TORONTO & DISTRICT MULTIPLE MYELOMA SUPPORT GROUP NEWSLETTER

Website: www.myelomatoronto.ca

May 2019 Newsletter # 130

In This Issue

Hello Fellow Members and Friends,

If you are now receiving paper newsletters, and you have an email address where we could instead email you the newsletter (in colour) please contact Dave McMullen – see contact below. Thank you!

Next Meeting: Saturday, June 8, 2019

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

We will have two interesting topics:

Speakers: Orlay Lopez-Perez, Technician, Cell Processing Lab, and Mileidys Alvarez, Supervisor, Cell Processing Lab, Princess Margaret Cancer Centre

Topic: Stem Cell Transplants – Processing the Stem Cells Before They Are Re-infused into a Patient

----

Speakers: Executive Committee members

Topic: Presentation and discussion of information resources available to myeloma patients and caregivers.

Meeting Time: 2:00 – 4:30 p.m.

Location: Jubilee United Church
40 Underhill Drive
Toronto, Ontario

The meeting starts at 2:00 p.m., but you are welcome to come any time after 1:30 p.m. to enjoy refreshments and socialize.

How to get there: Driving Directions
Take the Don Valley Parkway, exit east on Lawrence Ave. Immediately turn left at the first intersection, Underhill Drive, and continue north two blocks to the church. 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

Meeting Contacts:

• Dave McMullen	905-648-5146, davidanderika.mcmullen@sympatico.ca
• Don Hunter	416-759-6348, donhunter138@gmail.com
• Munira Premji	416-302-9459, mnpremji@rogers.com
• Jan Wleugel	416-760-7914, janwleugel@gmail.com
• Bob McCaw	905-836-2664, robert.mccaw038@sympatico.ca
• Patrick Taylor	416-537-8538, pdmtaylor@rogers.com

Last Meeting: April 6, 2019

Speaker: Dr. Rodger Tiedemann, Staff Hematologist, Myeloma Program, Princess Margaret Cancer Centre.

Topic: Advances in Multiple Myeloma: What's New in 2019? ASH Update.

A summary of Dr. Tiedemann's presentation can be found later in the Newsletter.

Announcements

1) Upcoming Guest Speakers

August 10, 2019: Suzanne Rowland, Nurse Practitioner, Princess Margaret Cancer Centre.
Myeloma 101, With a Primer on How to Interpret Your Blood Test Results

October 5, 2019: Alan Birch, Drug Access Navigator, North York General Hospital and an administrator at the Oncology Drug Access Navigators of Ontario.
Reimbursement of Cancer Drugs

December 7, 2019: Dr. Mary Elliott, Cancer Clinical Research Unit, Princess Margaret Cancer Centre; Assistant Professor, Psychiatry, University of Toronto
Psychological Aspects of Living with Myeloma

February 7, 2020: *1) Brief Highlights of 2019 American Society of Hematology Conference*
2) Circle Discussion (including patients with myeloma success stories)

2) Myeloma Canada News

Report on Myeloma Canada 2019 National Conference

Patients and caregivers from across Canada came together in Toronto on April 27 and 28 to hear presentations on a range of topics relating to multiple myeloma at the Myeloma Canada 2019 National Conference. Among the distinguished and informative plenary speakers were many experienced hematologists (Dr. Christine Chen and Dr. Donna Reece, Princess Margaret Cancer Centre; Dr. Martha Louzada, London Health Sciences Centre; Dr. Arleigh McCurdy, Ottawa Hospital; Dr. Hira Mian, Juravinski Cancer Centre, Hamilton; Dr. Anette Hay, Queen's University, and Dr. Chris Venner, Cross Cancer Institute, Edmonton). Their presentations covered diagnosis and treatment of myeloma, relapse, thrombosis, emerging therapies, clinical trials, and the Myeloma Canada Research Network and Database. Other plenary speakers covered topics such as cannabinoids for symptom management (Dr. Michael Verbora, Chief Medical Officer, Aleafia), side effect management (Suzanne Rowland, Nurse Practitioner, Multiple Myeloma Program, Princess Margaret Cancer Centre), and exercise (Oren Cheifetz, Oncology Physiotherapist, Juravinski Cancer Centre).

Smaller breakout sessions addressed diagnosis, relapse, and amyloidosis in more detail, and dealt with other important topics such as nutrition, caregiving, financial options, the myeloma journey from a patient's perspective, and the science of the myeloma cell. There were also sessions on Myeloma Canada and some of the resources and tools it has developed to assist patients and caregivers. Myeloma Canada's Gabriele Colasurdo demonstrated one such resource, the very useful Myeloma Monitor tracking tool, which can now be downloaded from: myelomacanada.ca/en/resources/myeloma-monitor. In addition, Myeloma Canada's Michelle Oana discussed the work of Myeloma Canada and presented information on starting a support group and volunteering for Myeloma Canada. Myeloma Canada also organized a special meet and greet for young myeloma patients and caregivers.

Following each presentation there was time to ask questions, and patients and caregivers had opportunities to meet and talk to presenters during coffee breaks, breakfasts, and lunches. Just as importantly, these social breaks and the very enjoyable Saturday night banquet provided occasions to meet old and new friends, share experiences and ideas, promote support groups, and affirm our care for each other. Myeloma Canada, led by Executive Director Martine Elias, and especially Gabriele Colasurdo, did excellent work planning and organizing the conference, with significant contributions from patient volunteers, including our own Dave McMullen, co-chair of the Toronto and District Myeloma Support Group, who did a very fine job chairing the national conference.

Bob McCaw Featured in Myeloma Canada Video

Myeloma Canada has released another insightful video on the patient journey, this one featuring Bob McCaw, a long-term member of the Executive of the Toronto and District Myeloma Support Group. An earlier video in this series featured Munira Premji, who is also on our Executive. Bob's inspiring story, and that of other Myeloma patients, can be accessed on the Myeloma Canada website and on YouTube at the following link: https://www.youtube.com/watch?v=m63pOXqZCWM

3) Provincial Funding of Daratumumab

In March 2019 the Ontario approved funding for daratumumab (Darzalex) for myeloma patients who have relapsed, in specific situations. Health Canada had previously approved daratumumab in combination with lenalidomide (Revlimid) and dexamethasone or in combination with bortezomib (Velcade) and dexamethasone in myeloma patients after one or more relapse. Quebec, Alberta, B.C. and Manitoba have already agreed to fund daratumumab. Daratumumab was the first monoclonal antibody (immunotherapy) to be approved by Health Canada. The Ontario Advocacy Committee and other myeloma patients and caregivers played a major role in advocating for provincial funding of daratumumab by writing letters of support and visiting MPP's at Queen's Park. Please consult your doctor if you would like to know whether daratumumab would be appropriate and funded for you.

4) Support Group Luncheon at the Joe Bird Restaurant, June 1, 2019, 12:00 Noon

The next support group luncheon will be held at the Joe Bird Restaurant, 207 Queen's Quay West, at Toronto's Harbourfront. The restaurant is accessible by TTC streetcar from Union Station or Bathurst Station and there is parking nearby. Support group luncheons provide a wonderful opportunity to meet members of the support group in a friendly and informal atmosphere. Participants at previous luncheons have enjoyed the opportunity to get to know each other better and share experiences. All are welcome. Information on the restaurant and the brunch menu is available at https://www.joebird.ca/

If you would like to join us for this occasion, we would be delighted. Please inform Bob McCaw by Thursday May 30 if possible, so we can tell the restaurant how many people we will have. Bob can be reached at robert.mccaw038@sympatico.ca, or 905-836-2664. Each person or couple will look after their own bill.

5) Support Group Survey

During our April 6 Support Group meeting, we offered a simple two-page survey form to all those attending. This form had several questions, all optional, where members could offer any suggestions they might have for some of our support group activities in future. These include:

- Meeting topics
- Newsletter topics
- Possible social outings
- Our website
- Any other suggestions you might have about the support group
- Any activities where you would like to contribute

We received some good and useful feedback - ***thank you*** to those who contributed. There was a variety of interests expressed in our future activities – it's good for us to know what they are.

We will offer the survey again at our June 8 meeting. The survey form is also included at the end of this newsletter, for anyone who cannot attend this meeting, and who would like email, phone, or mail in any comments. Please feel free to email or phone any survey comments to Dave McMullen at davidanderika.mcmullen@sympatico.ca, or 905-648-5146.

We will provide a summary of the survey results in our July newsletter.

For possible social outings, Saturday luncheons were the most popular option. A Toronto harbour cruise, and a picnic in a park were also popular options, and various other possible outings had significant interest. We will plan some of these social activities later this year and next year.

6) Get on the 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.

7) Videos from Previous Presentations

We have a selection of DVDs from previous presentations available for lending at our meetings. (*Please remember to return signed-out DVD's at the following support group meeting. If you need more time, let Bob McCaw know at the meeting or by email at* robert.mccaw038@sympatico.ca*, if you are not attending the meeting.)*

Many of our presentations are on the Myeloma Canada website, http://www.myeloma.ca, under Resources/Myeloma Canada Educational Videos/Videos. Our videos have a red gerbera daisy flower on the title page.

8) Myeloma Patient and Caregiver Meet and Greet in Hamilton, Monday May 27, 2019

Myeloma Canada will host a "Meet and Greet" session, from 6:00pm until 8:30pm, May 27, in Hamilton. An outcome of this meeting will likely be the formation of a new myeloma support group in Hamilton.

Dr. Ronan Foley, a well known hematologist at the Juravinski Cancer Centre in Hamilton will be the featured presenter, on the topic of "New Research and Treatment of Myeloma". Other health care professionals from the Juravinski Cancer Centre are planning to attend. Michelle Oana from Myeloma Canada will also be a presenter. Numerous other patient and caregivers will attend, including those who are proposing the new support group.

The location is Sandman Hotel, Albion A&B Room, 560 Centennial Parkway N., Hamilton. More details are found here: https://files.constantcontact.com/e7f4c46f101/d2e79d60-bc02-490c-af9c-8fb125deef28.pdf. This event is free of charge; however please RSVP in advance to confirm attendance at contact@myeloma.ca or by phone 1-888-798-5771.

9) Cell Therapy and Transplant Canada

Cell Therapy and Transplant Canada (CTTC) is a well established and structured organization, which until very recently was called the Canadian Bone Marrow Transplant Group (CBMTG). It was founded in the 1980s by a group of dedicated health care professionals, working in the area of bone marrow and stem cell transplants, including autologous stem cell transplants for myeloma patients. Since then, it has grown to include most, if not all, of the cancer centres in Canada which conduct stem cell or bone marrow transplants.

Previously, this organization was only for health care professionals. However, since 2015, they have opened membership to patients and caregivers. The CTTC vision is "Canada will be the best place in the world to have a blood and marrow transplant." One of their Strategic Priorities is "Outreach - Increase the visibility and influence of CTTC among members and the public".

Every year, the CTTC has a large three-day Annual Conference. In recent years they also hosted a one-day Patient and Caregiver Symposium, for transplant patients and caregivers. Patients and caregivers may attend the Symposium for free, and also attend the Conference for a nominal fee. This year, the Symposium and Conference will be held in Calgary, June 5-8. In future the Symposium and Conference will be held in Ontario during some years.

More information about the CTTC and the Annual Conference and Symposium can be found here: www.cbmtg.org

10) 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 Executive.

Major Events

Bloom Chair Walk for Multiple Myeloma, Princess Margaret Cancer Centre

Every year, individuals committed to raising awareness and bringing hope to multiple myeloma patients and their families raise funds by walking in support of myeloma research through the Molly and David Bloom Chair in Multiple Myeloma Research at the Princess Margaret Cancer Centre. This year's walk will take place on Sunday, June 16, 2019, at Princess Margaret. Many members of our support group like to join family and friends in this most agreeable walk along University Avenue in downtown Toronto.

You can register now at www.mm5kwalk.ca. Please ensure you register under "Multiple Myeloma MM5K Walk" in the drop-down menu.

More pictures from last year's walk can be found on the 2018 Multiple Myeloma M-Moving Together Toward the Cure MM5K Walk Facebook site, linked here: https://www.facebook.com/pg/mm5Kwalk/photos/

Myeloma Canada Multiple Myeloma Marches

Each year, communities across the country rally for a walk of up to 5km, to increase myeloma awareness and raise funds for clinical research and to support advocacy for accelerated access to new, life-changing therapies for Canadians living with myeloma. These walks are all festive events that support our myeloma community and celebrate hope. This year there will be five walks in the Toronto area: Hamilton on September 15, Mississauga on September 22, Kitchener-Waterloo on October 6, Oshawa on September 21, and Newmarket on September 22. These events were well attended last year and most enjoyable.

The details of these Marches and registration are available on the Myeloma Canada website, linked here:http://support.myeloma.ca/site/PageServer?pagename=register&s_locale=en_CA There are many nice pictures from each of these walks also on the website, under Past Marches, linked here: https://www.flickr.com/photos/135746311@N08/albums/with/72157695850072690.

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
12650 Riverside Drive, Suite 206
North Hollywood, CA 91607, USA
Tel: 800-452-CURE

Donations may be made online at 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

Report on Support Group Meeting – April 6, 2019

Advances in Multiple Myeloma: What's New in 2019?
ASH Update

Dr. Rodger Tiedemann
Staff Hematologist, Myeloma Program, Princess Margaret Cancer Centre

This is an abbreviated transcript of highlights of Dr. Tiedemann's presentation. More detail is available in the 90 minute video of Dr. Tiedemann's full presentation which is available on the Myeloma Canada website, linked here: https://www.youtube.com/watch?v=MUCOUPu_ogY

Dr. Tiedemann gave a brief overview of multiple myeloma and the various treatments beginning in the 1960s with melphalan and prednisone. It was not until the 2000s that multiple myeloma treatments advanced significantly. In cancer therapy, clinical trials ask specific questions such as new ways to prevent cancer, new ways to find and diagnose cancer, new ways to treat cancer and new ways to manage cancer symptoms.

The research pipeline for treatments begins with a discovery from basic research, followed by clinical trials. Clinical trials have three phases. Phase I trials consist of a few patients and last a short period of time, usually months. They are focused on the safety of a drug in patients. Phase II trials involve hundreds of patients and can last months or even years. They are still focused on drug safety but also examine the drugs efficacy. Phase III trials involve hundreds of thousands of patients and last for years or even a decade. Phase III studies are used to determine if the drug treatment is better than the current treatment. It is a very long process to have drugs approved. Out of 100 test drugs, approximately 16 are approved for patient use at a cost of 100 million dollars or so per drug.

There are different types of clinical trials. Investigator initiated trials are patient focussed and based on the combination of drugs. They take a long time to complete and funding is often difficult. Co-operative group trials are led by physicians who are focused on one treatment. They are run at the same time in different centres. Lastly, there are pharmaceutical company driven trials. They are usually large studies focussed on a particular drug developed by the company.

Why are Phase III studies important? It is because the patients are randomly chosen to be either in a group who receive the medication or in a control group who receive a placebo. When you participate in clinical trials, there are several benefits, such as access to new therapies and new treatments, with possibly fewer side effects, and to a high quality of care. On the down side, the treatment may not work or may have worse side effects than the current treatment.

To get accepted in a clinical trial, begin by asking your doctor or medical team. Your team will have access to the eligibility/exclusion criteria, an overview of the study, and the consent forms. It is always best to bring someone with you to take notes and ask questions. Always ask for the details of the treatment such as:

- Is it oral or by injection?
- How long does the trial last?

- How many visits are involved?
- How long is each treatment?
- Is the treatment randomized?
- If it is randomized, is there an opportunity for cross over later if you get the control arm?
- Are there tests needed during the trial, and if so, what and how often?
- What are the side effects?
- Are there extra costs?

Dr. Tiedemann presented updates from the December 2018 American Society of Hematology (ASH) conference. He noted that daratumumab has been approved for use in Ontario. Daratumumab is a monoclonal antibody that attaches to tumour cells and then attracts other immune cells to destroy the tumour cell. A monoclonal antibody is actually a protein made by a cell and engineered to recognize the myeloma cell to destroy it.

Cancer Care Ontario has very recently announced funding for daratumumab. It must be used in combination with either Revlimid and dexamethasone or Velcade and dexamethasone. The funding is based on two studies published in *The New England Journal of Medicine*: the Castor study and the Pollux study. The Castor study tested the addition of daratumumab with Velcade and dexamethasone in patients with relapsed myeloma. The study showed that 61 per cent of the patients had a lower risk of disease progression with the addition of daratumumab.

The Pollux study focussed on relapsed patients as well, but tested the addition of daratumumab with Revlimid and dexamethasone versus Revlimid and dexamethasone alone. A larger group was involved in this study, and again, the addition of daratumumab showed a 63 per cent lower risk of disease progression.

The side effects of daratumumab are quite reasonable compared to most drugs. It can cause an infusion-related reaction, which is usually a temporary condition and may result in a fever or hives. Often, it occurs only upon the first infusion of the drug. Daratumumab also does increase the chance of neutropenia.

The Castor study looked at patients who received daratumumab after one, two and three lines of treatment. It was found that the biggest benefit was after one line of treatment in the first relapse stage. It also showed that when daratumumab was added, it reduced the relapse risk by factor of 37 to 39 per cent and improved the median progression free response to roughly 22 months.

When daratumumab was added to front line therapy for non-transplant eligible patients, it was found that at 30 months, the median of progression free survival had still not been reached compared to Velcade, melphalan and prednisone that produced 18 months of progression free survival.

The MAIA study looked at the outcome of progression free survival when adding daratumumab to Revlimid and dexamethasone as the first line treatment. After more than 30 months, approximately 71 per cent of the participants were still progression free.

An update was provided of the Alcyone study, originally presented at the 2017 ASH conference. This study looked at the addition of daratumumab to Revlimid and dexamethasone as a frontline therapy. The update showed 60 per cent of the participants were still progression free after 30 months. This is encouraging data.

The take home message from these studies is that daratumumab works well in combination with Revlimid or Velcade. It is particularly beneficial when used in newly diagnosed patients or at first relapse; however, even after two or three lines of relapse treatment, it still works well.

Dr. Tiedemann provided an update on maintenance therapies following transplant. Most people receive Revlimid following transplant and remain progression free for a longer period of time. However, the Tourmaline study looked at the administration of ixazomib (brand name Ninlaro) for maintenance. Ixazomib is an oral proteasome inhibitor, in the same family of drugs as Velcade. Ixazomib reduced the risk of relapse by 39 per cent, compared to a placebo. The drug was found to be generally well tolerated.

Chimeric antigen receptor T cells (CAR-T cells): Dr. Tiedemann noted this was still in the investigation phase but was worth reviewing. CAR-T cells are engineered to recognize and attach to tumour cells. The patients harvest their T cells through a process called leukopheresis. The T cells are purified, and the antigen receptor is introduced and increased in a tissue culture to a large number of cells. The patient then undergoes chemotherapy to make way for the CAR-T cells, which are introduced by way of infusion.

Dr. Tiedemann noted that CAR-T cells were first investigated in the 1980s, and it has taken over 20 years to perfect them. It is important to note that most studies are still in the initial stage, as the CAR-T cells must be individually engineered to recognize one particular type of tumour. Numerous CAR-T cell studies were presented at ASH. The Bluebird 2121 CAR-T cell phase I study showed that the response rate was dependent upon the number of CAR-T cells received; the more CAR-T cells that were received, the deeper the response.

One of the drawbacks to CAR-T cell therapy, so far, is that the responses are not long lived. Overall, the patients in the BB2121 trial had an average response duration of only about a year. Part of the problem is the level of CAR-T cells drops within months, and the myeloma comes back. One early possible side effect is cytokine release syndrome, caused by the CAR-T cells releasing cytokines into the bloodstream upon recognition of tumour cells. This can cause a fever or a drop in blood pressure that can happen very suddenly. There are also other possible side effects. Patients must be watched very closely for the first few weeks.

The results are promising but still experimental. The CAR-T cells can produce deep response rates, but they are not yet as long lived as hoped. The current cost is around half a million dollars per patient, and with the short response rate, funding will be difficult with the current level of efficacy. It will likely take a few more years before it will be a treatment we can prescribe for myeloma. CAR-T is now being prescribed for some leukemia and lymphoma patients.

Another equally or potentially more exciting approach is using Bi-specific T cell Engaging antibodies or "BiTEs". These are custom antibodies that are specifically engineered to activate the body's T cells against a tumour cell. You do not have to harvest T cells for this, as the antibodies attach themselves upon infusion. A Phase I clinical study called AMG 420 was presented at ASH. A significant number of patients obtained deep responses. Significant side effects were reported.

There is another BiTE called BFCR4350A under trial at Princess Margaret. Dr. Tiedemann has one patient receiving the drug, who had a great response.

Another group of drugs called Antibody Drug Conjugates or ADCs are monoclonal antibodies designed to bind to a tumour cell. Instead of relying on your immune system to attack the tumour, these ADCs carry a drug to poison the tumour cell. A clinical trial was done at Princess Margaret by Dr. Suzanne Trudel. The majority of patients who were given the drug have responded to treatment and for many, it was a long-lasting response. Dr. Tiedemann has a patient who received the treatment and is still in complete remission after two years.

Dr. Tiedemann commented on minimal residual disease (MRD). He noted that when we see myeloma through the microscope, we are typically looking at just the tip of the iceberg of the disease. When we want to treat patients to a cure, we need to treat them all the way down to a single cell. We are hoping with the new treatments we will obtain deeper responses and eventually a cure.

There is a portion of patients now who live a very long time with myeloma, and that portion is increasing with improvements in treatments.

Dr. Tiedemann is very optimistic about a cure being found for myeloma. Dr. Tiedemann briefly described his lab at Princess Margaret, where his dedicated team is conducting great research, actively working toward a cure.

Q. If you've taken Velcade or Revlimid before, are you ineligible to receive funding for those in order to receive daratumumab?
A. You have to be eligible to have one of these drugs funded to receive daratumumab.

Q. Would you only take daratumumab after the first relapse has occurred?
A. It is not funded for newly diagnosed or maintenance patients yet. There are studies ongoing, but the data has not been released as yet.

Q. I'm on maintenance after my third transplant of Revlimid and dexamethasone. Do I assume that if I relapse, they will not add daratumumab?
A. If you're on Revlimid and dexamethasone, your doctor may have obtained that by applying for relapse funding. If so, you can add daratumumab to it.

Q. Does early detection improve the outcomes in terms of treatment?
A. In certain circumstances, it can and because of that, the International Myeloma Working Group (IMWG), has recently changed the diagnosis of myeloma to allow people to be diagnosed earlier. Some patients who were previously determined to be high risk smouldering myeloma are now considered to have active myeloma to allow them to begin treatment.

Q. For newly diagnosed patients on CyBorD, should daratumumab now be part of the treatment?
A. The truth is we don't have the answer as it hasn't been studied. It is not funded by the government for front line treatments using CyBorD. You may be able to make the case for funding if you have private insurance.

Q. If you add daratumumab to front line treatment, do we lose effect of it later on when we relapse?
A. You probably have, but you gain bigger benefits earlier on than later on. So, you're still better off using it earlier rather than later.

Q. For newly diagnosed patients, can we use genomic sequencing to change the treatment?
A. A lot of groups are looking at ways to personalize the treatment. Unfortunately, the number of drugs for myeloma is limited and we do not know which will act best for any one person.

Q. There's a lot of buzz in the U.S. about personalized medicine, is this because they have more medicines, or are they ahead of us in treatment?
A. I'd like to take one step back. Yes, if you find a mutation in one pathway, you may find a drug to treat it. Myeloma has fewer pathways targeted than other cancers. The downside is often it will work on some of the cells but not all the myeloma cells, which means it will come back, usually in a few months. I like the immune therapy procedure and I think we need to look at it more to get deeper responses.

Q. Is daratumumab beneficial for transplant patients or non-transplant eligible patients?
A. It is actually beneficial for both.

Q. Is there any way to keep smouldering myeloma from progressing?
A. We don't have any strong data for anything that would make an improvement. What I would say is that smouldering myeloma is held at bay by your immune system. So, basically, it is best to keep yourself as healthy as you can.

Q. If I have insurance that will cover daratumumab, would that be an option to add?
A. Most insurance companies are going to want some kind evidence of a clinical trial to show this is a good thing to do. A lot will want Phase III randomized trial information.

April 2019

Toronto and District Multiple Myeloma Support Group Survey

Any comments or suggestions you might have are most welcome and appreciated. If you were not at our April meeting, or would like to make additional comments, please return this survey with any comments to the welcome desk at the June 8 meeting, or contact Dave McMullen at davidanderika.mcmullen@sympatico.ca, or 905-648-5146, with any comments or suggestions you might have from this survey.

1) Are there any topics you would like for future meetings?

____

____

2) Are there any topics you would like to see in our newsletter?

____

____

3) We are considering possible social outings for 2019, and future years. Would any of the following outings interest you?

- Saturday lunch gathering at a modest restaurant_________
- Meeting for a meal at another time_________
- Toronto harbour luncheon cruise, similar to what we did last year_______
- Museum visit and restaurant (such as the Aga Khan Museum) __________
- Blue Jays game___________
- Picnic in a park___________
- Social meeting in someone’s home_________
- Any other suggestions? ____

Please turn over/…

4) Is there any other information you would like to see on the support group's website, www.myelomatoronto.ca ?

____

5) Would you have other suggestions or comments about the support group? Is there anything else we should do, or do differently?

____

____

6) Would you like to volunteer to help our support group?

- Help in meeting set-up and tidy-up______________
- Welcoming those attending meetings_______________
- Kitchen/food help_______________
- Secretarial/ administrating help_________________
- Executive committee______________
- Social outings_________________
- Any other activity? ____

7) Include your name, with email, or phone, if you wish:

____

Thank you,

Support Group Executive Committee:
Dave McMullen
Don Hunter
Jan Wleugel
Munira Premji
Bob McCaw
Patrick Taylor