Ottawa-Gatineau MULTIPLE MYELOMA SUPPORT GROUP NEWSLETTER

Website: www.myelomaottawa.com

October 2017 **Newsletter # 3**

In This Issue

Hello Fellow Members and Friends,

Welcome to our third newsletter. We hope you will find this information useful.

A special thank you to Dave McMullen of the Toronto Multiple Myeloma Support Group who is permitting the use of the material from the Toronto newsletter.

Our Mission:
The mission of the Support Group is to provide hope and to empower myeloma patients, family, caregivers and friends through education, advocacy, patient care and support and sharing experiences.

Your Team:
Robin Sully and Jean Shepherd - Co-Chairs and Advocacy;
David Rideout - Myeloma Walk Chair;
Gilles Caron - Gatineau Sub Committee;
John Podgorski, David Panich, Jasmine Kubski – Communications;
Marylyn Switzer - Patient Care;
Johanna MacDougall – Newsletter.

Next Meeting: Wednesday, November 1, 2017 at 6:45 at the Maplesoft Centre, 1500 Alta Vista Dr., Ottawa.

Dr. Khadija Bhimji will focus on pain management for myeloma patients.

Driving Directions:

Coming from the Queensway East:

Exit 117 onto Vanier Parkway towards Riverside Drive. Keep left towards Riverside Drive. Turn left onto Vanier Parkway towards Riverside Drive. After the Queensway overpass, get into lane marked "Alta Vista Drive only". Turn left onto Industrial Ave. Immediately turn right onto Alta Vista Drive. The destination is on the right.

Coming from Queensway West:

Exit 117 onto Riverside Drive. Get into lane marked "Alta Vista Drive only". Turn left onto Industrial Ave. Immediately turn right onto Alta Vista Drive. The destination is on the right.

Meeting Contacts:

- Jean Shepherd jean.shepherd@rogers.com 613-277-4886
- Robin Sully maplecrest2553@xplornet.ca 613-622-5461

Last Meeting: October 4, 2017

Speaker: **Dr. Renata Francovitch, MD, FCFP, Dip. Sport Med.**

Topic: The vital importance of exercise to maintain myeloma patient's bone and muscle strength.

Note: Biggest take-away from this presentation is that you should exercise 150 minutes per week and that even 10 minute exercise sessions count toward reaching that objective.

A copy of Dr. Francovitch's presentation is attached to this email.

Prior Meeting: September 13, 2017

Speaker: Change of plans! Our speakers were ill.

Topic: Due to unforeseen circumstances, we had an impromptu discussion about our myeloma journeys, both from patient and caregivers perspective.

Myeloma Canada Leaders' Summit in Ottawa

Robin and I attended the Annual Support Group Leaders and Advocacy Summits from Friday September 29 to Sunday October 1st.
It was attended by 34 leaders from across Canada and was a great opportunity to network and brainstorm on our shared issues.
On Friday evening we honoured the leaders whose myeloma journey came to an end this year. I was privileged to acknowledge Irene Podgorski's outstanding contribution to our myeloma community. She is missed both as a friend and colleague.

Some of the speakers on Saturday and Sunday included:
Marie-Claude Bourgeois-Daigneault, PhD from Dr. Bell's Lab here at the Ottawa Hospital's General Campus, talking about cutting edge research into Myeloma.
Gail Christy from Bereaved Families of Ontario.
Dr. Donna Reece, from Princess Margaret Hospital, Director of the Program for Multiple Myeloma, discussing all that is new in clinical trials and myeloma treatments.
Naveen from the Binding Site talked about blood tests and the best diagnostic tests.
Bill Dempster from 3Sixty Public Affairs told us all about advocacy and the world of reimbursement of myeloma drugs.

Some of the leaders and others involved in advocacy, spent Tuesday on Parliament Hill meeting MPs to discuss how the Federal Government can support us in advancing better and timely access to new treatments.

The whole event was excellent and we will pass much of the information on to the group at our next meeting and hope to have at least two of the speakers talk at one of our meetings in the New Year.

Jean Shepherd, Co-Chair, Ottawa-Gatineau Multiple Myeloma Support Group

Name change

There is a proposal to change the name of our Support Group to "Ottawa-Gatineau Myeloma Community Network" - same mission, values and focus activities. Why you may ask? There is a perception that the name of our group may detract potential members from joining. What are your thoughts and comments? Please send any feedback to either Jean or Robin.

Myeloma Information Booth

The proposal to have a myeloma information booth once a month at The Ottawa Hospital – General campus on a clinic day to provide information on myeloma and the Ottawa-Gatineau Myeloma Support Group to newly diagnosed patients or patients unaware of the Support Group and the benefits they might derive from going. Just an opportunity for patients and caregivers to meet a "healthy" patient or talk to a caregiver at the desk can be empowering. We are looking for volunteers to help (wo)man the booth and someone to coordinate the activity (which can be done by phone and electronically). Volunteers can contact either Jean or Robin.

Peer support volunteers

Not everyone feels comfortable sharing in a meeting. However, if they need support and would value talking to someone, patient or caregiver, who is living through the multiple myeloma experience, we would like to help.
Individuals who are willing to speak to them by phone (or as you decide) and share their experience on a one-on-one basis can volunteer. Volunteers' participation will provide valuable support to a newly diagnosed patient or perhaps one who has relapsed and is starting a new protocol. Again volunteers can contact Jean or Robin.

December Social on December 6

Dr. Kew will be the guest speaker at our Dec. 6th meeting. Rather than having our regular sharing session after our discussion with Dr. Kew, we will have a social and invite everyone to bring hors d'oeuvres or sweets to share.

Funding for Myeloma Drugs

Myeloma Canada has a campaign to have patients and/or caregivers contact their local MPPs to get support for the funding of carfilzomib and daratumumab.
The issue is that these drugs have been approved by Health Canada and received positive recommendations for funding by our Health Technology Assessment (HTA) government bodies, but are not yet reimbursed by the provinces.
Medication approval alone is insufficient. Patients need access to life-changing treatments.
Please follow this link http://myelomacommunity.ca to read all about it and join the campaign by contacting your MPP.

Personal Stories

Always of interest to readers are personal stories. Anyone, patient or caregiver, who wishes to share their personal story on their multiple myeloma journey in the Newsletter is invited to submit it to me, Johanna MacDougall at sunpeaksskier@gmail.com.

Meeting Speakers

We would like some input on the sessions and possible speakers we are planning for March-June, 2018.
The following are our current plans. The focus is on exciting research, blood tests and clinical updates but we have included an additional list of topics that patients may want to include, either from March to June or perhaps next September to December:

Currently we are proposing:

- Cutting edge and new research on cancer (including Car-T cells): a terrific, myeloma specific and very "digestible" presentation by Marie-Claude Bourgeois-Daigneault, PhD, Post-Doctorate Fellow, Dr. Bell Laboratory Ottawa Hospital
- Answering questions on blood and other tests, including light chains: representative from the Binding Site - again an excellent presentation of direct relevance to diagnosing and monitoring your blood results.
- Presentation on the myeloma research posters that were introduced at the Myeloma Walk
- Dr. Kew or Dr. McCurdy clinic update.

Additional possible session topics:

- A psychologist
- Reshowing our DVD on travel insurance
- Infections.

If you have any topic or news item you would like included in future meetings or newsletters, or other suggestions or requests, please contact Robin Sully, Jean Shepherd or anyone on the Executive Committee.

Announcements

Tony and Anne-Marie Gaston are organizing a performance entitled Anjali: Lady MacBeth.

1. Profits on the ticket sales will be given to Myeloma Canada
2. There will be a reception afterwards with snacks;
3. Running time is 1 hour without intermission, so attendees will not need to linger after about 8:45, supposing they have further plans for later in the evening.
4. Parking is available at Rideau Centre, just across the street at $3/hour.

Thank You

Once again, Robin and Antek hosted the Support Group for a fantastic BBQ at their farm at Fitzroy Harbour. The weather was iffy on June 24 but for the duration of the BBQ, the rain held off. It was a wonderful event and on behalf of all who attended, a heartfelt thank you to Robin and Antek. The roast of beef was outstanding! The company even better!!!

Major Event

2017 Ottawa-Gatineau Myeloma Walk - Steps to a Cure!

The annual Ottawa- Gatineau Myeloma Walk took place on a very hot Sunday September 24th at the Ron Kolbus Lakeside Centre at Britannia Beach.

A big **THANK YOU** to the organizers, participants, sponsors and everyone who helped make this walk happen. Each year the Walk brings the Myeloma community together to create awareness of the disease and raise money to support research and improve patient care.

Our fundraising goal this year was a very ambitious **$75,000**. We nearly made it! We raised $69,424.60 or 92% of our goal.

Half the funds will support the work of Myeloma Canada's National Research Network and half will go to support myeloma research initiatives at The Ottawa Hospital. All in the interest of improving patient care and ultimately finding a cure!

Figure 1: MPP Fraser cuts the ribbon – with a little help!

Our photographers, Antek and Frank, have memorialized the event in the PDF document attached to this email. Thank you, Antek and Frank!

Multiple Myeloma Support Group – Toronto

Summary of Presentation – June 3, 2017 Toronto Meeting

Kyphoplasty (Vertebral Augmentation) for Myeloma
The Cement Facts – Is It Worth It?

Dr. Roger Smith, MD, FRCSE
Department of Medical Imaging, Toronto Western Hospital
Assistant Professor, University of Toronto

Note: Below is an abbreviated transcript of the presentation. The full 1 hour 30 minute video recording of the presentation can be viewed on the Myeloma Canada YouTube website: https://www.youtube.com/watch?v=f9ZJ4sXnRqY&t=8s

Dr. Smith began by discussing the difference between an MRI and a CT scan in relation to myeloma, and advised that an MRI looks at water, while a CT scan looks at calcium. When you shine an x-ray through a body or through an object, the density of that object absorbs the x-rays so they do not hit the photographic plate on the far side. A CT scan is a more sophisticated use of a series of computerized x-rays.

An MRI actually turns the object into a radio transmitter. All water molecules give off a frequency, which can be changed in an MRI, which produces an image. In myeloma, particularly affecting the spine, any tumours or fractures will appear as white areas. While MRIs and CTs both provide a lot of detail about bone disease, a CT scan is sometimes better as you can occasionally miss a fracture on MRI.

What are the consequences of spinal fractures? Dr. Smith compared the spine to a high-rise building, with lots of floors, ceilings and walls. As the building gets older, the walls start getting thinner. Eventually, there is a point at which they are not strong enough to hold the floors and ceilings apart and they collapse. In osteoporosis, this can happen slowly and painlessly. Or, it can happen suddenly and be very painful, which happens in cancer and multiple myeloma.

In osteoporosis, when the bone cells come together there is a healing process which is why there is little pain. In cancer and myeloma, the bones continue to deteriorate and cause more problems. Because we carry weight in the front of the vertebrae, when the bones start to deteriorate, they form a wedge shape. As more wedges form, the spine develops into an arch. This can cause chest pain, as the sternum buckles inwards. Often people present with protruding bellies, caused when the gap between the bottom of the sternum and the pubic bone shortens.

So, why do patients get pain in their spine? As with any broken bone, there is pain with movement. When the fracture is in the spine, there is constant stress and movement, and very little can be done unless you are kept immobile. Vertebral augmentation seals the fractures, thus relieving the pain. Interestingly, fractures in the upper back often heal without intervention and almost always heal pain free.

There are two types of vertebral augmentation, vertebroplasty and kyphoplasty. Kyphoplasty is a procedure where a needle is inserted into a damaged vertebra, a balloon is inserted into the vertebra through the needle, and the balloon is then inflated to create a cavity in the damaged region of the vertebra. Cement is then inserted into the cavity, once the balloon is removed. Sometimes more than one vertebra has this procedure at once.

Vertebroplasty is a similar but older procedure (used since 1987), where cement is inserted into the vertebra, but without using a balloon to first create a cavity.

(Dr. Smith showed various x-rays of patients before and after the kyphoplasty procedure.)

There are several indications that vertebral augmentation is needed. Pain relief and restoring functional capacity are two of the major indications.

There are also instances when it should not be done.
- One is instability, where parts of the bone that hold the spine together are slipping.
- Epidural cord compression, where a tumour has grown into the space surrounding the spine, is a contraindication of the procedure. Here, the tumour would have to be treated first.
- Radicular pain (pain which radiates along a nerve from the spine) may not be relieved by kyphoplasty, as the pain is not localized. In this instance, physiotherapy is much more effective for relieving radicular pain.
- And obviously, if there is an infection, it must be treated before the procedure can be performed.
- Inability to localize the pain to a specific level used to be a contraindication. However for people with multi-level vertebral fractures it is becoming more common to treat multiple levels, with good relief of pain.

(Dr. Smith played a short video showing the kyphoplasty procedure.)

When injected, the cement has the consistency of caulking. Within five minutes of injection, it will be solid. During those five minutes, it will rise to a temperature of 60 degrees Fahrenheit and usually causes very little issues.

Of course, there are some possible side effects
- ➢ Leakage. The cement can leak causing nerve or thermal injury, however the risk is very small and depends largely on the experience of the surgeon.
- ➢ Infection. This is very, very rare because the patient should not have an infection when the procedure is started.
- ➢ Hemorrhage. Fractures do bleed, however it is usually contained to the fracture area.
- ➢ Further collapse. This occurs in the acute phase of the disease. Here, something goes wrong despite the procedure and the patient continues to lose function or suffer pain.
- ➢ Adjacent level fracture. Often, patients will return for further procedure due to another fracture as the disease progresses.

- Pulmonary embolism of the cement - risk is 1 /1000 of serious embolism.

So, what is vertebral augmentation good for?

- Pain relief. Some pain relief is immediate. The fracture will continue to heal for three months, so the pain relief will improve. The published success rate for pain relief is very high.
- Increasing patient mobility.
- Fracture reduction. As with a regular fracture, the bones are immobilized to permit healing.
- Height restoration. This can be achieved when two or three vertebrae are impacted.
- Immobilization. Stability of the spine.

Both kyphoplasty and vertebroplasty provide instant pain relief. However, with vertebroplasty there is a higher risk of leakage. Kyphoplasty is often used in myeloma patients who have tumours in one or two vertebrae. When the tumour is removed, it leaves a space, which is filled in by the procedure.

Some patients have fractures in the sacrum. The awareness of sacral fractures is becoming greater. Sacral fractures result in chronic pain. However, there is very little literature as to why this is occurring. These fractures also respond well to a procedure similar to vertebroplasty, called sacroplasty. Cement is injected around the fracture to support the bone.

Typically, surgeons like to use screws and plates for fractures. In patients with multiple myeloma or osteoporosis, the screws may not grip properly. In those cases, Dr. Smith typically uses vertebroplasty as he wants the cement to go around the screw.

(Dr. Smith showed several before and after x-rays of patients who had the procedure; some successful and some not.)

Dr. Smith advised that the Ministry of Health has finally agreed that the procedure should be publicly funded for cancer patients and that the treatments should be done in a timely fashion. When he first started doing this procedure, the time from referral to treatment was about six months. That has been reduced to three to four weeks.

Q. What impact would the use of bisphosphonates have?
A. They improve the outside of the bone, but have no effect on the inside.

Q. How long does it take to inject one level?
A. It's a scale. Six or seven levels would be an hour to an hour and a half.

Q. On a zero to ten pain scale, where would the procedure come in?
A. It is practically painless because you have an anaesthetist. The procedure itself is pain free.

Q. Has a study ever been done to show which of kyphoplasty or vertebroplasty is better?
A. Studies have been done that show comparable results, i.e. that they are giving the same pain relief. In terms of function, over time, patients get to the same point with either procedure. However, Dr. Smith thinks that with kyphoplasty patient function improves faster.

Q. Is there an increase in height more with one than the other?
A. Definitely with kyphoplasty, but that is not the goal.