

# ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

## Northside Virtual SG Meeting –

July 11, 2020

### Introduction & News

Thank you to **Nancy B**, IMF Regional Director - Support Groups, who hosted the meeting, with approximately 30 attendees. The meeting began with a guest speaker and then followed with an open discussion.

### Guest Speaker

Thank you to **Tracy Bonds**, RN, BSN, MBA, OCN, Nurse Liaison - Karyopharm Therapeutics, who has had a long career working with Multiple Myeloma (MM) doctors and patients. Tracy met with our group several years ago, and she joined us again to discuss Xpovio (Selinexor), a drug produced by Karyopharm

MM is a rare, chronic disease for which there are many treatments. Approximately 37% of MM patients are under the age of 65. It's common for MM patients to receive many different types of treatments, and to experience periods of remission, relapse and refractory states. It's never a good time to have MM, but it's much better now than it was five and even 10 years ago, with the availability of so many different types of treatments.

Selinexor is the first and only FDA-approved oral drug to treat MM in a new class called nuclear export inhibitors. Selinexor was approved in July 2019 to treat relapsed refractory MM patients who have received at least four prior therapies and their disease is refractory to at least two proteasome inhibitors, at least 2 immunomodulatory agents, and an anti-CD38 monoclonal antibody drug. It is currently used in combination with Dexamethasone (Dex), which boosts response rates. Healthy cells have a protein called XPO1, which is responsible for carrying important materials in and out of the cell's nucleus. Many of these materials help fight cancer but can only do so when they are inside the nucleus. Some cancer cells have too much XPO1 and take too much of the materials that fight cancer out of the nucleus, allowing cancer cells to grow and survive. Xpovio (Selinexor) targets and blocks XPO1 so that it can no longer carry the anti-cancer materials from the cell's nucleus, allowing these materials to accumulate in the nucleus and ultimately killing the cancer cells as they should.

This drug originally received accelerated approval on a Phase 2 clinical trial (CT) because it was the first of its kind, and the efficacy that it showed in refractory patients. Some of the patients in the Phase 2 CT had had as many as 13 prior lines of therapy, including stem cell transplant. 80% of the patients in this trial have had prior stem cell transplants. In the CT, 122 adults were treated with 80 mg Xpovio (Selinexor)

and 20 mg Dexamethasone (Dex) on Days 1 and 3 of every week. The median age of the participants was 65 years old. 1 in 4 patients responded to Xpovio (Selinexor) in the CT, with general response time within 4 weeks; and 3.8 months was the median response time. Participants took Xpovio (Selinexor) and Dex for a median of 8 weeks with some as long as 60 weeks.

Some side effects of the drug include tiredness, anemia, shortness of breath, nausea, vomiting, diarrhea, constipation, loss of appetite, decreased sodium level, low platelet and white blood cell counts, infections, and neurological effects. The right supportive care drugs and changes in drug dosage and schedules can alleviate these effects and it's not something that the patient should have to experience. For example, in the CT 86% of the participants experienced nausea and so now anti-nausea medication is automatically administered with the drug. Infections and neurological side effects happen to less than 1% of patients. They are the same type of infections seen with all of the other MM drugs. Pneumonia and upper respiratory are the two most common side effects.

Xpovio (Selinexor) continues to be administered with Dex, but a CT is in process to study the efficacy of the drug without Dex. The drug comes in 20 mg tablets and patients begin with 80mg (4 pills) two days a week (Days 1 and 3). The pills can be taken with any liquid and with or without food. Dosage and schedule changes occur frequently and so the pills at small doses make it easy to make changes without having to change prescriptions. Blood tests are required the first couple of weeks after starting the drug.

The manufacturer, Karyopharm has a patient support program called KaryForward that offers financial assistance and other support including active certified nurses that are available to answer questions and help with resources. The drug comes with a starter kit with supplies and a caregiver kit.

If you are considering this drug, both Karyopharm and the IMF have informational brochures about the drug, and it is recommended that you obtain these brochures in preparation of discussing with your doctor.

Tracy answered questions for us as follows:

**Q:** What other CTs are taking place?

**A:** There is a trial with 10 arms (10 drugs), where it is being studied in combination with ten other MM drugs, which is very exciting and looks promising. Another CT is wrapping up and accelerated approval from the FDA is expected for adding Velcade to Selinexor and Dex for patients with only 2 prior lines of therapies (so, patients would

be able to begin using the drug earlier in their MM journey). This “triplet therapy”, if approved early, will be available in early October.

**Q:** What are some good anti-nausea medications?

**A:** Zofran (Ondansetron), Kytril, Emenz, Sancuso, Olanzapine (Zyprexa). This information can also be found on the IMF website and WebMD. You can search the internet for “Class 5HT3” and get a list of anti-nausea drugs as well. Don’t ever suffer with nausea, there is no reason to.

**Q:** How long does the nausea from the drug last?

**A:** It lasts for about 3 days. If a patient starts taking the drug on Monday, they should take anti-nausea drugs through Friday.

**Q:** In Phase 3 CT’s, will the limitations of 4 prior lines of therapy be lifted?

**A:** Yes.

**Q:** What is NDA?

**A:** New Drug Application - a drug application needed to file with FDA for approval.

**Q:** Does the drug have a black box warning?

**A:** No, there is still no black box warning, which is a nice thing to have since it has been reviewed twice, with the third time in process.

### **Updates & Discussion**

**Ulysses H.** had a stem cell transplant in April and is doing well. He experienced very few side effects. He is currently not on any maintenance but is considering options for later.

**Jeff W.** reported that his recent test results were good. He is in a Phase 2 CT with Venetoclax, Daratumumab, and Dex. **Nancy** mentioned that Phase 2 CT’s are important because a drug can be approved in Phase 2 if there is a good response. Drugs are usually approved in Phase 3 CT’s.

**Janice B.** attended the meeting for the first time. Janice explained that in late June her general physician recommended that she see an Oncologist due to her blood test results and an out of range protein. She joined the meeting to learn more about MM and get tips for when she meets with her Hematologist/Oncologist later this month in a 30-minute Zoom call. She learned about the group from **Sandy**. **Nancy** recommended [myeloma.org](http://myeloma.org) publications - the patient handbook, the tip card- questions to ask your doctor when you are diagnosed, and understanding your test results. **Lory** recommended finding a way to record the meeting so that she can reference it later and will not be consumed with trying to take notes during the discussion. **Jeff** mentioned that an understanding of MM staging is important, as it is totally different than staging in other cancers. **Nancy** mentioned that in the April issue of Myeloma Today there is an excellent article on immune therapy that everyone should read. Remember to stay isolated and protect yourself. We’re grateful for this group with all the GOOD news!!

Submitted by Wendy R.

## Southside Virtual MM Support Group

July 25, 2020

**August Speaker:** Our August meeting will be dedicated to hearing from Myeloma patients, caregivers, and supporters about any updates and issues they choose. Sharing, teaching, learning, laughing... Grab a cup of tea or coffee and join us...

There were 32 people present by phone and computer for the July meeting. Our speaker was Emory Winship pharmacist Kathryn T. Maples, Pharm D. who is a Board-Certified Oncology Pharmacist (BCOP), a Clinical Pharmacy Specialist, and has enjoyed her first year with myeloma patients at Winship. She entitled her talk **Myeloma Pharmacy 101**. Dr. Maples first gave a brief overview of what myeloma is and the terms with which we all become familiar as we navigate the many aspects of the myeloma journey.

Being familiar with those terms can also help us understand better myeloma medications – old and new. Some of those terms include: bone marrow; plasma cells; monoclonal proteins; Heavy chains (IgG, IgA, IgM...); Light chains (Kappa and lambda). *Take a minute and define/write down your own kind of myeloma now. What are your cytogenetics?*

Take a few moments to review your comfort with the myeloma terms as presented by Dr. Maples -- MGUS, Smoldering, CRAB criteria and SLiMCRAB. You will hear these terms over and over again – and writing them down in a way that has meaning for you can help you communicate better with your physician and other healthcare providers.

Your oncologist will likely ask you to participate in making decisions on a next kind of treatment or for Clinical Trials participation. Since all of the drugs have at least two names, it helps to be somewhat familiar with the drugs and how they work. Dr. Maples provided both the clinical and brand names for the medications in her presentation. You will not be tested on these drugs but take some time to fit what you already know into some newer information.

Each of the drugs and classes of drugs has special ways to attack and destroy myeloma. We are fortunate because there have been so many new approvals of drugs just in the past 10 years. Each time, the drugs become more specific and more precise in how they attack the myeloma. For many years, the only drug available to specifically treat myeloma was Thalidomide. The increase in better drug availability has increased the average life expectancy from about 2-3 years to more than 7-10 years.

Dr. Maples then moved into the kinds of medications available – or classes of treatment options. All medications have side effects – and may not be tolerated the same from patient to patient. This is part of the reason it is so important to keep track of your side

effects and communicate with your providers about any changes you observe. The lists of side effects are long, some include diarrhea, constipation, secondary cancers, and shingles. There are effective ways to control many of the side effects, but you must speak up and help to weigh the benefits and risks of any medication you take. **It is not necessary that you know all the names of these drugs**, but if you have some familiarity and know where to find the information when you need it, you will be several steps ahead of the game.

Myeloma drugs and classes include:

**Immunomodulatory Drugs** (Thalidomide, Lenalidomide/Revlimid, Pomalidomide/Pomalyst).

**Proteasome Inhibitors** (Velcade/Bortezomib, Kyprolis/Carfilzomib, Ninlaro/Ixazomib).

Newer Drugs include **Monoclonal Antibodies** (Daratumumab/Darzalex [Anti CD38], Elotuzumab/Empliciti [Anti-SLAMF7], and Isatuximab/Sarclisa [Anti CD38]).

Even more novel mechanisms: Both oral meds and still in Clinical Trials. **Selinexor/Xpovio** is the first drug in its class – SINE (Selective Inhibitor of Nuclear Export) and is taken twice a week by mouth with proteasome inhibitors. Allowed for people who have failed on three other classes of drugs. **Venetoclax/Venclexta** is available for patients who have relapsed and have translocated chromosomes (11;14).

**Steroids** like Dexamethasone (Dex) and prednisone enhance the work of all the other drugs.

Continued research has led to easier ways to take medications. An example is Darzalex. When it was approved in 2015, Darzalex could take as long as 6 hours by infusion. With greater research outcomes, Darzalex was approved in May 2020 for subcutaneous (Sub-Q) delivery. There are also several treatment options that are oral medications, like Ninlaro, Pomalyst, and Selinexor, making it more convenient for patients and their families. These advances in research have been an unintended silver lining during COVID-19, when physical distancing and protection of immune systems became even more important. While there is convenience in taking these medications, you must be even more vigilant in keeping to scheduled lab monitoring and reporting any side effects to providers.

Dr. Maples shared several more drugs that are in different phases of research and trials. She discussed therapies with **BCMA** targets (**B**-cell **M**aturation **A**ntigen), including Belantamab Mafodotin, CAR-T therapy, and BiTEs.

Getting to know myeloma medications can be very confusing at best. The pharmacist is an intricate part of your care team and is there to help you. Roles of the pharmacist include education, supportive care/management of side effects, chemo-dosing, as well as dispensing drugs.

## Q & A –

**Where can we dispose of unused medications?** Emory Winship has bins around for disposal. You can find locations close to you using this link. <https://safe.pharmacy/drug-disposal/>.

**Why can't we share unused expensive drugs with patients who need them?** The safety of the drugs cannot be guaranteed. Exposure to hot, cold, or moist environments, dates of expiration cannot be verified. How long should one take Acyclovir? What about after getting the Shingrix shot series for shingles? As long as you are being treated for myeloma, continue taking Acyclovir. It is a drug that can be taken long-term without known harmful side effects. Shingrex is reportedly 68% effective without acyclovir. Better safe than sorry.

**How much melatonin is safe, considering age and other factors?** In children, melatonin seems to have the opposite effect from sleep. Dosages can range from 1-10 mg.

**There has been reporting that Vitamin D deficiency is higher in those with myeloma – especially African Americans and in those with COVID-19. What should we know and is Vitamin D3 better than D2 or vice versa?** Vitamin D is important to bone health and much more. We should get about 30 minutes of sunlight each day to help. Get your Vitamin D level checked and discuss the outcome with your oncologist. Both Vitamin D3 and D2 are effective. Vitamin D levels should be checked periodically (*gail: Insurance company would only pay for Vitamin D2. D3 was about \$13.*) Be sure to tell your doctor about all the vitamins, supplements, herbs, etc. you are taking. Green tea and Vitamin C have been shown to make Velcade less effective. Turmeric is a supplement that has been mentioned to be helpful in keeping Myeloma in MGUS or smoldering stage. Paulette suggests we ask Nancy about a member of the northside group who was participating in a trial with turmeric.

**What do we do about cramps, including stomach cramps?** First, try to determine the cause of the cramps. Often, is an electrolyte deficiency, like potassium or

magnesium. *Be sure you are consuming a diet rich in vegetables and fruits— nuts and beans for magnesium.* Some find that quinine is helpful. If stomach cramps are related to nausea, constipation, diarrhea, etc., there are medications that may help.

**Is there a genetic predisposition to myeloma?** We have seen some evidence of myeloma in families, but at this time the stronger evidence is that family members had similar exposures. The research is ongoing, however.

**What should we do about our dental visits during COVID-19?** Regular cleanings are no problem. Dental offices are providing high levels of protection from average risk of COVID-19. For procedures that go under the gum, please clear with an oncologist.

**Where can we look for Clinical Trials that might meet our needs?** Start with your oncologist. Then the IMF maintains a list of clinical trials that are ongoing at centers across the country.

**Are there any drugs (or a class of drugs) that are more (or less) effective based on race or ethnicity?** There is no one class of drugs that is less effective in African Americans. African Americans have more standard risk than Caucasians. High risk myeloma is more prevalent in whites.

### **Announcements/Resources/Upcoming Meetings**

- Vitamin D.** for Myeloma – for COVID-19. Get your Vitamin D levels checked. Best supplement is Vitamin D3 (not Vitamin D-2)
- Mental Health Services.** 24/7 Georgia Crisis Hotline/Access Line - 800.715.4225
- IMF.** Virtual Patient and Family Seminar. August 15 @ 4:00 PM. Register at [myeloma.org](http://myeloma.org). Resources listed for active participation.
- IMF.** Post-ASCO/EHA (European Hema Association). Replay available. <https://www.myeloma.org/videos/post-asco-eha-2020>
- LLS.** Understanding the Emotional Effects of Cancer. Replay from January 29. <https://www.lls.org/patient-education-webcasts/understanding-the-emotional-effects-of-cancer>
- MMRF.** Groundbreaking Launch of Cure Cloud. Research initiative to use genome sequencing, capture data and get the right treatment at the right time – to get closer to precision medicine in the treatment of myeloma. Patients can get their own genome sequencing free of charge. Genomics are shared across cancers. <https://mmrfcurecloud.org/>

•**MMRF.** Virtual Patient Summit. August 1 @ 9:00 AM. 2-Hour Summit covering information for newly diagnosed, maintenance therapy, state of myeloma, etc. Register at [mmrg.org](http://mmrg.org). List of study materials provided.

•**Patient Power.** Replay. Treating patients with renal insufficiency. <https://patientpower.info/multiple-myeloma/treatments/treating-myeloma-in-patients-with-renal-insufficiency>

•**Please Vote.**

•**Advocacy** – Two Bills: Increase Diversity in Clinical trials and require Medicaid to pay for Clinical trials therapy.

•**Smart Patients.** Cover topics including medications, side effects, treatment options, Medicare & MM, personal experiences, Clinical Trials, and more. [www.smartpatients.com](http://www.smartpatients.com)

**Emergency Resources** – some funds may have run out

•LLS - \$250 - not income-related. Call 877-557-2672

•Healthwell – COVID-19. \$250. <https://www.healthwellfoundation.org/fund/covid-19-fund/>

•Team Rubicon– reduced to \$300. Apply online: <https://teamrubiconusa.org/applynow>

•Cancer Emergency Fund \$250– Cancer Support Community - 1-888-409-4166

Respectfully submitted, Gail