

# ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

## Northside Meeting

May 2, 2020

### Northside Virtual Meeting

#### Introduction & News

Thank you to **Nancy B.**, IMF Regional Director - Support Groups, and **Jim M.** who hosted and co-hosted this very interactive meeting, with approximately 40 attendees. Nancy started the meeting with a presentation and then we had a general open discussion where we shared information and provided updates on treatment progress.

The Leukemia and Lymphoma Society (LLS) has \$250 funding available to help all blood cancer patients. From the website, <https://www.lls.org>, click the PATIENTS & CAREGIVERS tab for more information, or call the toll free number.

There is a \$500 grant for food assistance for cancer patients. To sign up, <https://teamrubiconusa.org/applynow/> This is for cancer patients who are on treatment or have had treatment within the last six months.

#### New Members

We welcomed several new members. **David B.** who met Nancy at the November conference, and **Donna S.** and her husband, **Jamil** all attended for the first time. We hope to get to know our new members better in our next meetings.

#### Presentation

The **IMF** has been serving the multiple myeloma (MM) community since 1990 with education, support, global research, and advocacy and is celebrating its 30<sup>th</sup> anniversary! The IMF's mission is to improve the quality of life of myeloma patients while working toward prevention and a cure. There are approximately 160 IMF Support Groups in the U.S. The IMF empowers patients through an abundance of educational resources including virtual Patient & Family seminars, teleconferences, weekly e-Newsletters, blogs, the Myeloma Minute (every Thursday night directly to you via email), and educational publications that are free.

Dr. Durie posts weekly blogs to keep us informed about COVID-19 and the impact on MM patients. He collaborates with MM doctors in the U.S. and in other countries to learn about their challenges. There are very few MM patients with COVID-19 globally, and those who have gotten it are recovering. The IMF website has fast-changing and pertinent information about MM and COVID-19. You can stay updated going to <https://www.myeloma.org/> Scroll down to the first link on COVID-19 updates. There is the replay of the Seattle Seminar and the weekly blogs. Be sure to scroll to the bottom of the page for resources and financial support.

The drug-specific publications provide information such as how the drug works, clinical trial (CT)

results, how the drug is administered, common side effects and managing side effects. One of the new publications is for SARCLISA (**Isatuximab**), a drug that was just recently FDA-approved in March 2020 for relapsed, refractory MM. Nancy presented information about several different types of treatments including Immune Therapy, Bispecific T-Cell Engagers, and CAR T Therapy.

**Immune Therapy treatments: Elotuzumab**, a monoclonal antibody drug targets, and attaches to SLAMF7, which is a protein that is unique to some types of MM cells, and activates a patient's natural killer (NK) cells to attack MM cells. **Daratumumab** is a monoclonal antibody drug that targets CD38 in six different ways to attack MM cells and assist NK cells to attack the MM cells. The FDA just approved Daratumumab to be administered via subcutaneous injection on May 1<sup>st</sup>, 2020, which will take 3-5 minutes, rather than hours for the intravenous administration. Another drug in this class is **Isatuximab** which also targets CD38.

**Bispecific T-Cell Engager (BiTE)** is a treatment that targets two antigens at once and is on the fast track for FDA approval expected for later this year. The drug targets and attaches to BCMA on the MM cell and attaches to T Cells. The link formed between T cells and MM cells direct the patient's immune system to attack the MM cells.

**CAR T Therapy** is a treatment that involves harvesting a patient's T cells, send them to a lab to genetically modify and grow billions more. These T cells are then infused into the patient after the patient is treated with lymphocyte-depleting chemotherapy. This treatment is currently considered a rescue treatment for patients who have failed multiple transplants and multiple CTs and the results have been good. A common side effect is cytokine release syndrome (a.k.a. cytokine storm) that causes high fevers and researchers are working to get that better controlled.

### **Open Discussion**

**Doris** is doing well and the Southside support group is doing great.

**Donna** asked about information available for newly diagnosed patients and **Nancy** and **Molly** recommended the Patient Handbook, available at the IMF website. It contains a glossary which is very helpful to everyone.

**Cynthia** was just released from the hospital on April 27<sup>th</sup> after having CAR T therapy. She was given a drug called Anakinra, which was injected into her stomach to prevent the high fevers that accompany this treatment. She is doing well and will be at Emory again soon for her next follow-up visit.

**Ulysses** had a stem cell transplant on April 2<sup>nd</sup> and is at home and doing well.

**Jeff** was glad to hear the FDA approved subcutaneous administration for Daratumumab. He's been on it for two months in a CT and it is "awesome".

**Walt** had a question – With all of the available MM drugs, why is there not a single MM drug that can take care of everything? Nancy mentioned that we are currently accomplishing this by combining drugs, but a single drug for all versions of MM is still being researched.

**Libba** is doing well and mentioned that she has failed treatments for both the Immunomodulatory Agents and Proteasome Inhibitors classes of MM drugs, but is now using Daratumumab (only) and has achieved complete remission. She had been taking Daratumumab and Pomalyst and the MM was not controlled but when she stopped taking Pomalyst, the MM is under control. Libba mentioned that she gets treated at St. Joseph's which is working out great

for her. There is free parking, free lunches, is close to where she lives, and the facility is efficient.

**Dirk** was taking Daratumumab and Pomalyst but had to stop taking Pomalyst because of issues with his WBC count. He reintroduced Pomalyst at a smaller dose after his WBC recovered and is doing well.

**Lory** asked if anyone has been on Pomalyst and not had serious side effects. **Jim** said that he has not had major problems while taking Pomalyst since last September. His WBC has changed but it is OK. Jim mentioned that when he was on Daratumumab he experienced shortness of breath and had to use an inhaler. When he was on Velcade he gained weight (20 lbs.) but is doing OK on Pomalyst. Someone else mentioned that when they were on Dex they experienced hot flashes and had a heart rate of over 100. They reduced the dose and then it was OK.

**Lory** asked if anyone else has experienced acute pancreatitis with any of their treatments. She has had this since last fall and wondered if it could be associated with any of the MM drugs. No one in the meeting has had this issue and Nancy suggested that she contact the IMF Info Line at to get more information.

**Sandy** is doing well and mentioned that her son-in-law, who is also a MM patient is doing well on Pomalyst. Sandy's son-in-law was in remission for six years, then had a stem cell transplant last August, and is now on Pomalyst. He is in remission and has had no side effects from the Pomalyst, but still has back pain.

We talked about how we are spending our time while quarantined. **Molly** enjoys online aerobics and several other members mentioned gardening and pilates on video. Nancy walks a couple of miles a day and is using weights at home. Anything that gets our pulse up is good for lymphatic fluids which only move when we do. Nancy's counterpart in the northeast is a certified yoga instructor. She has posted chair yoga sessions on the IMF webpage.

Submitted by Wendy R.

Everyone stay strong, stay safe, and stay home!

Submitted by Nancy Bruno

**Southside Myeloma Support Group**

**Virtual Meeting Minutes**

**May 23, 2020**

**Note:** On June 10, 2020, the International Myeloma Foundation issued a statement against racism and in support of Black Lives Matter. Please read and

share that statement which is at the conclusion of our meeting minutes for May 2020. This is an important statement from the medical arena in general and myeloma field specifically. We know that institutionalized racism is not confined to social or economic settings. ~ *Gail*

**Next Meeting:** June 27, 2020. Speakers – **Robin Tuohy** – Vice President, Myeloma Support Groups – IMF and **Shawn Garrison, Ph, D.** Psychologist. Morehouse School of Medicine. Director, Counseling Services, Assistant Professor, Department of Psychiatry. Dr. Garrison has led a team of physicians, students, and staff through one of the most challenging years yet at the Morehouse School of Medicine. COVID-19 is just one of the areas of concern for both physicians-in-training and veteran physicians. The mental and emotional impact on all of us has provided us with new skills and lessons learned. Topic - ***The Four Agreements: Happiness can be a way of Life for us all...*** Contact Paulette if you would like to be included in the email for linking to this virtual meeting – [ppmneely@gmail.com](mailto:ppmneely@gmail.com)

Our May meeting was our third one held virtually via the “GoToMeeting” platform, compliments of the IMF. May was also Mental Health Month – we encouraged everyone to take advantage of mental health services provided especially during COVID-19 by the Georgia Department of Public Health and NAMI (National Association of Mental Illness). Those resources have been provided in part by Emory Winship Social Worker, Kendelle Miller. They are in the Announcements section of these meeting minutes.

Our speaker was **Deborah Thompson, BSN, RN, OCN.** Deborah is a nurse at the Veteran’s Administration Hospital and has been a member of this Myeloma Support Group almost since its inception. She has treated several of our members at the VA in the oncology unit. She will celebrate 42 years at the VA Hospital this June. She is a leader in her profession and is the 2020 President of the Metro Atlanta Oncology Nursing Society (MAONS). Deborah has provided guidance for our group through her medical views with a healthy dose of common sense, that we call her “Pearls of Wisdom.”

Deborah is a woman of strong faith – and asked permission to provide a prayer written especially for the group. The prayer included references to how we handle the coronavirus, our fears for our health – physical, mental, and financial. She emphasized the importance of paying attention to our spiritual health, and to how one part of our being ties into other parts of our being – so that mind, body, spirit, and emotions are all interrelated. She had so many requests for the prayer and her “Pearls” that she generously allowed Paulette to send copies to all members.

Deborah opened with some facts about the coronavirus to keep in mind as we enter the Memorial Day weekend and are tempted to celebrate with family and friends. It is also graduation season, the weather is getting warmer, and we are getting “cabin fever.”

Deborah’s 20 Pearls of Wisdom include: Older adults and those with compromised immune systems, including myeloma, are at higher risk. The virus spreads mostly by person-to-person, close contact – particles are inhaled through the mouth and nose into the lungs. We should wash our hands vigorously after each time we venture out to a public place. Soap and water are the absolute best, but if they are not available, wash your hands with a hand sanitizer that is at least 60% alcohol (rubbing alcohol). Be conscious of keeping your hands away from your eyes, mouth, and nose – ports of entry to the lungs.

Treat everyone as if they are positive for the virus. At least 35% of those with the virus have no symptoms. Even at home refrain from embracing during this time when the virus continues to claim more victims – and we do not know enough about it – as it is the **novel** (new) **CO**rona**VI**rus **D**isease, identified in 2019 (COVID-19). *COVID-19 is caused by a coronavirus found in humans SARS-COV-2 (Severe Acute Respiratory Syndrome) Coronaviruses are a large family of viruses that cause a wide range of illnesses from the common cold to MERS-CoV (Middle Eastern Respiratory Syndrome, identified in 2012) (CDC).*

Be the CEO of your own life and your own health. Whenever people gather, use your cloth face covering to protect yourself and others. Do not use facemasks on children under two years of age. Some people, especially those who must wear masks all day, have shown allergic reactions to the materials of the cloths.

Disinfect handles, desks, toilets, steering wheels. Everyone at regular worksites should have their temperatures checked. We have to stay vigilant. Do not take your temperature immediately following exercise or immediately after taking medications.

These “Pearls” should be guiding Principles of Life – not disease. Learn to forgive yourself. Make reparations where needed. Give yourself permission for a fresh start. Let go of toxic people when necessary. Finding your Inner Peace means Finding your Inner Strength.

Be at one with nature. Listen to the birds – the wind rustling through trees. Listen to flowing water. Appreciate the colors and scents of nature. Be of a giving nature.

Strive for Excellence, not perfection. Bring down the curtain on drama. Laugh often – it boosts the immune system (*and has been shown to help control pain*). Know God. Know Peace.

Deborah read to us the inspirational poem by Jon Greenleaf Whittier. The poem talks about the twists and turns of life, and how we are challenged. It says, “Success is failure turned inside out.” The closing lines: “For all the sad of words by tongue or pen, the saddest are these: It might have been.” We must not quit.

During the discussion, several members shared the source of stress and anxiety which are well beyond Myeloma and which are further complicated by COVID-19. Some have grandchildren and were not aware that masks are not advised for children under age 2; others reported having hurt others with their words and have decided to seek therapy; what about visits to the hair salon? (Make a judgement based on how much your salon observes CDC safety recommendations – wearing masks, physical distancing, disinfecting between clients, etc.).

Deborah reminded us that we are social beings, and just being isolated and forced to quarantine can have negative effects. She also stressed the importance of getting outside, fresh air. She tries to walk four miles daily. Take one step at a time.

She advised us to think about the opportunities afforded us by the quarantine: cheaper gas, less wear and tear on your car, learning to relax and reflect.

Deborah closed our meeting with spiritual music selection: Stand Strong

### **Georgia COVID-19 Report:**

May 22, 2020. Confirmed cases – 41, 127. Deaths – 1,783

April 25, 2020 – Georgia has 21,012 cases (vs 2,000 on March 28); and there are 892 reported deaths (vs 64 in March).

### **Announcements/Upcoming Events**

- Reminder: Get **Vitamin D checked regularly** for *Myeloma and for COVID-19*
- Mental Health, 24/7 Georgia Crisis Hotline/Access Line - 800.715.4225
- IMF - [diversity.myeloma.org](https://diversity.myeloma.org)- Includes website and links to articles on current research for minority populations.
- IMF. 10 short Videos with Dr. Durie answering questions about MM patients and COVID-19.
- \_Ask Dr. Durie: Should Myeloma patients get COVID-19 antibody testing? Not currently recommended
- Fulton County Library online. Free eBooks, movies, music, virtual stories. Afpls.org
- MMRF. Precision Medicine and Immunotherapy. *Saturday, May 2, 11 AM – noon.*
- Patient Power. **More on Imaging** Video-2:38. Message – IMWG removed-Skeletal imaging/X-Rays from guidelines for Myeloma. Also, video with **Social Worker**.
- Please Vote.

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

- **COVID Services and Grants**

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

--**Healthwell** – COVID-19. \$250.

--**Team Rubicon** –\$500 (not income based) Patient Advocate Foundation and Bristol Myers Squibb Foundation-**Apply Online:** -

<https://teamrubiconusa.org/applynow>

--Georgia COVID-19 Emotional Health -24/7 – 1.866.399.8938

--Georgia Crisis/Access Line - 800.715.4225

Respectfully submitted, Gail

\* \* \* \* \*

Southside Multiple Myeloma Support Group – Southside group meets at 10:00 on the fourth Saturday of each month in second floor Meeting Room at the Macy’s on Greenbriar Pkwy. Doris Morgan 404-346-1372; [dorismorgana@aol.com](mailto:dorismorgana@aol.com), Gail McCray 770-996-4964; [mccrayg@aol.com](mailto:mccrayg@aol.com)

web site: [ssatlanta.support.myeloma.org](http://ssatlanta.support.myeloma.org)