TORONTO & DISTRICT MULTIPLE MYELOMA SUPPORT GROUP NEWSLETTER

Website: www.myelomatoronto.ca

November 2022
Newsletter # 151

In This Issue

Hello Fellow Members and Friends,

Next Meeting: Saturday, December 3, 2022

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

Speakers: Ellen Church, RN, Myeloma Clinic, Princess Margaret Cancer Centre, and Dior Caruso, RN, NP, Malignant Hematology Day Unit, Princess Margaret Cancer Centre

Topic: *Living with Myeloma Q & A*

Ellen Church and Dior Caruso have worked with myeloma patients over many years and are very familiar with the types of issues that patients face. (Ellen was presented with the Myeloma Canada Marion State Nursing Award in 2018 in recognition of her many years of dedicated care for myeloma patients.)

In view of ongoing COVID concerns our normal seasonal celebration will not include refreshments.

Meeting Time: 2:00 – 4:00 p.m.

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

PLEASE NOTE: Following our successful hybrid meeting in October, with both in-person and Zoom participation, **we will be continuing the hybrid format for this meeting.** The login link to Zoom will be distributed by email prior to the meeting.

Since many in-person attendees may have weakened immune systems, we ask that participants wear masks and observe social distancing while indoors. You may want to consider bringing your own water bottle, but please do not bring food. Water will be available.

The meeting starts at 2:00 p.m. but you are welcome to arrive any time after 1:30 p.m. If using Zoom, you may login after 1:50 p.m. to receive instructions on using Zoom and to meet other friendly faces. We suggest logging in early if you are not familiar with Zoom.

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

Contacts:

Dave McMullen, 905-648-5146, davidanderika.mcmullen@sympatico.ca
Munira Premji, 416-302-9459, mnpremji@rogers.com
Jan Wleugel, 647-627-4430, janwleugel@gmail.com
Bob McCaw, 905-836-2664, robert.mccaw038@sympatico.ca
Patrick Taylor, 416-522-8538, pdmtaylor@gmail.com
Rinat Avitzur, 647-554-7363, rinatavitzur@hotmail.com
Jocelyn Kervin, 416-873-4610, jkervs@gmail.com

Last Meeting: October 1, 2022

Topic: *Dentistry Concerns for Myeloma Patients*

Speaker: Dr. Erin Watson, DMD, MHSc, Deputy Chief of Dentistry, Princess Margaret Cancer Centre

A detailed summary of Dr. Watson's excellent presentation is appended at the end of this newsletter. A recording of the presentation is available on Myeloma Canada website under Educational Videos, linked here: https://www.youtube.com/watch?v=3REIDM5tswM.

Announcements

1) Upcoming In-Person Meetings with Guest Speakers

February 5, 2022:	1) Brief highlights of 2022 ASH Conference 2) Share and Care Group Discussion
April 1, 2023:	Speaker from the Myeloma and Related Diseases Program, Princess Margaret Cancer Centre *Myeloma Research and Treatment Update*

June 3, 2023: James Bond, a 30-year myeloma survivor, and Kathleen Bond, his caregiver
An Amazing and Uplifting Myeloma Journey

2) Upcoming Virtual Share and Care Meetings

Thursday, January 12, 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) Walk & Talk: Let's Get Moving TOGETHER – MM Walking Groups

In October Oren Cheifetz spoke to the support group about the importance of exercise, specifically for cancer patients. It was a powerful reminder of the health benefits that daily physical movement and exercise progression have for us all. As many of us are walkers (walking even more during the pandemic), we have been planning opportunities to get group members together to Walk & Talk. This 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.

The first Walk & Talk group met at Earl Bales Park to enjoy the lovely leaves and walk the trails. Participants at our November Share and Care meeting expressed a strong interest in continuing these walks and including High Park in addition to Earl Bales. Depending on interest, we could make these walks regular events, monthly, bi-weekly, or even weekly, on a day and time that works best for the group.

To gauge interest in future walks, please contact one of the following people and indicate your preferred day and time, and whether you would like to walk through the winter:

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

High Park: Patrick Taylor - pdmtaylor@gmail.com (416 522-8538)

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

4) Farewell, Dr. Tiedemann!

On October 29, the Toronto Support Group Steering Committee hosted a farewell event for Dr. Rodger Tiedemann, who is leaving PMCC in November 2022. Dr. Donna Reece graciously participated to honour and celebrate her friend and colleague, Dr. Tiedemann.

Dr. Tiedemann joined PMCC as a scientist and a hematologist specializing in multiple myeloma and lymphoma. Prior to joining PMCC, Dr. Tiedemann was a hematologist at Mayo Clinic. After 12 years at PMCC, Dr. Tiedemann, his wife Tania and their son Noah will be moving back to New Zealand to be closer to family. In New Zealand, Dr. Tiedemann will continue to work as a scientist and hematologist focusing on multiple myeloma.

Dr. Tiedemann has won many awards over the years for his research. One of his most significant findings was in 2013, where Dr. Tiedemann and his team discovered why patients with myeloma relapse after appearing to be in complete remission. This is a significant finding that will hopefully pave the way to a cure for this incurable cancer.

https://www.thestar.com/life/health_wellness/news_research/2013/09/10/resistant_cells_to_blame_for_multiple_myeloma_relapse.html

We thank Dr. Tiedemann for the care with which he attended his patients and for his incredible contribution and leadership in the field of myeloma. We wish him and his family tremendous success and fulfillment as they start another chapter in their lives in New Zealand.

(A little-known fact about Dr. Tiedemann: he was a prize winner in the Australian Mathematics Competition in 1988 and a representative to the 29th International Mathematics Olympiad!)

5) Dave McMullen Receives June Callwood Outstanding Volunteer Award

On September 22, the Ministry of Citizenship and Multiculturalism, Government of Ontario, announced that our co-chair, Dave McMullen, was a recipient of the June Callwood Outstanding Volunteer Award.

The Ministry's news bulletin summarized Dave's amazing contribution in the following terms:

> David McMullen is a driven and dedicated volunteer who seeks out every opportunity to support others, with tremendous help from his wife Erika.
>
> After both of his parents passed away from cancer, David started volunteering with cancer organizations. In 2012, David was diagnosed with Stage 3 myeloma, an incurable blood cancer, but his diagnosis did not stop him.
>
> A gifted communicator with extensive knowledge and experience with myeloma, David, through Myeloma Canada, has helped establish various new support resources and initiatives that have significantly improved the quality of life for many patients. He has also been a valuable resource to many volunteer groups, committees, and cancer-based research organizations, including the Canadian Cancer Trials Group, the Canadian Myeloma Research Group, and the Canadian Agency for Drugs and Technology in Health.
>
> Since 2013, David has been Co-chair of the Toronto & District Multiple Myeloma Support Group where he provides support and information to other patients as they navigate the health care system.

Congratulations, Dave! What a wonderful achievement!

For more information on the award see the formal announcement:
https://news.ontario.ca/en/backgrounder/1002332/june-callwood-outstanding-achievement-awards.

6) Premji Family Expresses Gratitude to Canadian Blood Donors

Many myeloma patients, especially those undergoing stem cell transplants, require one or more blood transfusions during treatment. This is also the case for patients who undergo invasive surgical procedures such as heart transplants or hip replacements. Many of these patients are themselves unable to donate blood because of their medications or overall medical condition. For this reason, we are extremely grateful to those anonymous donors who have quietly and unknowingly saved our lives.

Such is the case with Munira Premji, a long-term member of our steering committee, who was recently featured with her family in a Canadian Blood Services video and full-page newspaper ad in the Toronto Star, November 12, 2022. While preparing for chemo, Munira was informed that her organs were on the verge of shutting down. An emergency transfusion made possible by blood donors saved her life. "I feel those people with me. I know they are part of me," says Munira, "They gave me hope for one more day." You can read Munira's deep expression of gratitude on the Star's website and view her family's very moving video on the Canadian Blood Services YouTube site: https://www.youtube.com/watch?v=qtVcBNecA3c.

7) Support Group Leaders Summit

Myeloma Canada hosted a summit for support group leaders from across Canada in Halifax, Nova Scotia, from November 10-12. In addition to Myeloma Canada updates and presentations on Myeloma Canada's Patient Advisory Council (PAC), there were excellent research updates by two leading hematologists, Dr. Alfredo De La Tore, QE II Health Sciences Center, Halifax, and a participant in Myeloma Canada's Scientific Roundtable in 2022, and Dr. Joe Mikhael, Chief Medical Officer, International Myeloma Foundation.

A specific focus of the summit this year was health equity, or rather, inequities in access to health based on race, ethnicity, age, geography or other factors, a topic on which speakers such as Dr. Mikhael and Mei-Lin Yee, a patients' rights advocate and health policy advisor, contributed very eloquently. Anthony Mohamed, a senior equity and community engagement specialist with St. Mike's Hospital in Toronto and member of our support group, led an excellent workshop on equity in healthcare—helping us all to understand how forms of discrimination, such as racism, sexism, ableism, homophobia, ageism, and class bias work at a systemic level, where we fit into those systems, and what we can do about it.

Another conference highlight was "Knowing My Why," a presentation by Thomas Goode, who was diagnosed in 2005. A myeloma patient ambassador, support group leader, and member of the International Myeloma Foundation's African American Initiative Advisory Council, Thomas shared his motivating story of diagnoses and treatments; setbacks and successes; acceptance and commitment; faith, family, and friendship. (For more on Thomas' journey with myeloma, listen to his podcast posted on the International Myeloma Foundation website earlier this year: https://www.myeloma.org/audio/day-life-podcast-thomas-goode.)

Halifax oncologist, Dr. Rob Rutledge, focused on living "an anti-inflammatory lifestyle," one in which bodily health (exercise, diet, sleep etc.) and mental health (values, intention, spirituality, gratitude etc.) sustain each other to build a strong immune system. Emphasizing the value of mindfulness mediation, Dr. Rutledge led the group through some simple, relaxing exercises. Dr. Rutledge is co-author, with Timothy Walker, of *The Healing Circle*, a book based on their ongoing work empowering patients who are dealing with cancer.

8) BioCanRx Public Forum on Immunotherapy

Dave McMullen co-chaired a BioCanRx forum on immunotherapy on November 15 with Dr. Stéphanie Michaud, President & Chief Executive Officer of BioCanRx. Panelists included Stefany Dupont, a teacher who had leukemia as a child, Dr. John Bell, Scientific Director of BioCanRx, and Dr. Rebecca Auer, a surgical oncologist and leading immunotherapy researcher at the Ottawa Hospital. BioCanRx is a pan-Canadian research network whose goal is to bring the benefits of immunotherapy research to patients through the development of Canada's immunotherapy research infrastructure, manufacturing capacity, and clinical trials. BioCanRx is funded by the Federal Government's Centres of Excellence Program and industry partners. In their presentations, Dr. Bell and Dr. Auer pointed to the ways in which immunotherapy treatment can target specific cancer cells instead of destroying all cells in the way that chemotherapy does, discussed how new therapies can treat and possibly cure now incurable cancers, and explained why Canada needs to build its capacity and promote clinical trials in this area. As a patient, Stefany had to go to the United States for CAR-T treatment at great cost and personal disruption to her life and that of her family. Yet, the treatment saved her life. How much better it would have been for everyone if she could have been treated in Canada! As audience questions and panel responses indicated, new developments in immunotherapy such as CAR-T's can lead to more sustained remissions and even cures, and cancer patients, including myeloma patients, have much to look forward to. The Forum can be viewed on the BioCanRx website at the following link: https://www.youtube.com/watch?v=oWpFh_oQRbI.

9) Family Medicine Forum (FMF)

On November 9-11 Bob McCaw and Rinat Avitzur along with other patients and Helen Mahshie from Myeloma Canada attended the 2022 Family Medicine Forum (FMF) in Toronto. FMF is the largest annual meeting of the College of Family Physicians of Canada. Up to 5000 family physicians, residents, and other health care professionals attended from across Canada, along with several hundred exhibitors. Myeloma Canada was invited to participate in a shared booth with Sebia, the company that produces the equipment and products used in serum protein electrophoresis (the M-spike test). The conference was a great success in increasing awareness of myeloma among family physicians, residents, and other health care professionals across Canada, and awareness of signs and symptoms that will help them detect myeloma. This is tremendously important to enable early diagnosis.

10) Myeloma Canada

Myeloma Canada Website: www.myelomacanada.ca

Myeloma Canada has excellent information on multiple myeloma on its website, including virtual support groups, educational videos, 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. Information guides can be downloaded from the Myeloma Canada website, under the resources tab, including the newest guide, "Mental Well-Being and Relapse: A Resource Guide for People Living with Myeloma," which complements a short but very useful video on the same topic, linked here: "Multiple Myeloma Relapse and Mental Wellbeing."

Myeloma Canada Peer Support Program

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

InfoWebinars

Upcoming Webinars (in partnership with Connected Canadians)

- COVID-19 Vaccination in Myeloma: What Patients & Caregivers Should Know
  Monday November 21, 2022, 12:00 EDT Register here!
- Phishing Scams (In French with English translation)
  Thursday, November 24, 2022, 11:00 am EST Register here!
- Recognizing Fake News (In English with French translation)
  Wednesday, December 14, 2022, 11:00 am EST Register Now!

Myeloma Canada webinars provide important, timely information on multiple myeloma.

For updated information, see the following link:
https://www.myelomacanada.ca/en/news-events/infosessions-and-meetings/webinars

Past Webinars

Past webinars are posted on the Myeloma Canada Channel on YouTube. Some of these are listed here:

- Have you Met Your Pharmacist yet? - view recording
- News in Multiple Myeloma Research - 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
- Oncology Drug Access Navigators - 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
- Get to know your Myeloma Canada Patient Advisory Council (PAC) - view recording.

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, at: http://www.myeloma.ca/.

11) Pandemic Updates

The New COVID Environment

Myeloma patients need to be continually vigilant in assessing their risk tolerance as COVID-19 conditions change and the winter weather brings people indoors. Multiple myeloma is a cancer leading to a high risk of getting very sick from COVID-19. Epidemiologists and doctors recommend that immunocompromised persons, including most myeloma patients, continue to mask indoors, socially distance where possible, avoid crowded locations, and isolate if exposed to the virus. In addition, it is important for immunocompromised people and their families and caregivers to be fully vaccinated. Although vaccinated persons can become infected, there is a lot of evidence showing that those who are vaccinated are at a significantly lower risk of hospitalization and death.

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.

COVID Antibody Tests

COVID-19 vaccines are generally not as effective for myeloma patients as they are for the wider population, and, in addition, vaccines may be less effective over time. Myeloma patients may wish, therefore, 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.

Evusheld Prophylactic Treatment to Prevent COVID

Evusheld has been approved by Heath Canada for immune compromised people who may not get enough protection from COVID-19 vaccines. This includes recent transplant recipients and persons on active treatment for hematological cancers. Treatment consists of two injections of a combination of monoclonal antibodies that enable the immune system to fight infection. Evusheld is administered by select healthcare facilities, such as transplant and cancer centres, according to priority need. Princess Margaret Cancer Centre is one of these facilities. Many members of the support group have already received the treatment. Speak to your oncologist for further information.

Booking Your Bivalent Vaccine Booster Dose

Approved by Health Canada, bivalent vaccine booster doses target both the original COVID-19 virus and the most recently circulating COVID-19 variants, including Omicron. Normally, the vaccines are administered at least six months after the last dose. (In special cases the interval can be three months if booked through the Provincial Vaccine Contact Centre at 1-833-943-3900.)

Vaccinations can be booked online at Government of Ontario COVID-19 booking portal, linked here: 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. Patients at Princess Margaret Hospital may book appointments through the Princess Margaret Pharmacy.

Timing Vaccinations

Myeloma patients should contact their hematologist or oncologist for advice on the timing of each vaccination in relation to their current treatment regimen.

- The hematologist or oncologist may make changes to the timing of specific treatment regimens around the time of each vaccination.
- Patients receiving Evusheld should consult their hematologist or oncologist regarding the timing of the booster dose.
- Vaccinations are usually delayed temporarily for persons recovering from stem cell transplants.
- Patients recovering from a stem cell transplant or CAR T-cell therapy should be revaccinated with a new COVID-19 primary series, even if previously vaccinated, because stem cell transplants wipe out the immunity provided by earlier vaccinations. Revaccination has been approved by Public Health Ontario.

VaxFacts

If you would like more information about the booster dose or other vaccines but are unable to consult with your hematologist or healthcare provider in a timely manner, you may want to consider contacting VaxFacts, a service offered by Scarborough Health Network. You can book an appointment to speak with a doctor about vaccines through the VaxFax website, linked here: https://www.shn.ca/vaxfacts/.

COVID Online Resources

Canada’s National Advisory Committee on Immunization: Immunization (NACI)
Myeloma Canada: https://www.myeloma.ca/en/news-events/covid-19
International Myeloma Foundation: https://www.myeloma.org/covid19-myeloma-patients

12) Your Toronto Group

Support Group Brochure

The support group has a new, updated brochure, thanks largely to the work of Jan Wleugel. These 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.

Support Group Website

Our website, myelomatoronto.ca, includes a "Useful Links" page, which provides links to organizations that offer assistance and 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, provides information about the support group for Facebook users or others who may not have found our regular website. The Facebook page is passive at this time 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 and equipment and Zoom meetings, greet new members, organize the kitchen and refreshments, and participate on the Steering Committee. Your assistance in all these areas is greatly appreciated by all support group members. At this time the Steering Committee is particularly eager to strengthen the kitchen roster (pending return to serving refreshments at meetings) and to find someone to assume some secretarial duties associated with the work of the Committee. 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 DVD's to keep, and would like to make a modest donation, please speak to Bob McCaw at the next support group meeting at the resource table or contact Bob by email at robert.mccaw038@sympatico.ca.

Suggestions or Requests

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

Annual Events

MM5KWalk in Support of Bloom Chair, Princess Margaret Cancer Centre

Part of The Journey to Conquer Cancer, this walk takes place annually near the Princess Margaret Cancer Centre. Funds raised support the excellent work of the Molly and David Bloom Chair in Multiple Myeloma Research, led by Dr. Donna Reece, and have resulted in greatly improved treatment outcomes for myeloma patients. In September 2022, many members of our support group, joined by family, friends, co-workers, caregivers, doctors, and nurses, marched through downtown Toronto to raise funds to improve the lives of multiple myeloma patients. Information on plans for the 2023 walk will be forthcoming.

Myeloma Canada Multiple Myeloma Marches

Myeloma Canada Marches are held 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. Walks take place in locations around the Greater Toronto Area and attract a lot of support and participation from 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. Further information on plans for 2023 will be forthcoming.

Fabulous photos of the 2022 March from across Canada can be viewed at the following link: https://www.flickr.com/photos/135746311@N08/albums.

My Myeloma

--Tanya Zigomanis

In early 2019, I was working as a fast-paced litigation lawyer at a downtown Toronto law firm where I had been employed for over 11 years. I was married to my high school sweetheart and had a daughter in grade 1 and a younger daughter in preschool. I always considered myself healthy and resilient. Life was busy and at times stressful.

In February, I travelled to Ottawa by airplane for work and I lifted my heavy luggage into the overhead bin. Days later I had terrible pain in my ribs that was constant. I also had drenching night sweats that I dismissed as hormonal. I began to work from home more often and I had trouble starting my workday after school drop off because I was exhausted.

By March, I was distracted by a nagging feeling that something was not right. I went to my GP’s office and asked for bloodwork and a chest x-ray. The chest x-ray was normal, but my bloodwork was not; I was anemic.

We had booked a Disney cruise after March Break. In late March 2019, I picked up a new requisition from my GP for more extensive bloodwork, with the guidance of my best friend who is a gastroenterologist. That night we flew to Florida, and I left the bloodwork for when we returned.

I was unwell during most of the trip. I had nausea, vertigo, and fatigue. I needed to rest and lie down a lot. I picked up every anti-nausea medicine I could find and went on the Disney cruise with Gatorade attached to me at all times. It was a magnificent cruise with amazing food and drinks; however, I could barely eat or drink. I was just grateful that my kids were enjoying themselves despite my symptoms.

By the time we returned from the trip, the vertigo had worsened. I would work most mornings for a couple of hours and then return to my bed to rest. I even went back to my GP’s office and was prescribed an anti-vertigo drug. I had lost 15 pounds in 2-3 weeks.

By mid-April, I realized I should do the rest of my bloodwork. When my hemoglobin came back even lower than before, I began to research online and was concerned that I was dealing with an autoimmune disease or, at the very worst, cancer. Only one hour after my results were released, my doctor's nurse called to tell me that I had been urgently referred to a local hematologist/oncologist.

Before I had even met with the hematologist, I realized that the bloodwork pointed to either MGUS, smoldering myeloma, or multiple myeloma. I had never heard of this type of cancer before. I prayed it was MGUS or even better, an autoimmune disease.

I went on to have a bone marrow biopsy at my local hospital. My doctor called me days later to tell me it was full blown myeloma. This was the night before my 4-year-old was to be a flower girl in my cousin's wedding and the same day as my 7-year-old's birthday. It was also Mother's Day weekend. It remains a hard weekend for me.

While my diagnosis came as a shock, it also brought an odd sense of relief to finally confirm what was wrong and to hear that the doctors had a plan. I immediately put my mind to fighting for my life, with my family in my thoughts at all times, and vowed to be as positive as I could through this journey.

I began CyBorD chemotherapy (cyclophosphamide, bortezomib, and dexamethasone) at my local hospital and quickly moved on to Southlake's Stronach Cancer Centre in Newmarket after researching that they had a few doctors that were experienced with myeloma. While the treatment wasn't too intense, family and friends insisted that they accompany me to appointments and chemo. I had an outpouring of support from so many people who sent me care packages and gift cards. My friends and co-workers set up something called a care community calendar where friends and family would send us groceries once per week, take-out meals once per week, and help with outdoor maintenance. It was as if I had a giant hug wrapped around me.

In June 2019, when I began to regain a bit of energy, we signed up for the Princess Margaret Hospital cancer walk. Within 10 days we had raised over $10,000 for myeloma research and on the day of the walk, 25 of my family members and friends walked with me. The entire experience was exhilarating and inspired me to stay strong through treatment.

In September 2019, I began the stem cell transplant process. I had my stem cell collection on September 11 and managed to collect enough in one day, which was a relief. I had a surgical procedure to insert a Hickman line in my chest at Toronto General Hospital on September 20. This was likely the worst part of the entire process.

On September 21, my husband, Adam, and I moved into a monthly rental unit near Princess Margaret Hospital so I could start the stem cell transplant as an outpatient. We also wanted to isolate away from my kids as they continued to attend school and we knew they would bring home colds and flu which we wanted to avoid. It was also easier for their lives to be uninterrupted. Family members took turns helping with our kids, and my parents took them away on vacation for two weeks. This was a perfect distraction for them during the 10 days I was at my worst.

On September 22, over 30 of our family members and friends marched in Newmarket for the Myeloma Canada March. I had planned to attend, but my medical team advised me that it would be wise to avoid crowds as I was scheduled to receive high dose chemo on September 23. This time my team raised over $15,000 and I was awarded a top fundraiser plaque by Myeloma Canada. My aunt delivered it that week and it served as part of a shrine of hope for each day of my transplant.

On September 25, I received my stem cells, and I managed the transplant process with the help of family and friends who dropped off food and care packages. My husband was a meticulous caregiver, charting every supportive medication so that I was not too ill. The outpatient team at Princess Margaret was so amazing that I cried when they discharged me from daily visits and again when they discharged me completely.

In early 2020, I began to realize that my mental health needed healing. I had spent most of 2019 in fight mode and I finally began to process the gravity of what had happened. I began mental health therapy, started doing yoga, and found the joy of nature walks. My therapist encouraged me to create a bucket list of things to look forward to. Unfortunately, COVID-19 derailed plans temporarily.

The transplant was successful in terms of bringing my kappa light chains down to a reasonable number. However, it did not put me into full remission. I started on Revlimid maintenance in January 2020, and I continue to be on this drug with stable numbers that are very slowly rising. With the help of my favourite doctor, Dr. Reece, I've learned to appreciate that even slow rising numbers are a good thing in this marathon.

I have continued to be passionate about fundraising for myeloma research and advocacy. While I have little control over this disease, I feel at the very least I can bring myeloma awareness to the forefront and fundraise every dollar I can toward new treatments and a cure.

I am so grateful for the myeloma community. The Toronto Support Group was where I found my first myeloma friends. In 2021 I became involved with Myeloma Canada as an Ontario Representative for the Patient Advisory Council, and I have started a support group in York Region. I am still working on healing mentally and physically every day and I'm living in the present as much as possible, enjoying time with my family and friends. Myeloma has taught me to appreciate even the little things and I now do not take anything for granted.

Feel free to reach out if you would like more information on the York Region Myeloma Support Group. You can contact me at yorkregionsupport@myeloma.ca or tzigomanis@gmail.com.

Fundraising

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

Myeloma Canada

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

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

Email: info@myeloma.ca
Website: http://www.myeloma.ca
Telephone: 1-888-798-5771

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

The Princess Margaret Cancer Foundation
610 University Avenue, Toronto, ON M5G 2M9
Telephone: 1-866-224-6560 Email: 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

Summary of Presentation at Support Group Meeting – October 1, 2022

Dentistry Concerns for Myeloma Patients

Dr. Erin Watson, DMD, MHSc

Deputy Chief of Dentistry, Princess Margaret Cancer Centre

Assistant Professor, University of Toronto

(The full video recording of Dr. Watson's presentation may be viewed at the following link: https://www.youtube.com/watch?v=3REIDM5tswM.)

Today we're going to talk about dental care for patients diagnosed with multiple myeloma. We have noticed in the department that many patients with multiple myeloma have been very hesitant to see the dentist during COVID, which is normal because some patients are immuno-suppressed, and many have had transplants and feel concerned about going out in public. I would like to reassure you that very good studies have been done regarding COVID and dentistry. We haven't seen any increased transmission in dental offices. Dentists didn't catch COVID more than anyone else even though we are performing aerosol procedures. I think the fact that we closed dental offices for a period of time implied to some people that it was more dangerous than it is. So, if you have been holding off going to the dentist, I would encourage you to go.

At Princess Margaret, we treat approximately 200 to 250 new multiple myeloma patients every year. Personally, I have treated approximately 350 newly diagnosed multiple myeloma patients over the past five years. I also advocate for dental care to address the specific needs of cancer patients. We have a working group with Cancer Care Ontario that is seeking to expand access to dental care and increase dental funding through OHIP.

At Princess Margaret, we have started a fellowship to train two dentists every year on how to treat cancer patients. As well, I have started a course at the University of Toronto on dental care and treatment for cancer patients.

General Suggestions

Oral health can play a very big role in your cancer care journey. If you are going to be receiving a stem cell transplant, you will be sent to a dentist to make sure you don't have any dental infections. If you are a patient who has been started on intravenous bisphosphonates, you are going to want to see a dentist before you start those medications to make sure you don't have any infections. So, sometime depending on the treatment you are going through, you can require specific care.

Patients often ask what to do before starting treatment. Before you start your treatment, you should get an overall check-up. Sometimes a dentist will take x-rays to check for cavities but not necessarily look for infections or other forms of disease, so be sure to get an overall check-up. I encourage patients to get a cleaning too, but if time is limited, you should concentrate on eliminating infections rather than on cavities.

Once you are in treatment, it's very important that your dentist checks your blood work before any type of dental procedure. There are two things we really look at in particular: your platelet count—you need platelets to stop bleeding—and your neutrophil count, you need neutrophils to prevent infections.

After treatment, we highly recommend regular check-ups and making sure you are taking more x-rays and catching problems while they are still small and easy to fix. Often times, when patients have been through treatment with a number of CT scans and MRIs, they are reluctant to get dental x-rays. A dental x-ray is much, much less strong than a CT scan. You don't need to be concerned about having dental x-rays.

Dentistry Following Diagnosis

The first time dentists see a patient, they initially take an x-ray that shows their entire jaw, as well as any teeth with fillings or root canals. This allows us to detect infections. Once you are going for regular routine check-ups and cleanings, you don't get this deep assessment. In theory, we are supposed to repeat that every five years, but in practice, that doesn't often happen. It's important to ask your dentist to take more than just the x-rays related to check-ups. You want to make sure you are treating any actively infected teeth.

So, what should I expect when I go to see my dentist for an exam? It would be very common for your dentist not to know very much about your diagnosis. At Princess Margaret, we do lots of stem cell transplants, so we see lots of myeloma patients. You may need to educate them a little bit. One of the most common issues is bisphosphonates, so you may have to tell your dentist about it. I encourage patients to bring their blood work to show the dentist and get them in the habit of checking your blood work. You may have to advocate to your dentist about taking x-rays. Often, after we've seen a patient at Princess Margaret dentistry, we will send a letter with them for their dentist, to advise them what work has been done, what blood work to check, what medications are concerning, et cetera.

Dental Concerns During Treatment

There are various forms of chemotherapy with different strengths and side effects. Patients who are taking CyBorD (cyclophosphamide, bortezomib and dexamethasone) may experience some side effects, while those going through stem cell transplants or other treatments may notice even more side effects. Maintenance therapy may also be a concern and patients should continue to monitor their bloodwork.

Tooth Sensitivity

Some patients may experience tooth sensitivity, particularly to hot or cold. One way to treat this is with Sensodyne toothpaste. I often tell patients if your teeth are feeling really sensitive, you can take some of the toothpaste, rub it on to the teeth and leave it there. It can be quite effective. As dentists, we also have desensitizers we can apply to the teeth, but ultimately, sensitivity will disappear in time.

Mouth Sores and Infections

Mouth sores are also something that will go away on their own. They are common during chemotherapy. Use bland mouth rinses to keep the mouth clean. We usually recommend warm water with a teaspoon of baking soda added. Ice chips can be helpful. Numbing agents can be prescribed, particularly if patients are having trouble with eating. In very rare cases, patients have to take a break from treatment due to extreme mouth sores. Mouth sores happen less frequently in patients whose mouths are very clean. You can sometimes develop a neutropenic ulcer, which develops when your neutrophils are low. As the chemotherapy stops, the ulcers will clear up on their own.

If you develop a mouth infection, you will require medical attention. Our mouths are full of different bacteria, viruses, and fungi which all happily live together. Certain medications can lead to one of those species taking over in your mouth. Thrush, a fungal infection which is very common in babies, can result from certain medications. It is treated with antifungal agents and clears up very quickly.

Patients who have a dormant herpes virus can see it become active on certain medications, triggering cold sores. If this happens frequently, patients will be placed on antiviral medications.

Lastly, we worry about dental infections. Untreated, they can become quite serious. A good rule of thumb is if your mouth sore or suspected infection has not gone away in two weeks, you should see a dentist.

Dry Mouth

Something very important to pay attention to is dry mouth. Your teeth cannot live in a dry environment. Teeth are basically a crystal that is held in place with calcium. In a dry mouth, the mouth becomes more acidic and that can cause that calcium crystal to dissolve. Technically, this is called a dry mouth cavity. We prevent that from happening by using fluoride to replace the calcium lost in the tooth. Sometimes that can just be using a high fluoride toothpaste (such as PreviDent 5000) which can prevent dry mouth cavities. When patients have a very dry mouth and develop tons of cavities, we provide trays which allow them to put fluoride on their teeth every night to prevent cavities.

When a patient has dry mouth, they are also at risk of developing gum disease. So, it is important to get regular cleanings and practice regular dental care at home. This means brushing twice a day but also cleaning between the teeth. As you get older, the spaces between your teeth get a little bit wider. Floss is good for people with small spaces between their teeth, but as you start getting a bit of gum disease, you need something bigger to get between the teeth. I love water flossers such as the ones made by Waterpik. They do a magnificent job of keeping teeth clean and preventing gum disease from becoming worse.

If you do develop a dry mouth, I would be concerned if it lasts for more than three months. Up to three months does not cause much damage to the teeth. After three months, we worry about damage to the teeth. How do you know you have a dry mouth? You wake up at night because your mouth is dry, or you wake up in the morning feeling like your cheeks are stuck to your teeth.

Hairy tongue can also happen with a dry mouth. This is basically just bits of protein that grow on roof of the tongue. They can be scraped off with a tongue scraper. Products that are developed or marketed for dry mouths will only help you feel better but will not change the condition. BioXtra and Oral Science are two companies which produce products to make you feel better.

Blood Counts

When a dentist is asking for your blood counts, we are looking at your white blood cells, specifically your neutrophils, your haemoglobin, and your platelets, which you need for clotting blood. Every institution is different, but if you have a pic line, most will want you to have antibiotics prior to any invasive form of dental procedure because in theory, bacteria from the mouth can get into the bloodstream, travel to the line, and infect it.

When are blood counts worrisome? We typically send patients into the dental community as long as their platelet count is above 60 or 70. When it gets below 50, we start to get worried about bleeding. And when it drops below 30, we'll order a platelet transfusion. Sometimes if your neutrophil count becomes low, your oncologist may recommend you stop brushing or flossing until the count rises back up. Typically, when neutrophils drop below 1.0, we consider giving antibiotics before dental procedures. And a prescription mouth rinse can be a good way to keep the mouth fresh if there's a period of time that you're not allowed to brush.

After treatment, dentistry really depends on maintenance medications. Make sure you keep an eye on dry mouth and address any issues, but most patients can get back to regular dental care.

Dentistry Specific to Multiple Myeloma Patients

Bisphosphonates and Osteonecrosis

Many are placed on Zometa (zoledronic acid), which is part of the group of medications called bisphosphonates. They turn off a bone-eating cell. In everyone's body, there is a bone-eating cell and a bone-making cell. Sometimes in myeloma, the bone-eating cell gets out of control and makes holes in the bones. Bisphosphonates turn off the bone-eating cell so that only the bone-making cell work.

However, there are times when you need that bone-eating cell, and one is when we pull a tooth. It is the job of the bone-eating cell to eat the jagged area in the jaw after a tooth is pulled. Sometimes when we pull a tooth of someone on these medications, the extraction area does not heal the way it's supposed to and patients develop medication-related osteonecrosis of the jaw, or MRONJ. That is a fancy way of saying death of a jawbone due to medication.

This is more common when patients have been on bisphosphonates for a long period of time, for example, a year versus a single dose. The risk does seem to plateau when you have been on the medication for approximately two years. Most patients will be placed on bisphosphonates once a month for two years and then every three months for two years before it is usually stopped. The reason it can be stopped is it lives in the bones for many, many years. We estimate it takes about 12 years before half of the bisphosphonate has left the jawbone.

If you are going to be started on bisphosphonates, it is important to see your dentist and remove any teeth which you will not be likely to keep for the rest of your life. It is important not to be too aggressive but also remove any problems that need to be addressed. We do not see cases of MRONJ as frequently now as dentists become more aware of what to do.

Just as your dentist may not know about myeloma, they may not be aware of intravenous bisphosphonates and their use or outcomes. People with osteoporosis are often prescribed bisphosphonates in pill form, which is much less potent, so you may need to educate your dentist about that.

How Do You Prevent MRONJ?

You can prevent it by:

- changing how you think about your teeth after you begin medication. Once you start medication, you should really not remove any teeth unless you have a very good reason, such as infection or pain which cannot be controlled without treatment.
- taking care of the teeth you have, keep them clean, perhaps go in for cleanings more frequently.
- getting regular x-rays for early detection
- using fluoride if you have a dry mouth

Remember, dentists are perfectionists. Sometimes when you can't pull a tooth, putting an okay filling in is better than causing other risks.

What happens if you get MRONJ? Approximately 20 to 30 per cent of cases will get better. Most cases will wax and wane over time. If possible, try to stop the medication.

Which Dental Work is Safe?

Check-ups are very safe. It's best to catch problems when they are small and easy to fix. Cleanings, fillings, x-rays, crowns, root canals are all safe; it is only things that involve bone that are not recommended.

Other Problems in the Mouth

Sometimes, myeloma can occur in the mouth, looking like a gum abscess. When that happens, your dentist will refer you to specialist to take a biopsy to confirm the diagnosis. Some patients with myeloma can have amyloid (protein) deposits. One place they can accumulate is in the tongue. This can wax and wane with treatment. Sometimes myeloma can look like holes in the jaw upon x-ray. It does not put the patient at an increased risk of breaking their jaw. It is just an incidental finding.

Funding

Lastly, I want to discuss dental funding. Currently in Ontario, there is a Seniors Dental Care Plan for people 65 and over. It is based on your income level. There is an online application form. Unfortunately, dental work under this plan must be delivered at public health units. Due to this, the wait times for treatment are exceptionally long.

There is also a new federal government dental program, but so far, it is only available for children under 12 years of age. It is supposed to be expanding to other age groups. This care is available everywhere in Canada and is provided as a Canada Revenue Agency rebate.

Questions and Answers

Q. Does Xgeva have the same effects as Zometa or Pamidronate?

A. They work slightly differently. In theory, Xgeva lives in the body for about six months before half of it is eliminated. The risk of developing MRONJ is similar on Xgeva; however, if you develop MRONJ and are taken off Xgeva, you will recover slightly faster than a patient on Zometa. Pamidronate is 67 times less potent than Zometa. So, on Pamidronate, we see

MRONJ less frequently. However, more patients are on Zometa as it does a better job of protecting the bones.

Q. What is surgical cleaning?

A. Once in a while, your dentist, usually a gum specialist, will recommend lifting your gums off the teeth and cleaning deeply. You wouldn't want to do that.

Q. If you are a patient with myeloma and would like to have dental services similar to those offered at Princess Margaret, where can you go?

A. That is very tricky. One of the reasons we have so much knowledge at Princess Margaret is because we see so many patients with myeloma. Unfortunately, there are not a lot of places you can go. At Princess Margaret, we see 30 to 40 new cancer patients every week. When you've recovered enough, you must go back to your community dentist so we can help the new patients coming in. We do have fellows who graduate from the program every year and are now working in private practice. If you go on the Princess Margaret website, you can find names of the fellows who have graduated from the program. There are some hospitals that accept patients not treated at their centre. For example, Sunnybrook has a dental clinic. Toronto Rehab Institute also accepts patients from the general population and often treat patients with Alzheimer's or mobility deficits. Baycrest also has a dental service that accepts patients from the community. I am hopeful we will see more dentists in the community in the coming years.

Q. In the past MRONJ was treated with hyperbaric oxygen. Is there a reason why this is not done anymore?

A. Hyperbaric treatments are most typically done in patients who have death of jawbone due to neck and head radiation, where the area doesn't have enough blood vessels to heal itself. Many studies have shown it is not effective except for very rare cases. It is not a simple procedure as patients must undergo approximately 30 treatments every day for several hours, and if it's not really that effective, why put patients through it?

I don't know of any cases of MRONJ caused by medication that we've tried to treat with hyperbaric oxygen at our centre. I would imagine there would be a contra-indication because patients have active disease, and you worry about putting a lot of oxygen in that type of environment.

There is, however, a group of medications which are given to patients with necrosis caused by radiation. They include medication to help blood vessels re-grow, a steroid to help settle inflammation, and a bisphosphonate in pill form which turns on the bone-making cells without impacting the bone-eating cells. This regimen shows a little bit of promise in radiation and may show promise in MRONJ, but we don't have the studies that support it yet.

It is very difficult when a patient develops MRONJ to have access to hospital-based treatment because most places that treat myeloma don't have dental clinics and it is usually oral surgeons who treat this type of complication. So, it's very difficult when a patient develops MRONJ to find access to oral surgeons in hospitals who can treat it.

Q. You talked about myeloma patients asking for more x-rays that are slightly more robust than regular x-rays. Can you identify what those x-rays are called?

A. The type of x-ray you get at a dental check-up is called a bite wing. They are not enough to diagnose infection. You either need a panoramic x-ray (which shows the entire jaw) or an intra-oral x-ray (which are close ups of each tooth that look at the tip of the root).

Q. *If you are on daratumumab and scheduled for surgery, do you need to cancel the appointment or stop the drug?*

A. Daratumumab is not a medication that's implicated in poor healing after dental surgery. You would need to reschedule your appointment only if your platelets or neutrophils drop too low.

Q. *Can you say what procedures are not safe for patients on IV bisphosphonates?*

A. Anything that involves manipulating bone, i.e., pulling teeth, implants, surgeries, or root canal treatment where the dentist lifts the gum and tunnels through the bone to cut off the root; braces are also not recommended.

Q. *I was taking Pamidronate and have been off it for about 12 years. Do I need to ask my oncologist if I need to get back on that or something stronger like Zometa?*

A. The decision is usually based on a bone survey. If they don't see holes in your bones or if your calcium level is not high, there is no reason to go back on the drug.

Q. *My teeth seem to be falling apart.*

A. You might need fluoride.

Q. *I had to discontinue Zometa due to kidney damage. Is Xgeva given every six months as affective?*

A. I think typically to be as effective as Zometa, it is given monthly but ask your oncologist. The decision is based on how your bone health is doing versus the damage to your kidneys.

Q. *Does the dental clinic at Princess Margaret do root canal treatments?*

A. We do have one dentist who works on root canals on a regular basis. He is not in our clinic but works with our patients.

Q. *I have been on Zometa for several years and have developed spontaneous bone exposure. The dentist is having difficulty confirming MRONJ. How is it diagnosed?*

A. The decision is based on a clinical exam.

Q. *There is a new technology called a Cone Beam CT scan which gives lot of detail on teeth. When would you recommend that kind of scan?*

A. A Cone Beam CT scan is like a little CT that focuses on one area of the jaw and we really only use it for very specific reasons. For example, if I saw a patient who had a root canal that looked like it was failing. You don't use it just to see what is going on in the jaw.

Q. *If you are on Zometa, should you be concerned if your dentist says you have inflammation?*

A. What they are really telling you is that your gums don't look healthy. That is something to be concerned about because you are at risk of losing bone around the teeth. The best thing to do is get a water flosser.

Q. *I've been on Zometa, and I am experiencing issues, but my dentist doesn't seem to know what to do about it. Should I get a second opinion?*

A. It does sound like you need a second opinion. There are some very good dental surgeons in the community. Princess Margaret will only see a patient who has received care at Princess

Margaret. Outside of that, I would ask to be referred to the surgery group at Mount Sinai Hospital.

Q. I've been seeing my dentist who is very good but reluctant to take x-rays. I have been on Zometa for a few years. Secondly, would any dentist be able to review a panoramic x-ray and know what they are looking for?

A. The first thing I would say is it's important to detect infections before you start on the medications. Normally, we recommend a panoramic x-ray every five years. All dentists should be able to review a panoramic x-ray and say what they see.

Q. I was treated at Princess Margaret dental clinic and had a panoramic x-ray. Should I have another one there for comparison?

A. A panoramic x-ray can be done anywhere. You can always obtain a copy of your previous one from us.

Q. If you're someone who doesn't have dental insurance and you're brushing your teeth every day using a toothpaste with fluoride, do you still need to get the fluoride treatment from your dentist?

A. To be honest, that is probably more for younger patients. If you're not getting a lot of cavities, it's probably not necessary.

Q. Where would a patient in Windsor go for dental treatment?

A. Write to your MP and complain that there is nothing in Hamilton, Windsor, or London.

Q. Are there any myeloma treatments that increase gum recession and is there anything other than good oral hygiene and a Waterpik available to reduce gum recession?

A. There are no myeloma treatments, to my knowledge, that increase gum recession. Other than a water flosser and good oral hygiene, get regular cleanings at your dentist.

Q. Can my dentist call you for advice?

A. Yes.