



# TORONTO & DISTRICT MULTIPLE MYELOMA SUPPORT GROUP NEWSLETTER

Website: [www.myelomatoronto.ca](http://www.myelomatoronto.ca)

September 2023

Newsletter # 156

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*Dr. Anup Joseph Devasia, Princess Margaret Cancer Centre*

**Hello Fellow Members and Friends,**

## Next In-Person Meeting: Saturday, October 14, 2023

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

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

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

**Meeting Time:** 2:00 – 4:00 p.m.

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

**PLEASE NOTE:** This will NOT be a hybrid meeting. As usual, a summary of the talk will be in the next newsletter and a video will be posted online for anyone who cannot attend in person.

You are welcome to wear a mask in view of rising COVID cases. Some refreshments will be available.

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.

## **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: August 12, 2023**

**Topic:** *Multiple Myeloma Basics*

**Speaker:** Dr. Anup Joseph Devasia, MBBS, MD MSc

Clinical Research Fellow, Division of Medical Oncology and Hematology, Princess Margaret Cancer Centre

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

<https://www.youtube.com/watch?v=SJKeteu6R5c&t=4864s>

## **Announcements**

### **1) Upcoming In-Person Meetings with Guest Speakers**

December 2, 2023: Dave McMullen, Co-Chair Emeritus, Toronto and District Myeloma Support Group

*CAR T-Cell Therapy: A Patient Perspective*

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

2) Share and Care Group Discussion

April 6, 2024: Dr. Guido Lancman, Clinical Associate, Myeloma Program, Princess Margaret

Cancer Centre; Adjunct Assistant Professor, Department of Medicine,  
Temerty Faculty of Medicine, University of Toronto

*News in Myeloma Treatment and Research*

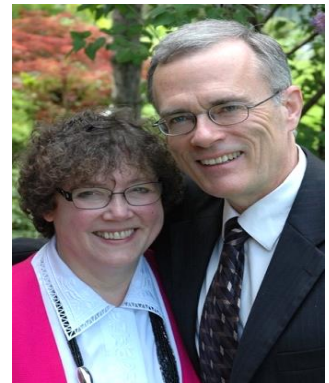
## **2) Upcoming Virtual Share and Care Meetings**

Thursday, November 2, 2023, 7:00-8:30 p.m., Virtual Zoom Meeting

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

## **3) Dave McMullen Steps Aside as Co-Chair of Our Support Group**

For nearly twelve years, members of the Toronto and District Multiple Myeloma Support Group have come to know Dave McMullen as a dynamic, knowledgeable, and personable member of the support group, and co-chair for the past ten years. In May, Dave announced to the steering committee that he would be stepping aside from his role as co-chair at the end of September. He then announced this publicly at our Share and Care Meeting on September 7. He has kindly agreed to remain on our steering committee in the role of “past chair” and will continue to share his wealth of experience and knowledge with the steering committee and other members of the support group.



Although Dave lives in Ancaster with Erika, his wife and dedicated caregiver, they are closely connected to the Toronto community and have served our community in numerous ways. A steady guide to the steering committee and the entire support group, Dave has always been there to listen and respond to members, co-ordinate and chair meetings, introduce and thank speakers, and make sure that everything runs as smoothly as possible. At the same time, in a spirit of generous collegiality and friendship, he has mentored many members of the support group, encouraged their participation, and shared responsibilities with them. Because of this, he can step aside knowing that the group is in good hands under the very capable direction of co-chair Rinat Avitzur, who is working closely with the steering committee to ensure a smooth transition.

Even as Dave is known as a person who is super organized and gets things done, he is also recognized and appreciated for his depth of understanding of myeloma and its treatments. Dave knows myeloma from having lived it. He has had many different treatments for his myeloma since his diagnosis in 2012, including three clinical trials. He has also done a lot of research on myeloma and closely follows the latest developments in the field. Each February, he does a brief talk to the support group on the latest research presented at the annual meeting of the American Society of Hematology (ASH). This year, he has also generously agreed to share his experience undergoing CAR T-cell therapy at our support group meeting in December.

You might expect that Dave would take a well-earned break now that he is resigning as co-chair, but that would not be Dave! Although he hopes to be able to spend more time with Erika, family, and friends, he will not only remain active on our steering committee and in our support group but will also continue his many other activities associated with myeloma. Dave belongs

to several other myeloma support groups in southern Ontario and is on the steering committee of two of them. He continues to participate in fund-raising activities and advocacy initiatives. He will also continue his work as a patient representative with Myeloma Canada, the Canadian Myeloma Research Group (CMRG), and the Canadian Cancer Trials Group.

We all have stories about Dave, his caring support, his positive energy, and the encouragement and hope he has provided to each of us. Thank you, Dave, for all that you have done for the support group and for all myeloma patients and caregivers!



*Steering Committee and Partners at Rinat's Appreciation Dinner for Dave and Erika. Photo Credit: Nagib Premji*

#### **4) Advocacy – Blood Cancer Awareness Month**

##### **“You Can’t Go Through this Alone” – Rinat Avitzur**



Rinat Avitzur, co-chair of the Toronto Support Group, was featured with Martine Elias, executive director of Myeloma Canada, in a special supplement of Mediaplanet dedicated to rare blood disorders. The supplement was prepared to promote awareness of lesser known and rare blood cancers for Blood Cancer Awareness Month in September. Diagnosed in 2020, Rinat underwent chemotherapy and two stem cell transplants, but was soon back on her feet walking, running, travelling, but also learning more about the disease and its treatments, and feeling the need to support other patients.

“You can't go through this alone. I am a mother of three, a wife, a daughter, and a sister. I am not usually the one getting support . . . you have to be OK with accepting physical, mental, and social support . . . I am hopeful. When I was diagnosed, I was told that myeloma is treatable but not curable. Today they say that a cure is within reach.”

Rinat also appeared recently on X, formerly Twitter, promoting Blood Cancer Awareness Month: “After a long journey, I am proud to share that I am in remission and recently ran my first 4km! Gratitude fills me for family, friends, science and life. Living with blood cancer taught me to be strong and kind to myself and others and to use my voice to help ease the journey for my community.”

The full Mediaplanet supplement can be viewed at the following link and in the latest issue of MacLean’s Magazine: <https://www.healthinsight.ca/wellness/blood-health/treatment-advancements-changing-lives-of-individuals-with-multiple-myeloma/>

## **“Trust Your Instincts and Advocate for Yourself” – Jocelyn Kervin**



Jocelyn Kervin was featured in an article in Yorkregion.com online news promoting Newmarket’s Multiple Myeloma March at Riverwalk Commons on Sept. 24. Jocelyn was also featured in a CBC Sickboy podcast in which she shared her story of resilience as she dealt with the ups and downs of her experience with myeloma.

A busy music teacher, Jocelyn was diagnosed in 2019. She had been experiencing back and shoulder pains for some time but thought it was normal aches and pains. Then one of her ribs cracked. She was still in early 40’s.

“Doctors told me that my scans ‘lit up like a Christmas tree,’ with fractures and bone damage everywhere . . . The absolute last thing I could have imagined was that I would be diagnosed with an incurable cancer, let alone a cancer I had never heard of. Although I was in utter shock, the diagnosis provided me an odd sense of relief to finally know what was wrong. I knew that I wasn’t just tired.”

Following induction therapy and two transplants, the myeloma went into remission for a time, only to come back once more. Fortunately, there are many new treatments and Jocelyn’s new regimen is working well. Jocelyn is now energetically promoting awareness about myeloma. “The biggest challenge is balancing treatments while continuing to live your life,” Jocelyn advises. “Trust your instincts and advocate for yourself. Don’t wait to go to the doctor like I did. An early diagnosis can be the difference between life and death.”

Read the full article on the Yorkregion.com website at the following link:

<https://www.yorkregion.com/news/i-was-diagnosed-with-an-incurable-cancer-i-had-never-heard-of>.

In the CBC Sickboy podcast, “The High Notes and Low Notes of Multiple Myeloma,” Jocelyn delves into the challenges of myeloma and hopes for the future in more detail. The CBC Sickboy website provides a wonderful introduction to the podcast:

Get ready for a rollercoaster ride with this week's guest, Jocelyn Kervin! She's not just rocking the high school music scene but also strikes a chord in the world of Multiple Myeloma awareness. Imagine going from running 5K races around Toronto to receiving a life-altering diagnosis at 43 of a disease you've never even heard of! We chat about everything from the rapid advancements in MM treatments to the urgent need for early diagnosis. Once considered an "older person's cancer," MM is making its appearance in younger populations, and Jocelyn is here to say it's time for a wake-up call, especially for family physicians and the general public.

The podcast is available at any of the links below:

CBC Podcasts: <https://www.cbc.ca/listen/cbc-podcasts/434-sickboy/episode/16007236-the-high-notes-and-low-notes-of-multiple-myeloma>

Spotify: <https://open.spotify.com/episode/6AuPc5GS5vBJjoQpN7Wxp?si=ms11o6h0SLhfT0-CA30Ag>

Apple Podcasts: <https://podcasts.apple.com/ca/podcast/the-high-notes-and-low-notes-of-multiple-myeloma>



## 5) Social Outing in Earl Bales Park



Photo Credits: Marius Kalisiak and Patrick Taylor

On September 26<sup>th</sup>, members of the support group enjoyed an early fall picnic in lovely Earl Bales Park, the same location we used for the picnic last year. (This is also the meeting point for the bi-weekly Earl Bales walks.) The weather was fabulous, the company great, and the conversations rich with shared experiences. Participants enjoyed mingling and chatting in the quiet, relaxed ambiance of the park.



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



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



*We currently have two Walk & Talk groups. The first meets every second week at **Earl Bales Park on Tuesdays**. This group has been enjoying walks throughout the summer and will continue into the fall.*

*A second group meets every second week at **High Park on Thursdays**. This group stopped for the summer but resumed in September and will be walking through the fall and winter.*

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



*All are welcome to Earl Bales and High Park for the walks!*

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

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

**High Park: Patrick Taylor - [pdmtylor@gmail.com](mailto:pdmtylor@gmail.com) (416 522-8538)**

**Rosa Bergman - [rbergman@rogers.com](mailto:rbergman@rogers.com) (416 662-5671)**

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

## 7) Canadian Myeloma Research Group (CMRG) Educational Webinar 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.

The CMRG has launched a new webinar series for patients and caregivers under the direction of Dr. Donna Reece, with the assistance of Suzanne Rowland, an experienced myeloma nurse practitioner, and Ledia Mataj, CMRG administrator and physiotherapist.

The first webinar in the series was held on September 14, 2023, and can be viewed on YouTube:

Seminar 1: Myeloma 101. Dr. Donna Reece and Suzanne Rowland  
<https://www.youtube.com/watch?v=cCMV80V7Dlo>

To register for the second webinar, click on the link below:

Seminar 2: Lab Results and Imaging Studies - [register](#)  
Thursday, October 12 from 5.00 PM-6.30 PM

## 8) Myeloma Canada Webinars

Myeloma Canada webinars provide important, timely information on multiple myeloma. For up-to-date information on webinars, see the following link:

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

### Upcoming Webinars

- October 4th - 6:30 pm (EST) - [register](#)  
Logging Out: Preparing Your Digital Life for End of Life (The webinar will not be recorded.)

- October 6th - 12:00 pm (EST) - [register](#)  
Navigating Through a Cancer Diagnosis and Employment
- November 22nd - 12:00 pm (EST) - [register](#)  
End of Life and Palliative Care

### **Past Webinars**

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

- Bringing Oncology Therapies to Market in Canada: What Does It Take?
- Living Solo with Myeloma - [View recording](#)
- Infections and Severe Hypogammaglobulinemia in Multiple Myeloma Patients Treated - [View recording](#)
- The IMF and Diversity - The M-Power Program - [View recording](#)
- Multiple Myeloma and Immunotherapy Made Simple – [view recording](#)
- COVID-19 Vaccination in Myeloma: What Patients & Caregivers Should Know - [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](#)
- Myeloma 101: Diagnosis & Treatment - [view recording](#)
- Drug Interactions in Myeloma and How to Avoid Them - [view recording](#)
- Following & Understanding Your Serum Free Light Chain Test Results - [view recording](#)

## **9) Myeloma Canada News**

### **Myeloma Priority Setting Partnership Article Published**

Myeloma Canada's Priority Setting Partnership (PSP) has published the full results of its project on **patient, caregiver, and clinician engagement in research**. This follows on the earlier PSP publication which identified the top ten priorities for multiple myeloma research in Canada as determined by patients, caregivers, and clinicians. The new article was published in the journal, *Research Involvement and Engagement* and can be read on the journal website at the following link: "[How Should Multiple Myeloma Research Change in a Patient-Oriented World? Findings and Lessons from the Pan-Canadian Myeloma Priority Setting Partnership.](#)"

## **10) Myeloma Canada Resources**

### **Myeloma Canada Website: [www.myelomacanada.ca](http://www.myelomacanada.ca)**

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



## Myeloma Canada Peer Support Program

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

## Myeloma Canada Newsletter Mailing List

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

### 11) COVID-19 Update – Rising Cases, New Vaccines!

*With new variants spreading quickly, COVID cases are rising and are expected to increase as we move into the fall season. **Health Canada has recently approved Moderna's Spikevax XBB COVID-19 vaccine and Pfizer-BioNTech's Comirnaty COVID-19 vaccine, both of which are designed to target new COVID variants.** Ontario expects to start receiving doses in early fall and will prioritize vaccinations for those with the highest risk of infection.*

*The vaccines are strongly recommended for those over sixty-five or with underlying health conditions, including myeloma. Like the annual flu vaccine that targets the specific variants of the flu present each year, it is likely that there will be an annual COVID vaccine. **Hematologists recommend that myeloma patients get the new COVID vaccine and the flu shot.***

***In addition, myeloma patients should get the new vaccine approved by Health Canada for RSV when it becomes available in Ontario.** Respiratory syncytial virus (RSV) is a common respiratory virus that typically causes mild, cold-like symptoms. Infants, older adults (65 years of age or older), and immunocompromised individuals are at a higher risk for developing more severe illness from RSV.*

Multiple myeloma is a cancer leading to a high risk of getting very sick from COVID and other infectious diseases. It is important for immunocompromised people, which includes most myeloma patients, to be fully vaccinated. Close family and caregivers should also be fully vaccinated. Although vaccinated persons can become infected, they are at a significantly lower risk of hospitalization and death. Myeloma patients should also monitor the COVID situation as it changes to determine if they should mask and/or avoid crowds and indoor spaces.

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

## **Booking the New COVID Vaccines**

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

## **Timing Vaccinations**

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

## **VaxFacts**

If you would like more information about vaccines or booster doses but are unable to consult your hematologist or healthcare provider in a timely manner, you can contact VaxFacts, a service offered by Scarborough Health Network, to make an appointment online to speak to a doctor by phone. See the VaxFacts 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 a COVID-19 antibody test to detect COVID-19 antibodies following vaccination. The test to take is the COVID-19 spike protein test (SARS-COV-2 Antibody Panel) which is available at Dynacare Labs at a cost of \$80. This requires a requisition signed by your oncologist or family doctor. The test indicates if you have antibodies to COVID-19, either because of previous exposure to vaccines or to COVID-19. However, it does not indicate the actual ability of your immune system to resist infection. For further information and to download the requisition form see the Dynacare website: <https://www.dynacare.ca/covid19-antibody-test.aspx>.

## **COVID Online Resources**

Canada's National Advisory Committee on Immunization (NACI): [Statements and Publications](#)  
Myeloma Canada: <https://www.myeloma.ca/en/news-events/covid-19>  
International Myeloma Foundation: [Dr. Durie's Blog, Sept 21, 2023](#)

## **12) Your Toronto Group**

### **Support Group Brochure**

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

### **Support Group Website**

Our website, [myelomatoronto.ca](http://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-102359991539387](https://www.facebook.com/Toronto-and-District-Multiple-Myeloma-Support-Group-102359991539387), 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 Dave McMullen or Rinat Avitzur 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

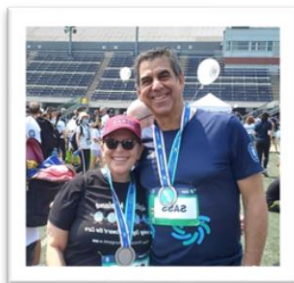
Videos from previous presentations at our support group meetings are posted on Myeloma Canada's YouTube channel, linked to the Myeloma Canada website: <http://www.myeloma.ca>, under Resources/Educational Videos/Videos. Our videos have a red gerbera daisy flower on the title page. We will no longer be 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](mailto:robert.mccaw038@sympatico.ca).

## Suggestions or Requests

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

## 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 10<sup>th</sup> 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>

For further information on the 2023 MM5KWalk or to donate, see the following link:

[Journey to Conquer Cancer 2023.](#)

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 15<sup>th</sup> Anniversary 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 honour of the 15<sup>th</sup> 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 can 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. Further information is available on the [Multiple Myeloma March website](#), linked here. See also Myeloma



*Newmarket Multiple Myeloma Marchers!*



Canada's new [Multiple Myeloma March Mini Mag](#) with full details of the various walks, including fund-sharing research partnership arrangements for this year's march.

The 15<sup>th</sup> Anniversary March sites and dates in the Toronto area are listed below. While most walks will have taken place before this newsletter is distributed, you can still donate to your favourite team and fund research using the links below!

**Virtual March** - Fall 2023 > [More details](#)

**Brampton** - October 1, 2023 > [More details](#)

**Cobourg** - September 24, 2023 > [More details](#)

**Hamilton-Niagara** - September 16, 2023 > [More details](#)

**Kingston** - September 17, 2023 > [More details](#)

**Kitchener-Waterloo** - October 1, 2023 > [More details](#)

**Mississauga** - September 23, 2023 > [More details](#)

**Newmarket** - September 24, 2023 > [More details](#)

**Oshawa** - September 30, 2023 > [More details](#)

Fabulous photos of the 2022 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](http://www.myeloma.ca).

Myeloma Canada  
1255 TransCanada Hwy., Suite 160  
Dorval, QC H9P 2V4

Email: [info@myeloma.ca](mailto: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  
Telephone: 1-866-224-6560 Email: [info@thepmcf.ca](mailto:info@thepmcf.ca)

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

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## Highlights of Presentation at Support Group Meeting – August 12, 2023



### Multiple Myeloma Basics

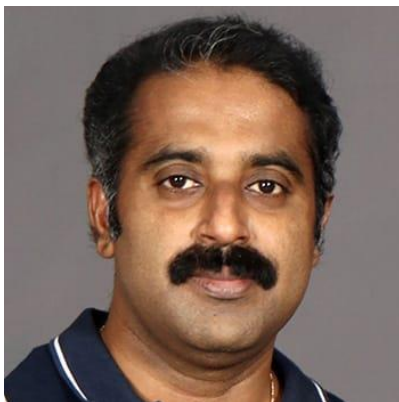
**Dr. Anup Joseph Devasia, MBBS, MD, DM**

**Clinical Research Fellow, Division of Medical Oncology and Hematology  
Princess Margaret Cancer Centre**

*Dr. Devasia's full presentation may be viewed on Myeloma Canada's website (under Educational Videos) and on YouTube at the following link:*

<https://www.youtube.com/watch?v=SJKeteu6R5c&t=4864s>

#### What is Myeloma?



I'm here to talk about the basics of myeloma. This is an overview, and I will try to make it as simple as possible. I may still have a few medical terms here and there, so if you have any difficulties, please let me know.

Hematopoiesis is a term which is used for blood stem cell formation. The stem cell can become either a myeloid or lymphoid cell. The myeloid stem cell ultimately becomes a red blood cell, platelets or myeloblast (which are neutrophils, basophils, or eosinophils). The lymphoid stem cell becomes a lymphoblast and can become a B lymphocyte, a T lymphocyte, or a natural killer cell. The B lymphocyte goes through various degrees of maturation and eventually becomes a plasma cell. The plasma cell is the culprit cell of myeloma.

In a normal person, the plasma cell is found only in the bone marrow, making up 2 to 3 per cent of the bone marrow. Its function is to focus on immunity-creating antibodies called immunoglobulins. Each immunoglobulin has two identical heavy chains and two identical light chains. Each plasma cell produces only one type of immunoglobulin or antibody, which produces

clonal cells. In myeloma, one clonal cell overtakes the others and starts multiplying one type of antibody rapidly, eventually taking over the others. This is called the M spike.

There are several types of myeloma: intact immunoglobulin multiple myeloma, light chain multiple myeloma, and nonsecretory multiple myeloma. Intact immunoglobulin myeloma has both light and heavy chains. This makes up approximately 82 per cent of all myelomas. The light chain myeloma, where the plasma cells produce only light chains, makes up approximately 15 per cent of myelomas. And nonsecretory myeloma has monoclonal protein production which is undetectable. This makes up 2 to 4 per cent of all myelomas.

What causes myeloma? This is the million-dollar question. The exact cause is unknown, but age is the most significant risk factor, occurring mostly in the 7th decade of life. It is more common in people of African descent and is least common among Asians. Some chemical/environmental factors have been seen but have not been proven to be 'the' cause. These include exposure to pesticides or radiation, or working in the leather, wood, or metal industries.

Multiple myeloma constitutes only 1 per cent of all cancers and 10 to 15 per cent of all blood cancers. It is the most common primary cancer affecting the bone. The incidence is 4 to 5 per 100,000 people. Around 1/3 of patients are 75 or older. 10 per cent of patients are under the age of 50 and only 2 per cent are under the age of 40. It is seen in men more often than women.

There are several precursor lesions which occur prior to myeloma developing. The first is monoclonal gammopathy of undetermined significance or MGUS. This progresses to a smouldering myeloma. As the tumour burden increases, it becomes multiple myeloma. In the MGUS stage, the monoclonal gammopathies or M protein is less than 30 grams per litre, plasma cells are less than 10 per cent and there is no organ damage. It is important to note that MGUS is prevalent in the general population and increases with age. Typically, in people under 50, MGUS levels will be 3 to 4 per cent, increasing to 8 per cent by age 85.

It is also important to note that all myelomas have a precursor stage, but 90 per cent of patients will not know they are in that stage as the tests for myeloma are not commonly done. Of the patients diagnosed with MGUS each year, 1 per cent will develop multiple myeloma. In smouldering myeloma, 10 per cent of patients will progress to multiple myeloma in the first five years. However, in the next five years, that number drops to 5 per cent, and drops to 1 per cent in the following five years. This means that if you are diagnosed with smouldering myeloma, the chance of progressing to multiple myeloma is greatest in the first five years.

There are many different theories about predicting when smouldering myeloma will develop into multiple myeloma. The best one is the 20-20-20 rule for risk factors, where the bone marrow plasma cells are more than 20 per cent, the M protein is more than 20 grams per litre, or the light chain ratio more than 20. If you don't have any of these risk factors, you have a low risk of progression to multiple myeloma of 6 per cent in the next two years. If you have one risk factor, you have an intermediate risk, which raises your risk of progression to 18 per cent in the next two years. And if you have two or three risk factors, your risk of progression is high and raises the possibility of progression to 44 per cent in the next two years.

The history of cancer dates to 1600 BC in Egypt. By 3 or 4 BC, blood cancers were being described in Greece. The first recorded case of myeloma was in 1844. Sarah Newbury, 39, was diagnosed with fatigue, bone pain, and multiple fractures. In 1845, Thomas McBean, 45, reported he felt like something had snapped or given way in his chest. In 1873, the term

multiple myeloma was first used. In 1880, the term Bence Jones Proteins was first used. In 1939, the M spike (then called a "church spire") was first demonstrated on electrophoresis. In 1958, melphalan was first used in the treatment of multiple myeloma and continues to be used today.

## Symptoms and Diagnosis of Myeloma

Let's talk about the symptoms of myeloma. Myeloma is caused by a proliferation of plasma cells in the bone marrow, decreasing the normal collection of red blood cells. This causes anemia and infections. If the blood becomes viscous, you can develop kidney failure and neuropathy.

Generally, bone formation occurs from birth until you reach maturity. As we age, our bones naturally decrease in density. In myeloma, the bones start to deteriorate and break, without the normal formation of replacement bone. On an x-ray, you can see the punched-out lesions of myeloma patients. As the bones weaken, you may suffer pathological bone fractures from simple bumps. You may have compression of the spinal cord or collapse of the vertebrae. The plasma cells may collect outside of the bone marrow, which is called a plasmacytoma. As the bones continue to erode, the calcium is leached from the bones causing hypercalcemia.

The clinical presentations of myeloma vary. Bone destruction can cause pain, fractures, spinal cord compression, and nerve compression. When the bones deteriorate, calcium enters the blood causing hypercalcemia, which can cause increased thirst and urination. If the calcium is very high, you can have nausea, vomiting, brain fog, difficulty sleeping, and constipation. Renal failure can cause nausea, vomiting, malaise, and weakness. Bone marrow infiltration can cause anemia and bleeding tendencies. Reduced globulins can cause recurrent infections and pneumonia. And hyperviscosity (when proteins are high in the blood) can cause shortness of breath, stroke, renal haemorrhage, bleeding, and blood clots.

The most common clinical features of myeloma are referred to by the acronym **CRAB**. This stands for increased **C**alcium (28 per cent), **R**enal failure (48 per cent), **A**nemia (73 per cent), and **B**one pain (58 per cent). Fatigue and weakness are found in 32 per cent of patients. Weight loss is seen in about 24 per cent of patients.

When do you suspect myeloma? When there is:

- bone pain with lytic lesions
- bone breaks with simple trauma
- an abnormal protein concentration
- unexplained anemia
- high calcium
- anemia with renal failure

How do you diagnose myeloma? There should be two changes: clonal plasma cells in either the bone marrow or elsewhere, and effects caused by plasma cells. The current criteria for myeloma diagnosis are clonal bone marrow plasma cells greater than 10 per cent or plasma cells found in any other area confirmed by a biopsy (plasmacytoma) and one or more **SLiM CRAB** symptoms.

- **S**ixty per cent or more clonal plasma cells
- free **L**ight chain ratio greater or equal to 100
- **M**RI with more than one focal osteolytic bony lesion
- **C**alcium greater than 0.25 mmol/L above the ULN (upper limit normal) or greater than 2.75 mmol/L



- Renal: CrCl less than 40 ml/min or creatinine greater than 177 mmol/L
- **A**nemia: hemoglobin less than 20 g/L below the LLN (lower limit normal) or less than 100g/L
- **B**one: greater than or equal to 1 osteolytic lesion on X-ray, CT, PET/CT

The investigations which are done include a blood count, renal and liver functions, electrolyte and LDH levels, calcium level, uric acid level, serum and urine proteins, Bence Jones protein in the urine, light chain counts, immunofixation electrophoresis (which determines the type of myeloma), bone marrow, cytogenetic and FISH studies, immunoglobulin levels, skeletal surveys, beta-2 microglobulin and tissue biopsy.

What is the best type of imaging for myeloma diagnosis? X-rays require a 50 to 75 per cent bone loss. A whole-body low dose CT scan offers superior quality and detects bone lesions in 25 to 50 per cent of patients who have a negative skeletal survey. The benefit of a PET/CT scan is that it will also tell you how active the lesion is. If you are looking for the infiltration of the bone marrow, an MRI is best.

Risk stratification assesses how the disease is expected to progress based on certain criteria: the genetics of the disease (done by a FISH test on the bone marrow, a genetic panel, or DNA sequencing), the tumour burden, extramedullary diseases (when bone marrow exists outside of the bone), circulating myeloma cells in the blood (plasma cell leukemia), and rare organ involvement.

## **Treatment of Myeloma**

What is the natural progression of myeloma? How does it behave? Myeloma starts out with smouldering myeloma and is asymptomatic. It then progresses to active myeloma, which will be symptomatic. This is when patients will receive the first line of treatment. There will be a response and a plateau but invariably, the disease will relapse, and patients will receive their second line of treatment. This cycle of plateau and relapse can recur again and again. At present, there is no cure for myeloma, but it can be controlled. The main aim in treating myeloma is to increase the plateau/disease free phase for as long as possible.

Fortunately, there are good medications to assist in this, with more and more being developed. There are antibodies, such as daratumumab (Darzalex), isatuximab (Sarclisa); alkylating agents, such as melphalan and cyclophosphamide; proteasome inhibitors, such as bortezomib (Velcade) and carfilzomib (Kyprolis); steroids, such as prednisone and dexamethasone; immunomodulators, such as lenalidomide (Revlimid) and pomalidomide (Pomalyst); and novel agents such as venetoclax and selinexor, as well as newer agents such as CAR T-cells and bispecific antibodies (BiTEs). In myeloma, treatment is always given in combination with two or more drugs.

When do you start treatment of myeloma? When patients are diagnosed with MGUS, they do not receive any active treatment but are followed closely every six months. Once they move into smouldering myeloma, they are followed every three months, but still receive no treatment. Once a patient develops multiple myeloma, the first line of treatment is begun.

How is myeloma treated in newly diagnosed patients? The first step is to determine if they are transplant eligible or not. It used to be that 65 was the cut off age for a transplant. Now, the criterion has shifted to the overall health of the patient. For example, a healthy 72-year-old with no other health issues is more likely to receive a transplant than a 65-year-old with cardiac issues.

If a patient is eligible for a transplant, they receive induction therapy consisting of RVD (Revlimid, Velcade and dexamethasone) or CyBorD (cyclophosphamide, bortezomib and dexamethasone). This is followed by melphalan and a stem cell transplant after two days. Once the blood count has returned to normal, maintenance therapy begins with lenalidomide or ixazomib (Ninlaro) which is continued until the myeloma relapses. If a patient has high risk myeloma, tandem transplants are done three months apart, followed by dual maintenance of lenalidomide and ixazomib.

If a patient is not eligible for transplant, they receive continuous therapy. This could be daratumumab combined with Revlimid and dexamethasone, RVD-lite (for frail patients), Revlimid combined with dexamethasone (also for frail patients), or ixazomib combined with Revlimid and dexamethasone. The benefit of the latter combination is that it is all oral medication.

Your doctor will rate your response based on how your M protein reacts. The lower the level, the better the response to treatment. The deeper the response, the longer the symptom free plateau will be. But what happens when you relapse? Relapse occurs when the myeloma becomes resistant to your drug protocol. In this case, a new set of drugs are used. This is based on the prior drugs used, the age and fragility of the patient, if they have any other health conditions, drug toxicity, patient preference, logistics of drug administration, and clinical trials.

Along with the treatment for myeloma, the patient's pain should be addressed. Analgesics and radiation can be beneficial for bone pain. Surgical stabilization and augmentation procedures are beneficial for fractures. And bisphosphonates, vitamins C, D, and calcium supplements are essential when on myeloma treatment.

Vertebral fractures affect a patient's quality of life. They can cause pain, bent posture, loss of height, increased risk of subsequent fractures, reduced quality of life, and emotional disturbances. There are two treatments to address these fractures, percutaneous vertebroplasty and balloon kyphoplasty. Both procedures involve injection of bone cement into the breaks.

Infections are common in myeloma patients. These are caused by T-cell dysfunction, low immunoglobulins, low neutrophils, poor mobility, increased age, fragility, and renal failure. The best treatment is to be proactive with prophylactic antibiotics, anti-herpes medication, Septra/atovaquone (to prevent PJP – a form of pneumonia), and IV or subcutaneous immunoglobulins to increase immunity.

What is new in myeloma? Previous treatments focussed on chemotherapy. CAR T-cells and bispecific antibodies are two newer treatments which focus on immunotherapy and target specific receptors on plasma cells. They will make a huge difference in the treatment of myeloma. Myeloma is now considered a chronic disease for some patients, thanks to new treatments.

## **Questions and Answers**

*Q. With modern treatments, do you find the toxicity is reduced?*

A. Yes. As science progresses, the toxicities can be controlled more effectively.

*Q. There's been some discussion about reducing the dosage of dexamethasone in maintenance programs including daratumumab-based regimes. What are your thoughts?*

A. As long as you continue daratumumab once a month, it should not be a problem to reduce the dose of steroids. It is a trade-off between how well the disease is controlled and your side effects.

*Q. How do you know if someone is cured?*

A. There is no answer for that. As of now, myeloma is considered incurable.

*Q. Generally, how are treatments in Canada for myeloma compared to other countries?*

A. Canada has an excellent publicly funded health care system. In India, where you have to pay, one dose of daratumumab is equivalent to \$4,500 Canadian. People cannot afford it. In Canada, you have access to drugs, but the difficulty is approvals for funding new treatments. In Europe, approvals are much quicker.

*Q. For someone who has received all the COVID vaccines, should they get another booster now or wait until fall?*

A. If you are on daratumumab, you should get a booster every six months as that drug decreases your immunity. High risk patients should receive a booster once every six months.

*Q. We know that Black men in the U.S. have a weaker response rate or survival rate with myeloma. We know that there is race and gender bias in the U.S. medical system. Is there any similar race/gender-based information in Canada?*

A. I'm not sure if there is, but I can raise this with the CMRG. They do have a data base so there should be some data.

*Q. For a person with low platelets on lenalidomide, are there any guidelines or standards on whether to reduce the dose or duration?*

A. This is mostly based on the experience of the doctor and how low is safe for low platelets. It really varies patient to patient.

*Q. What level of vitamin D should we have?*

A. Calcium and vitamin D are necessary because they support bone health. You should have a vitamin D test to determine the base line. Once that is determined, you should repeat it every six months to ensure it is consistent.

*Q. With regard to the upcoming flu season and RSV, what recommendations do you have?*

A. That's a tough question for me. I'm not an immunity specialist. All viruses are bad. When you go out to crowded places, wear a mask. In your own house, it's up to you.