

# ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

## Meeting Minutes

### Northside February Virtual SG Meeting

February 6, 2021

The meeting began with updates from some of the members.

**Jim** said that his counts went up in December and January. His doctor is keeping him on Dara/Pom/dex along with an antibiotic. He will have an MRI and PET scan to check his myeloma. His colon cancer is under control.

**Dana** had CAR-T therapy in July of 2018 and is still in remission. He still must get platelets every Saturday and he said he prefers that to being on treatment for his myeloma. The healthcare team is concerned that his blood counts have not recovered and are exploring causes and/or treatments. They may take his spleen out to help the platelets recover. He will keep us posted.

**Bob** was on Revlimid maintenance for ten years and did not have a transplant. His healthcare team said it was time for a break and he has been off Revlimid for 70 days. It has not made a significant difference in the diarrhea problems, but the team said it may take 6-8 months for things to get back to normal.

**Sandy B.** is changing her Revlimid to 14 days on and 14 days off next month. Her M-spike is 0.4 and she is only taking one dex pill per week.

**Dirk's** light chain numbers were going up on Dara/dex, so Pom at 3 mg was added. He has the normal dex side effects, and he will continue to monitor his numbers with the team.

**Jeff** has been on Venetoclax for two years and doing well.

**Kyle** gave us an update on his journey. He was diagnosed in 2005 with smoldering MM and it went to full myeloma as he was under stress from final exams to become a nurse. He noted, as many others have said, stress is not good for myeloma patients or most anyone else! He is six years from transplant and work at a senior care hospital where he sees about six MM patients over 80 years old who are doing well. His numbers are good and blood counts are normal. He is on a low dose of Pom with few side effects. He told stories about working at the beginning of the COVID pandemic and how much he had to do to stay safe. The facility learned that if all patients wore masks, then the healthcare workers were less likely to become infected. He stills wears the PPE gear and will not enter a room unless the patient has the mask on correctly. He is glad to be working in healthcare. Kyle's story started a great deal of discussion about the COVID vaccine. Since the meeting, the state of Georgia has set up an online site to register for a vaccine: [MyVaccine \(myvaccinegeorgia.com\)](https://myvaccine.georgia.com) This is a central point for appointments.

Nancy then talked about the Best of ASH teleconference from IMF and the January ASH review with the Winship team. At the ASH meeting last December, there were 688 research abstracts for myeloma. There are so many clinical trials going on around the world and the news is very exciting and hopeful. Nancy showed a few slides from the teleconference and the full slide set is available at [IMF Videos | International Myeloma Foundation](#) under the ASH videos. Some of the slides reviewed were two long-term follow-up projects. The newly diagnosed participants (not eligible for transplant) in the MAIA clinical trial were followed for four year and the graph showed that 60% of those on Dara/Rev/dex were still in remission vs. 38% still in remission on just Rev/dex. In the trial for early transplant (at first remission) vs. later transplant at first relapse, a difference of 12 months progression free survival. At eight years. The median time of remission was 47.3 months with an early transplant vs. a median of 35-month remission for those who had RVd until relapse. Another slide from the teleconference compared BCMA targeted therapies: Antibody drug conjugate, CAR T-cell therapy, and Bispecific antibody treatment. There were two CAR-T therapies reported at ASH. CARTITUDE-1 showed an overall response rate (ORR) of 96.9% and bb2121 KarMMa had 100% response rate. These are great numbers, and both these therapies were submitted to the FDA for approval.

Nancy then urged everyone to visit the IMF web page [www.myeloma.org](http://www.myeloma.org) to read Dr. Durie's blog about the COVID vaccine for myeloma patients. There are also prior blogs about trends in myeloma care and new research. These are quick reads to help us all stay current. The IMF also has publications for every approved myeloma drug including the latest drugs: Xpovio, Sarclisa, and Blenrep. If your doctor is considering a new treatment, go to the IMF site and click on Publications at the top of the page to find the Understanding Series on treatment and side effects. This will provide insight into treatments and help patients participate in the decisions. The first generation of immune therapy (Darzalex) was approved five years ago and is working very well for so many patients. Now, there are more drugs that work in new ways within the MM cell and more treatments coming. Within the last year and a half, five therapies have been approved. Another one, Melflufen, went to FDA for fast-track approval and we should be hearing that answer in the next few weeks. CAR-T is also in the pipeline for approval this year. So much good news and hope for longer survival with good quality of life. For this, it is important to stay informed and empowered.

From our meeting with Winship, Nancy took some screenshots to show at our February meeting and help clarify the discussion. The message is the same as just discussed: there are many new drugs which allows numerous combinations at various relapse stages. So, how do you and your doctor prepare for next steps? Primary is patient characteristics and preferences. The doctor may ask you for input into this decision. Second is the myeloma characteristics such as risk factors

and rate of increase. Other considerations include response and effects of prior treatments as well as understanding of access to treatment. Your input is a big part of the treatment decision. Clinical trials should be part of your perspective. Many of the trials are showing great results and some are testing new combinations of existing drugs to compare effectiveness.

In the presentation, several of the immune therapies were compared by dosing, side effects, and outcomes. A chart was presented of the MM mutations. The chart showed over 60 identified mutations, most are present in less than 5% of patients and not every myeloma cell may have that mutation. We know that every patient is different, and this confirms what we have shared in our meetings. Work continues to identify any targets that can be treated, but MM is so different from the genetic trends in other cancers. Winship is studying the changes when myeloma develops resistance to BCMA CAR-T therapy. Some groups of patients have shown that myeloma can lose BCMA to evade CAR-T cells. This is important for future treatment plans. Another study is trying to predict who will respond to Venetoclax and they have found a unique B cell-like signature. So many questions being addressed by this outstanding research team in our backyard! Stay tuned for more news.

Then the discussion turned to COVID vaccines and some FAQs were presented before opening for questions. Can a vaccine make me sick with COVID? No, the vaccine does not contain a live virus. Will I test positive after a vaccine? No, if your body develops and immune response, then you may test positive on antibody tests, but not viral tests. If I have already had COVID, should I get the vaccine? Yes, experts do not know how long someone is protected after recovering from COVID. Current recommendations are to wait 90 days from your positive test. Will the vaccine alter my DNS? No, vaccines do not change or interact with your DNA in any way. The doctors at Winship recommend getting the vaccine when it is available to you. Winship has a clinical trial to determine how long the immunity to COVID lasts in MM patients. They will draw blood at scheduled intervals to test immunity.

**Questions with answers from the group :**

**Q:** Has anyone had COVID and how was it tolerated? **A:** No one in the group reporting having had COVID.

**Q:** Has anyone received their COVID vaccines? **A:** Many in the group (both patients and caregivers) have received either the first vaccine and/or both vaccines. Some had received the Moderna vaccine and others had received the Pfizer vaccine.

**Q:** How was the COVID vaccine tolerated by those who have been vaccinated? **A:** Very well! The only side effect mentioned by one person was pain in the arm at the injection site after the vaccine was administered.

**Q:** Which is the preferred vaccine – Moderna or Pfizer? **A:** The short answer is: “The one that gets in your arm”! There is no preference at this time, and please note that the IMF and Emory both recommend getting COVID vaccines for myeloma patients and their caregivers. **Sandy W.** provided some information that she learned from a webcast that mentioned that it is a good idea to schedule to have the COVID vaccine during a break from treatments. In general, it is a good idea to ask your doctor about timing and what will give you the best chance of immunity and help you get the most from the vaccine while in treatment.

**Q:** Where did you receive the vaccine? **A:** Some reported receiving the vaccine at Emory; and the Publix pharmacy was also mentioned. **Dave O.** provided some additional information from his experience: “Please be aware, Emory is not providing vaccines for caregivers. However, Publix, Fulton County and others are providing vaccines for up to two caregivers”. **Sandy W.** reminded caregivers to be prepared to be able to respond about your role during the screening process, especially if you are under the age of 65.

**Q:** How do I sign up to receive the COVID vaccine at Emory? **A:** To register for the COVID vaccination online, go to the portal and sign in using your account credentials. Navigate to the COVID section and click the register link where you will be able to sign up. Or call the general number and get transferred to the COVID Center where you can sign up for the COVID vaccination. **Jim M.** provided the new BMT phone number: 404-778-0519.

**Q:** I have acquaintances from out of the area and from out of state, one of which is an Emory patient. Is it OK to share our information and/or can they join our group? **A:** Yes, you can share our information with them, and they can join our group. Also, they can go to the “Resources and Support” link on the IMF Home page to find a support group to join in their area if that is preferred.

**Q:** Once everyone in the group has received their COVID vaccines will we resume the in-person group meetings? **A:** It depends on when the church will reopen, and some other standards and recommendations. Once we are back to meeting in person again, we may continue with the virtual meetings so that more people will be able to join.

**Q:** Where can I find the information that was presented in today’s meeting? **A:** **Nancy** provided a demo for navigating <https://myeloma.org> where the information was sourced. Some highlights include:

- From the Home page, scroll down and see the “COVID-19 Update” section.
- Back at the top of the page in the navigation bars, click on “Publications and Videos”, “IMF Videos” for Best of ASH, and “Blogs”.

Submitted by Nancy B and Wendy R

## **Meeting Minutes** **Southside Virtual MM Support Group** **February 27, 2021**

**Next Meeting:** March 27. Patient and Caregiver Voices, Vaccine Updates  
February was National Heart Health Month. March is Myeloma Action Month, National Nutrition Month and National Colorectal Cancer Awareness Month

We opened the meeting with a moment of silence and acknowledgement of all the lives that have been lost and families impacted due to COVID-19. We also celebrate Black History Month through key individuals in history, including Kizzemikia Corbett, who has been researching the coronavirus in her NIH laboratories for more than 10 years. **Nancy B.** shared that one of her favorite remembrances is the 1,500 Tuskegee Airman who made tremendous contributions to our country during World War II and beyond. Her Dad was an Air Force man.

### **COVID-19 Vaccines Update**

We talked about the COVID-19 vaccine, people's progress with securing vaccinations and COVID-19 vaccine clinical trials. While getting an appointment is still very difficult for those who want one, some shared their experiences.

One of the websites that is easier to navigate is: <https://myvaccinegeorgia.com/> that is maintained by GEMA/FEMA. Some updated information and new sites are located at the end of these minutes.

After trying for weeks, and having an appointment scheduled in Macon, GA for the same week, **Vermell** was able to go into her community Walgreen's, get information, get her appointment and get her first vaccine (Moderna) at Walgreen's Cascade. **Emma's** sister encouraged her to try their Walgreen's in Fayetteville and she was able to get her appointment and successful first dose within a week. Both Vermell and Emma are age-eligible and have a pre-existing condition that should have taken them to the top of the lists at any rate. **Glenda** got her second Moderna injection at Piedmont. People are having varying reactions from none to headaches and fatigue. She took Tylenol afterwards and was fine. She spoke to the group about her anesthesiologist/daughter-in-law who has to witness the pain and death of so many and the family disruption, because we cannot grieve and touch as usual. She encouraged the group to use the thought of the loss in one year of more than 500,000 US citizens, and more than 18,000 Georgians who would be here, but for the pandemic. **Yvonne** was advised not to get a *mammogram* until at least 60 days after the second shot of the vaccine. False positives could result. **Nancy** shared about a healthy neighbor who had COVID and recovered, but is still suffering from residual effects, like lingering blood clots and fatigue.

## *Vaccine Hesitancy*

**Gail** presented a brief PowerPoint on some possible reasons for vaccine hesitancy in the African American community beyond the Tuskegee Syphilis Experiment and the Henrietta Lacks travesty. She talked about the history of medical experimentation in the United States and slavery. Slaves were the most obvious and a vulnerable population on whom to conduct experiments to save lives and advance science. The distrust, biases, stereotypes, lack of confidence and respect have been a part of the fabric and culture of medicine and race story in our country ever since. Unfortunately, this has an impact on the attitudes and behaviors of blacks towards the medical system long before COVID and towards the medical community and medical experimentation like clinical trials today. The historical practices led to the term, **iatrophobia**, or fear of the healer. She talked about the importance of mutual respect, clear communication and building and maintaining trust. “Trust takes years to build, seconds to break, and forever to repair.”

**Carolyn H.** shared that her three very educated white adult children refuse to get the vaccine. Their Priest got COVID and even this did not change their minds. She is seeking information that will help with the family discussions about the vaccine. Trusted information from NIH and CDC on Facts and Myths about the Vaccine, including *how to talk to family and friends about the vaccine*. It is important to provide information to those who hesitate to help them make their own *informed* decisions. **Candice** says fear is a huge factor with hesitancy. We have to identify and name the fears, the questions, and provide information – empowering people with knowledge, sometimes just to get the vaccine for the safety of others we love.

One of the biggest expressed concerns is the apparent “**Warp Speed**” with which the vaccines were developed and *how safe could they possibly be?* The short answer is that scientists have been researching these viruses for decades. When a virus is discovered, its job is to mutate – it never fully goes away. We have had in the 21<sup>st</sup> century SARs, MERs, and Ebola – many upper respiratory diseases that have required vaccines. Therefore, much of the answers for COVID-19 vaccines were already in place with our technology to advance progress more quickly and the research was well funded. Competition among the pharma companies was reduced in cooperative agreements with the government due to the pandemic. All vaccines are continuously studied. They have an Emergency Use Authorization (EUA) from the FDA – not full approval. Continue to find answers through reliable sources. Become an amateur scientist. People also want to know the ingredients of the vaccine. On the consent forms for Pfizer and Moderna at least, the ingredients are listed for our viewing. You can “google it.”

## **Patient Update**

We were excited to have **Alma** back at the meeting. She was admitted through the ER at Emory on New Year’s Eve and was there through February 1. She expressed sincere gratitude to each and every one for their prayers and expressions of well wishes. She had a high fever and a bad cough but tested negative for COVID twice. She was first in Intensive Care for a couple of weeks until they could determine a diagnosis. Her oxygen was low while in the ICU at 20 milliliters (normal range is 80-100 ml Hg). She was then moved to critical care after finding she suffered from a very serious fungal pneumonia. After so long in the hospital and confined to bed, she now must learn to walk again. Her myeloma treatment, which is the clinical trial drug in the iMID (same class as Revlimid and Pomalyst) family, Iberdomide (CC-220) is on hold for at least two weeks. Her sister, Gwen, was always there. She helped to keep us updated on Alma’s progress. She could not visit,

however. They could only communicate by phone and by their “Sister Love”. We are so grateful to Gwen, as sister/caregiver/advocate. Welcome back, Alma and Gwen.

**Emma** is also going through some challenges and needs some extra prayers. She had bad pain under her breastbone, and fortunately, they have ruled out breast cancer. She has a problem with Revlimid, yet that is the current advice. She is being asked to do radiation therapy and is unsure about what to do. Emma and her sister have gone to the Mayo Clinic to get second opinions on her various issues. She has been told that a clinical trial might be her best next therapy. Additionally, she lives in Fayetteville and her hem/onc is at Emory Winship. Transportation is an issue. She is checking resources with the Emory Social Workers and LLS. We wish Emma and her sister safe navigation through this part of their journey.

### **Increasing Awareness of Myeloma among African Americans**

We discussed efforts to increase awareness about myeloma and the support group for all, but especially among African Americans. Being COVID aware, we know that many businesses and clinics are going paperless, so paper flyers would be minimal. **Candice** shared that she found out about the group from a flyer in the break room for employees at Atlanta Medical Center. She can put more flyers there when we send the flyer via email. **Paulette** will see if she can place a few flyers at the Camp Creek Grady clinic through a contact she has there. **Doris and Gail** will place the new flyers with information about our virtual meetings in Atlanta at Emory in a designated location in the infusion Center. Doris has already shared the information through her NPU (Atlanta named neighborhoods) e-newsletter (over 100 active members). She will share and Gail will support sharing with other NPUs (25 in ATL). We will request that all members share the information about myeloma through their social, civic, religious, and political networks.

### **Myeloma Awareness Month**

Our theme once again for Myeloma Awareness and Action Month (MAM) is Resiliency. We practice Resiliency daily as we work to improve our quality of life – mind, body, and spirit. Vena always encourages us to stay positive and to stay around positive people. Exercise, eat well, and call a friend to encourage them. Sometimes the best medicine for us is to help someone else. Gail will request Myeloma information be placed in the electronic publications for the Georgia Primary Care Association. **31 days of Resiliency in March!** How will you show resiliency each of the remainder of days in March?

IMF has branded masks and other merchandise for sale at <https://mam.myeloma.org/>

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

- **COVID-19 – Vaccines.** <https://myvaccinegeorgia.com/> ; <https://dph.georgia.gov/covid-vaccine>; <https://www.fultoncountyga.gov/covid-19/covid-vaccine>
- Optimal Health Lifestyle Intervention. Workshop focused on plant-based diets. FREE. Jennifer Rooke, MD
- **IMF.** Patient and Family Webinar. **Saturday, March 13 @10:00 AM/ From Vaccines to Variants: The Latest in COVID-19**
- **IMF.** Community Workshop, SE Region. Saturday, March 20, 2021
- **Evaluation Project Proposal** – Emory University School of Public Health
- **LLS.** Treatment Updates on Multiple Myeloma. March 2, 1:00 PM. Register by phone: 855.676.7723
- **MMRF.** <https://mmrfcurecloud.org/>. Personalized data from your free genome report.

- **Patient Power. Dinner with the Doctors.** Myeloma Connections for Georgia residents. March 8, 10, and 12. In partnership with Emory Winship.
- **Patient Power. Q & A with a Cancer Dietician.** [https://patientpower.info/living-well/diet-and-nutrition/q-and-a-with-a-cancer-dietitian?utm\\_source=e-News+Subscribers&utm\\_campaign=04835879b0-EMAIL\\_CAMPAIGN\\_12\\_18\\_2020\\_12\\_1\\_MMY\\_US\\_COPY\\_01&utm\\_medium=email&utm\\_term=0\\_9e75b45127-04835879b0-288801964](https://patientpower.info/living-well/diet-and-nutrition/q-and-a-with-a-cancer-dietitian?utm_source=e-News+Subscribers&utm_campaign=04835879b0-EMAIL_CAMPAIGN_12_18_2020_12_1_MMY_US_COPY_01&utm_medium=email&utm_term=0_9e75b45127-04835879b0-288801964)
- **AMAZON Shopping?** [Smile.amazon.com](https://smile.amazon.com) – You can choose IMF, Atlanta Area MM SG, or a charity of your choice.
- **Search for Clinical Trials:** SparkCures – [myelomacrowd.org](https://myelomacrowd.org)
- **Smart Patients.** IMF.

### **Vaccine Information and Resources, including Phone Appointments**

1. How to talk to Friends and Family about COVID

<https://www.cdc.gov/coronavirus/2019-ncov/vaccines/talk-about-vaccines.html>

2. Vaccine Opportunities – all must still abide by Georgia/Federal Guidelines

I would try the Walgreen's and CVS stores in your neighborhood. They seem to have quick turnarounds.

This **link, well-maintained** and updated by GEMA/FEMA is easy to navigate.

<https://myvaccinegeorgia.com/>

### **New Appointments released by Mercedes Benz on March 22, 2021**

The direct link for appointments is: <https://gta-vras.powerappsportals.us/>

Appointments and more information can also be accessed through the Fulton County COVID-19 Vaccine landing page at [www.fultoncountyga.gov/covidvaccine](http://www.fultoncountyga.gov/covidvaccine)

**Need to schedule by PHONE?** Appointments can also be scheduled through the Georgia Health Department Vaccine Scheduling Resource Line at **(888) 457-0186, Monday – Friday 8 AM – 8 PM ET, Saturday – Sunday 8 AM – 5 PM ET.**

Respectfully submitted, Gail.