

# ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

## Northside Virtual Meeting

June 6, 2020

### Introduction & News

Thank you to **Nancy B**, IMF Regional Director - Support Groups, who hosted the meeting, with approximately 35 attendees. The meeting began with a guest speaker and then we had a short open discussion.

### Guest Speaker

Thank you to **Jennifer Shannon**, a Clinical Pharmacist and Owner of Lily's Pharmacy in Johns Creek for 7 years. Also joining the call was **Katie Groover**, a myeloma patient and advocate. Jennifer explained that patients should have a direct relationship with a local pharmacist for the best possible care, especially patients with life-threatening diseases. Pharmacists in general are very educated and accessible. They are able to see the big picture and will advocate for you. When patients have a direct relationship with their pharmacist in can drastically improve their quality of outcomes and having your pharmacist as part of your care teams can help prevent problems.

Jennifer strongly believes that patients should be able to choose their pharmacies and that Insurance companies should not force patients to go to pharmacies that are not of their choice. Jennifer has insight into her customers' care and has worked to advocate for them. She is highly involved and passionate in her work to drastically improve patients' rights to get their medications from a pharmacy of their choice. She has worked with legislatures and now, as of January 2020, patients in Georgia can get their medications at a pharmacy of their choice. This is known as the Patient Choice Law SB 313.

When you have a single pharmacist on your care team, they know you and are aware of your history and all medications that you are taking. They can caution you about side effects and dangers of drug interactions. Katie commented on

her experience with establishing a good relationship with your pharmacist. Since changing to a privately owned pharmacy (Lily's) and getting all of her medications from one source, she has seen first-hand how important this is. When her doctor prescribed new medications to her, her pharmacist called her to warn her of potential and serious side effects due to the introduction of the new medications. Her pharmacist understood the big picture, and this could not have occurred if she were receiving her medications from multiple sources. Katie said that it is very comforting to her and makes her feel safe.

Jennifer provided a contact email address: [jen@lilyrx.com](mailto:jen@lilyrx.com), and she answered questions for us:

**Q:** Please comment on riders on health care plans. **A:** Riders on health care plans and assistant cards are not always applied to Cancer patient deductibles, but they should be. This is something that we are fighting for. **Q:** I have very high co-pays. How are those determined? **A:** It depends since it is very complex and convoluted, and there are things to consider such as plan formulary allowances. Ask your pharmacist to help you select a health care plan that fits your needs. Especially if you are stable and on a regimen, your pharmacy can help you select a good plan for you. **Q:** My medication used to be mailed to me directly but now it is getting mailed to a chain pharmacy. Why? **A:** This is not allowed, and medication should be delivered to patient directly. **Q:** Please comment on the Medicare Gap (donut hole). **A:** Recommend not signing on with an Agent without checking with your pharmacist first. Jennifer has experience with being able to save her customers thousands of dollars of out of pocket costs by recommended a different plan for them. Your pharmacist can review your regimen and recommend a plan for you. **Q:** If you go to a large chain pharmacy to get your medications, how can you establish a direct relationship with a pharmacist? **A:** Request that they review your history and establish a relationship, and if they will not agree, then highly recommend changing pharmacies. Patients should choose their pharmacists the same way that they choose their doctors. **Q:** Please comment on copay relief from non-profit organizations and patient assistance programs from drug manufacturers. **A:** These are great resources, but the funding can run out.

**Molly** commented that she has had very positive results with financial and copay assistance from the following organizations:

- 1) Patient Advocate Foundation

2) HealthWell Foundation

3) Leukemia and Lymphoma Society (LLS)

### **Group Discussion**

There was some discussion about the recently approved Daratumumab subcutaneous injection that takes approximately 5 minutes, rather than three hours for the intravenous administration. Several people in the group commented that they are happy with this drug being administered this way.

We also discussed COVID-19 and the effects on myeloma patients. Dr. Durie posts frequent updates on the IMF website [www.mywloma.org](http://www.mywloma.org) to keep us informed about COVID-19 and the impact on MM patients. There are very few MM patients with COVID-19.

Someone mentioned that they were surprised when, in the infusion center at Emory they encountered a person accompanying another patient who had removed their mask, which is against protocol. When they asked them to put their mask back on, they were polite about it and did so, however it was still alarming to them that this occurred. We discussed that as COVID-19 restrictions are lifted and the weather becomes warmer, we may encounter others who are less likely to wear masks, even when required. It is important to speak up any time you do not feel safe. Also ask the medical staff to enforce rules when necessary.

Submitted by Wendy R.

**Southside Virtual MM Support Group**

**June 27, 2020**

Next Month's Topic: "**Myeloma Pharmacy101 – and the new kids on the block.**" Speaker: **Kathryn Tyler Maples. PharmD, BCOP\***, Clinical Pharmacy Specialist. Emory Winship.

\*Board Certified Oncology Pharmacist® (BCOP)

In June, we were fortunate to have two great speakers who brought very different and varied messages to our group. – Robin Tuohy and Shawn Garrison, PhD. We had 32 members join us by computer and by phone. We did have some technical issues that were thankfully quickly resolved by our IMF partners.

We opened with a moment of silence and a special prayer for our member, **Jameca**, who had suffered a traumatic accident the evening before. Jameca is well on the path to healing now.

Our first speaker was **Robin Tuohy** who is the Vice President for Support Groups for the International Myeloma Foundation (IMF). We wanted to remind some members and introduce to others the many roles and services that IMF provides in its patient-centered approach to research, education, and resources to the myeloma community. We also introduced Jon Fitzpatrick who is the IMF IT support person for over 120 Support Groups. He came to our rescue again for this meeting.

Robin started by conducting a quick review of the '[myeloma.org](http://myeloma.org)' website and of the Southside Atlanta Myeloma website as well. Dr. Durie (Co-Founder of IMF; Chairman of the Board for IMF, Chair of IMWG, etc.) provides an updated one-stop shop of COVID-19, as it relates to myeloma; each Thursday, the Myeloma Minute is published and distributed via email – let us know if you want

to receive it. COVID-19 Triumphs and tragedies – the number of cases, hospitalizations, and deaths continue to climb in the U.S., while in Iceland, where there is ongoing myeloma research, there are zero cases of COVID-19. What can we learn? The one-hour webinar from June 25, which provides an update of ASCO meeting (American Society for Clinical Oncology) was excellent – and is already available for replay—worth the time. It includes Drs. Durie, Mikhael, and Cole. Also, a reminder to take advantage of COVID-19 grants from LLS, BMS/Team Rubicon, and Healthwell.

Robin then pivoted to share updates on therapies for myeloma. The first drug was **Sarclisa**, also called Isatuximab. Sarclisa is in the same class of drugs as Daratumumab (aka Dara or Darzalex) and Elotuzumab (aka Empliciti). The class is **monoclonal antibodies**. They work with the immune system to fight myeloma cells with a 1-2 punch. It is usually taken with Pomalyst (Pomalodomid) and the steroid, Dex (Dexamethosome). **Gail** reviewed the new drugs in our May meeting as part of the introduction of new vocabulary and will send information again to the group.

Dara was recently approved by FDA to be delivered subcutaneously. Originally, Dara treatment could take over four hours to be administered. It is an effective drug, and since its initial FDA approval in 2015, much work has been invested to make it more convenient for patients. It now takes less than 30 minutes. More good news is that the injections can cost as little as \$5.00 per injection through a patient assistance program. In June, FDA approved **oral XPOVIO®** (selinexor), as a first-in-class, **Selective Inhibitor of Nuclear Export (SINE)** compound, for the treatment of adult patients with relapsed or refractory diffuse large B-cell lymphoma. XPOVIO® is used in combination with **dexamethasone** for the treatment of adult patients with relapsed or refractory multiple myeloma who have received at least **four prior therapies** and whose disease is refractory to at least two **proteasome inhibitors** (Velcade. Ninlaro, Carfilzomib), at least two

**immunomodulatory agents** (lenalidomide, revlimid, pomalidomide), and an anti-CD38 monoclonal antibody (Sarclisa/Isatuximab, Dara/Darzalex).

Iceland is central to a research project called iSTOPMM (Iceland **S**creens **T**reats or **P**revents **M**ultiple **M**yeloma). This is a national effort to prevent myeloma before it starts, and part of the Black Swan Research Initiative® -- the effort to find a cure for myeloma. Every one of the over 120,000 adults over 40 years of age has completed informed consent to undergo routine blood tests for precursors of myeloma or MGUS (monoclonal gammopathy of undetermined significance). One of the important unique features of Iceland is that most of the family genealogy is easily traceable, and contributors to diseases may also be traceable.

Finally, Robin was able to share with us the statement of solidarity of the IMF with the Black Lives Matter movement. There are disparities and inequities that contribute to the difference in treatment and outcomes for African Americans in general in medicine. IMF commits to do all it can to name any structural racism that exists “and will work tirelessly to improve healthcare access for Black Americans and diverse communities all around the world.”

**Dr. Shawn Garrison** is a psychologist and long-term Director of Counseling at Morehouse School of Medicine. COVID-19 impacted Morehouse students at another level of intensity, as they are preparing as medical professionals to serve on the front line amid the pandemic. This trial was then compounded by the deaths of George Floyd, Ahmaud Arbery, and many others that resulted in the nationwide demonstrations, marches, and the Black Lives Matter movement. Dr. Garrison had the responsibility of helping these high achievers, who are also primarily people of color, navigate this multiplicity of issues, while remaining focused on their learning.

Dr. Garrison chose to present lessons we can all use in **The Four Agreements**, which grew out of the Toltec knowledge and traditions. The Toltec are men and women of science in ancient Mexico who seek to conserve the spiritual knowledge and practice of the ancient ones. No matter our situation or circumstances, we can find wisdom and guidance in the foundation of The Four

Agreements. First, take time to Breathe – and clear the outside noise and clear your mind. We can protect and improve our mental health if we abide by the Four Agreements.

- Ø The First Agreement - **Be Impeccable with Your Word**
  - o Hold yourself accountable. Seek first to understand, not to be understood.
- Ø The Second Agreement - **Don't Take Anything Personally**
  - o Be sure to tell the truth – to yourself.
- Ø The Third Agreement - **Don't Make Assumptions**
  - o Don't assume but clarify. Humans have a unique gift – as storytellers.
- Ø The Fourth Agreement - **Always Do Your Best**
  - o Self Explanatory.

Gratitude is like an anti-inflammatory drug. It releases cortisol. When there are traumatic events, like Ahmaud Arbery, George Floyd, et al., acknowledge it, show compassion, breathe, and accept it.

The Four Agreements can be found in a series of books by Don Miguel Ruiz.

**Resources** for 24/7 mental health services can be found below. We must all acknowledge – tell the truth that we are negatively impacted by the uncertainty surrounding COVID-19, where we are on the Black Lives Matter Movement, and how we handle all these new stressors with our myeloma.

Dr. Garrison has volunteered to conduct some small group mental health counseling sessions with the group. We will follow up on this.

Respectfully submitted, Gail