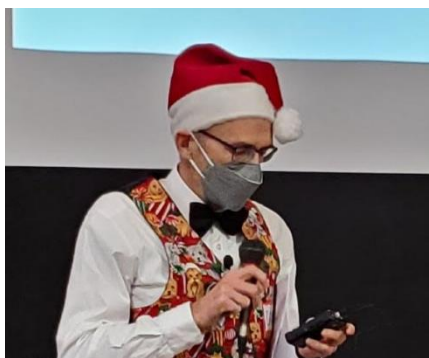
Dave and Erika's CAR T-Cell Therapy Experience

Dave McMullen

Co-Chair Emeritus

Toronto & District Multiple Myeloma Support Group

Dave McMullen's full presentation may be viewed on Myeloma Canada's YouTube channel, linked here: <https://www.youtube.com/watch?v=VWOeie0CN1c>



*Dave Prepares his Presentation,
December 2, 2023*

In October 2022, Dave became refractory to his existing treatment. It was suggested he participate in the Princess Margaret Cancer Centre CAR T-cell trial. Fortunately, he met the stringent inclusion criteria and was enrolled in the trial. He did not do it alone, as his dear wife, Erika, has been with him every step of the way since he was diagnosed 12 years ago, and even more so in the CAR T process.

So, what is CAR T? I'm sure you've all heard of it. It's the abbreviation for what are called chimeric antigen receptor T-cells. T-cells are part of your immune system. They are modified and re-engineered to have these chimeric antigen receptors attached to them. Antigens are a type of protein on the surface of myeloma cells. Chimeric means that they are being

changed so they have specific gene features. And the receptors are what grab onto antigens on the myeloma cell.

Your own T-cells are harvested using a pheresis process, similar to stem cell collection for a stem cell transplant. They are sent off to a manufacturer to be genetically re-engineered for a specific target such as BCMA (B-cell maturation antigen) on the surface of the myeloma cells. Lentiviral vectors are used. In a nutshell, lentiviruses are viruses with slow incubation, and vectors are used to make changes to the genes.

Once the vectors are deployed, the modified T-cells are "expanded," or mass produced, and returned to the hospital to be infused into the patient. These T-cells then latch onto the myeloma cells and destroy them. There are side effects which occur, but they are usually fairly well managed by the oncology team. This is still an area of research. The medical community is still learning as they go.

For myeloma, BCMA is a good target. There are other targets, but so far BCMA is the one most frequently used.



Collecting T-cells by Leukapheresis

As Dave's treatment was part of a clinical trial, there were many screening tests before being accepted into the trial. Once accepted, the first part of the process is called leukapheresis. "Leuka" refers to white blood cells, and pheresis is the method used to collect the cells for manufacturing. In his case, the blood cells were sent to a manufacturing facility in California where the T-cells were extracted from the white blood cells and then reprogrammed to attach the CARs to the T-cells.

Before CAR T cells are infused into the body, you undergo a process called lymphodepletion, where lymphocytes, which are part of the immune system, are depleted by chemo. This is so the body can accept the modified T-cells without rejecting them. The chemo is similar to the melphalan that you receive prior to a stem cell transplant. However, it is not as strong or as onerous. It can cause some side effects such as nausea. Three days later, the modified T-cells are infused into the patient intravenously.

Dave was diagnosed in 2012 and has had two stem cell transplants and numerous other treatments, including Revlimid, daratumumab, pomalidomide, carfilzomib, and cyclophosphamide. As well, he has taken part in two clinical trials with bispecific antibody treatments, cevostamab and talquetamab. Cevostamab worked well initially but unfortunately only for one month. Talquetamab did not work at all for Dave but does work for most patients. Although they did not work for him, Dave does not regret taking part in these trials, as you never know what will work for you until you try.

The CAR T process has been around for a number of years and has been approved for some types of leukemia and lymphoma by Health Canada and funded by the provinces. CAR T-cell treatment for myeloma is more recent. There are two commercial myeloma CAR T-cell therapies: ide-cel and cilta-cel. These have been approved by Health Canada. Ide-cel has not been recommended for funding by the provinces, in part because the median remission time was only about a year. Cilta-cel has been recommended for funding as it has shown a better median remission time of about three years. This is significant as most people who will receive this treatment have already been through several lines of failed therapy. Negotiations for cilta-cel funding are underway. However, very few countries have approved funding so far because it is so expensive.

There are many countries and companies developing CAR T-cell therapies. There is a new company called CARsgen Therapeutics from China, which has developed a new CAR T for myeloma called CT053. It has had phase 1 and 2 clinical trials in China. They are now proceeding with an early phase trial at a few centres in North America. Dave is on this trial.

Dave provided an overview of the entire process. First, you begin with reviewing and signing the Informed Consent Form, a 28-page document describing the trial, potential side effects, tests, and procedures. The patient and their family are sent home with the form to review thoroughly so they can understand what possible risks and hazards there are. The most useful part of the document for Dave was a table called "Sequence of Events." It describes the various tests and procedures he would undergo, and their timing.

Next is the initial screening process, which is quite extensive for any trial of this nature. For this trial, you must have had prior therapies including a proteasome inhibitor such as Velcade, an immunomodulatory drug like Revlimid, and daratumumab. You need to be refractory to your

last treatment. You cannot have had any prior BCMA treatment without a response. You must be reasonably healthy and must pass many blood tests. As well, there are many physical exams and other tests, and a 24-hour urine test.

If you are accepted, there is a washout period where you cannot take any anti-myeloma drugs for at least two weeks prior to leukapheresis. In pheresis for a stem cell transplant, you receive drugs to mobilize the stem cells five to ten days in advance. That is not needed for the CAR T process. Your blood is run for a couple of cycles through the centrifuge machine to collect white blood cells.

The manufacturing facility takes approximately four to six weeks to complete the process. There are some newer processes which are looking to speed up the cell production, but they are still in the study stage. Although closely monitored, there can be glitches in the manufacturing process or transport. In Dave's case, the CAR T cells were held up briefly at airport customs.

While waiting for the return of manufactured cells, most patients go through bridging therapy to keep the myeloma under control. There are a few treatments which can be used for this. While waiting, Dave remained in isolation. His kappa free light chains increased to 5400 and his hemoglobin dropped, both signs the disease was becoming more active. You also undergo baseline tests while waiting, including a physical and mental assessment, bone marrow biopsy, brain MRI, and many blood tests.

Once the CAR T cells are ready, you go through lymphodepletion three to five days before having the CAR T cells infused. This entails a large dose of chemo for three days, including cyclophosphamide and fludarabine. This is done as an out-patient.

Two days later, Dave was admitted, and he had his infusion on the following day. There were approximately 180 million cells in about 20 millilitres of fluid in the infusion. This was called "Day zero," much like a stem cell transplant. He did not notice any immediate side effects. The infusion takes about ten to fifteen minutes, and you are monitored very carefully by the hospital staff. You receive lots of prophylactic drugs at this time and some continue to be taken during the first month, including antibiotics, antifungal and antiviral medications. Since the T-cells can go through the blood-brain barrier, there is a risk of seizure, so an anti-seizure medication is given for the first thirty days.

Dave spent sixteen days being closely monitored in the hospital. Initially, he was supposed to be an out-patient, staying close to the hospital. However, as this was his eighth line of therapy and he had been relapsing quite significantly, it was determined he should be kept in the hospital.

On Day +4, he developed fever, a symptom of cytokine release syndrome (CRS). He was glad to see that because it meant the CAR T cells were working. This lasted for four days during which he received tocilizumab, a drug frequently given to relieve CRS. This greatly reduced his symptoms. Dave had no neurological toxicity, one of the possible side effects from the CAR T-cell therapy.

ICANS or immune effector cell-associated neurotoxicity sndrome is possible in CAR T therapies and can be life threatening, so you are monitored very closely. You are frequently given a test of ten normally easy questions, and you must pass it 10 out of 10. For example: "What year is it?" "What month is it?" "What city are you in?" Once he was at home, Erika had to administer the test, and was instructed if Dave didn't get 10 out of 10 to call the hospital immediately.

Dave had a few issues and therefore was kept in hospital a bit longer than average for close monitoring, but it was nothing serious. When he was close to being released, both he and Erika attended "CAR T School" so he could be managed at home, as there are quite a number of protocols which need to be followed. He was then an out-patient for four weeks, going to the hospital roughly twice per week. The days that he didn't go into the hospital, he received a call from the nurse checking on his status. Dave's blood counts were slow to recover, but this was likely due to his many prior lines of therapy. He was advised to stay in isolation for three months to allow his immune system to recover. This meant no support group or other meetings, and no visits, other than to the cancer centre.



Dave and Erika

There was an amazing response to the infusion. Within a very short period of time, his kappa light chain cells went down to less than two. He has had no myeloma cells in his bone marrow samples. So far, he has not had an MRD test (minimal residual disease) but he may have one soon. His last blood counts were still excellent, and now 12 months post treatment, he is doing well. His hemoglobin is still low; he can do some aerobic activity but must go slower than normal and breathe more deeply. His doctor advised it could take two years for it to come back to normal. Overall, he is happy to be off anti-myeloma drugs. He is regaining muscle strength and re-doing his vaccinations. Every day is a blessing.

So, what about CAR T therapy in general? What's the future? Dave feels there is tremendous hope. There are a lot of studies looking at various types of CAR T. This therapy is very resource intensive, with a need for nurses and doctors to monitor each patient. Many of the studies are looking at ways to make it less of a drain on health care resources. It is not a panacea yet, but it holds great possibilities.

Q. On the day they put the T-cells back in, did you have any side effects?

A. Not for me. I've heard some patients did notice something, but the amount of fluid infused is very low.

Q. You've had a lot of different therapies. Was the CAR T one of the roughest ones?

A. No, for me the roughest ones were the stem cell transplants.

Q. Because of stringent requirements, would age be an exclusion?

A. To my knowledge, no. Every centre is different, but as far as I know they look more at your overall health status.

Q. If a person came out of remission after having CAR T therapy, could they have a second CAR T treatment?

A. Right now, it's not available or funded in Canada. But there are patients that I am aware of who have done two CAR T-cell therapies elsewhere.

Q. In what sense are CAR T-cell or some of the other therapies being developed considered a cure?

A. From my own observation, I think myeloma doctors don't use the word "cure" for CAR T in myeloma, at least not yet.

Q. Are you on any maintenance therapy?

A. No, it's not part of the protocol for this trial. There are other trials where maintenance therapies of various types are used.

Q. How many people at PMCC have received this CAR T therapy?

A. Not very many. There are just a few slots available.

Q. What does CAR T therapy cost?

A. I've heard that in the US the price for CAR T manufacturing is approximately \$475,000. I don't know if that is true or not. In Canada, the pricing is always negotiated down. There is also the cost of the hospital care that is on top of the manufacturing costs.

Q. Do you have any sense when CAR T might be funded in Ontario for myeloma?

A. I don't know. For cilta-cel, there is a pan-Canadian organization which does negotiations on behalf of the provinces. Negotiations are starting. So, fingers crossed, it may be sometime soon. A lot depends on the pricing. As a patient, I would argue that a three-year remission saves the cost of myeloma drugs during that time, and patients might have longer remissions than with other therapies.

Q. Do we have any information from other blood cancer treatments about the length of time from research to funding approval?

A. The best comparison would be for lymphoma. I think there the math is a little more favourable because I believe the median duration of remission is longer, but I don't know what the time frame is.

Q. How often do you go in for checkups now?

A. Initially, it was twice a week, then once a month. In early fall, it went to once every two months. If things look good, it might go to once every three months sometime next year.