

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes Northside Virtual MM Support Group March 6, 2021

Northside AAMMSG April meeting will feature Shannon Pawley, J.D., LL. M.-- Setting the Course for Your Estate Planning Journey – Focus of this presentation will be on the importance of having a plan for both life (securing your independence and preparing in the event of incapacity) and your legacy after your passing. Though setting the course often involves many difficult decisions, the relief in knowing your wishes and intentions are known both during life and after your passing is priceless!

Patient session

Twenty-five patients joined the video conference including several new members.

There was a great deal of discussion about patients getting the COVID vaccine. Although most doctors highly recommend getting the vaccine, some issues are causing confusion. Most doctors have the patients suspend treatment the week of the vaccine and some doctors pause treatment for a month. What are the exceptions for getting the vaccine? It is recommended that patients within 100 days of transplant should not get vaccinated. Some patients with active myeloma are not comfortable with suspending treatment. Jim said that he did not take the Dex the week of the vaccine but took other treatment. Most patients have gotten the vaccine under the guidance of their doctors. Another issue discussed is *how long will the vaccines be effective for myeloma patients vs. non-cancer adults.* Emory (and some other centers) is doing studies of MM patients by checking their antibody level every 1-3 months after vaccination. This will help patients understand the vaccine efficacy and what precautions they may need to take. Until there are clear answers, all patients should continue wearing masks and social distancing.

Dirk led the discussion by asking how patients feel about the term “survivor” and what that means to them. **Roslyn** said that she did not like the term and thinks that it sounds like you are not getting treatment. **Jim M.** calls his MM “The Beast” and said that it has its own personality. He prefers “living” rather than surviving. **Mary** said that the Asheville group calls themselves “thrivers” who are living with good quality of life and still thriving. **Dirk** noted that when solid tumor cancers are removed, the patients believe that they “beat it” and have survived past their treatment. MM is a journey and treatment that may continue for many patients.

Dirk's next question was how many patients have a handicapped window tag for parking. His tag is due for renewal and he is debating whether to renew since he is much more mobile than he was when he first got it. He was asking opinions if he should get it for stand-by when needed. **Sandy B.** said that she needs it since she has so much pain when walking. The peripheral neuropathy (PN) was from Thalidomide in the early days of her 31-year journey with MM. She relapsed in 2016 and is on Revlimid and the PN is still there. She is changing to two weeks on Rev and two weeks off. She will let us know if that improves her energy level and alleviates some of the

fatigue. **Roslyn** saw patients at the clinic with canes and now she understands PN and bone pain that require a cane for stability. **Jim M.** said he has severe PN from his feet to his knee. He cannot feel his feet and is tripping and losing balance. He can't wear shoes and is glad he can work from home. He gets relief from roll-on lidocaine and it lasts about an hour and a half. **Gail** has PN and recommends that Dirk hold on to his handicap tag as treatment changes. It is important to take extra steps if you can, but use the tag when you need it.

Patient updates: **Carl** was diagnosed June 2020 and is 130 days post-transplant. He has 17p deletion high risk MM and is on Rev/Kry/dex. **Chuck** was diagnosed in September 2020 and not eligible for a transplant due to heart issues. He is exploring his options and glad to hear from other patients. **Jeff** has had 27 cycles of Venetoclax with Dara/dex. He has t(11;14) high risk MM and pleased to announce that his M-spike is zero. **Doris** had both of her vaccine shots and had no reaction. She is on Rev two weeks on and two weeks off and is thriving after 17 years with MM. **Nancy** was diagnosed in 2007 and had two transplants in 2009. She has had no treatment in three years. Her light chain ratio has decreased and she is doing well and keeping active. **Vanessa** was diagnosed in 2009 and is in remission and has been off Rev for one year. The stress of COVID brought on a craving for sweets and she received a diagnosis of diabetes. She has cut out sweets and carbs and lost ten pounds. The diet change has also alleviated the GI issues.

Caregiver Session

Nancy B. led the caregiver meeting of approximately 20 participants. We welcomed new members joining for the first time – Susan, who cares for Chuck who was recently diagnosed; and Linda who cares for her husband who was diagnosed last October.

Our topic for discussion was stress - both good and bad, how it can make things difficult for caregivers, and how we can manage it. We started by talking about our current stressors and challenges. Many in the meeting have had major life changes recently, not only related to multiple myeloma (MM), but also from the pandemic. The two combined can be extremely overwhelming, especially for caregivers who are dealing with a new MM diagnosis during the pandemic.

Specific changes affecting the caregivers in our group include new MM diagnosis, changes in residence, business ownership and moves, job changes, new retirements (some completely unexpected), and patient decisions to work indefinitely and never retire. Some who are no longer working miss the structure and comradery that a career provides. It was noted that quality of life for caregivers is often different from quality of life for patients. When these different versions clash, additional stress can ensue, and maintaining a balance can often fall on the caregiver, adding even more stress.

We also discussed the challenges that we face trying to manage the nagging voices in our heads and constant fears of relapse that caregivers experience, even when things are going well. This fear of the unknown can affect our goals, knowing that relapse could change our plans and vision of the future quickly, and sometimes resulting in us not making plans at all and feeling stuck in a rut. This feeling of lack of control can be difficult to manage. Someone offered that while she has never been able to stop thinking about relapse, she has, over time, learned to accept it and grow with it, having faith that she will be able to manage relapse if/when it occurs.

We shared ways that we relieve stress. Having positive and healthy ways to stay busy and distracted is the key. Remembering to schedule time to take care of ourselves and having outlets that we enjoy is essential. Practicing meditation and yoga can help calm our minds and quiet our fears. Staying physically active and maintaining a routine as much as possible are both important. Staying socially active is also important and taking walks in nature with friends and golf were mentioned as ways to remain social and physically distanced from others. Trying new and different things not only keeps us busy but can also help us feel more confident. Several in the group mentioned getting an RV and hitting the road has been a new and enjoyable experience for them. Other outlets mentioned were gardening, pets, online lectures, and classes. Remember to think positive and to always keep moving forward. When you move forward it might be in a different way that you envisioned, but that is OK. The important part is to just keep moving and progressing, even in tiny steps, which will help you feel more accomplished, and more in control. And remember to recognize and celebrate your achievements along the way and keep the positive flow continuing!

Submitted by Nancy B and Wendy R

Meeting Minutes

Southside Virtual MM Support Group

March 27, 2021

Agenda for Next Meeting (April 24): Dr. Ping Moore, Department of **Ophthalmology**, Emory University to talk about the interaction of Myeloma new drug therapy on vision. **Ms. Cheryl A. Simpson**, Program Lead from NIH-sponsored Research Program, *All of Us*, designed to recruit one million Americans to build a diverse database to help determine how biology, lifestyle, and environment affect our health.

We opened the meeting with a moment of silence, led by **Doris**. We then went to a check-in for new members. We welcomed back **Petula**, who was not new, but we had not seen her in some time. She has been meeting with a myeloma group on Facebook. She is on the site daily, looking at new therapies and engaging with other patients. This is one of the few members who has reported using a Facebook site to assist in staying up-to-date on myeloma therapies. She brought us up to date. She was diagnosed in 1995 and had a Stem Cell transplant (SCT) in 2014. For 2 years after her transplant, she was on no maintenance. She is currently on Velcade by injection and is being treated at the V.A. Hospital.

We then conducted a vaccine check-up survey. Who had received vaccines? Anyone having trouble getting the vaccine if they wanted it? Anyone still on the fence about getting the vaccine,

and perhaps need more information to decide? Under the Announcement/Resources section of these minutes, there are websites and phone numbers for information on finding a reliable site. There is a link to CDC's website for Frequently Asked Questions about the vaccine. Myths and facts are addressed on that same website. Several reported on having stated or completed their vaccinations. **Carolyn, Bernard, Alma, and Gail** all got the Pfizer vaccine – most with no side effects. A couple reported more fatigue or headache that went away in 24 hours – some with the help of Tylenol. These vaccines were from Emory and Bernard's from his oncologist's office at Northside. **Gloria** received her Moderna vaccine from the Fayette County Health Department. Petula is not planning to get the vaccine. She has competing health issues, including allergies that have led her to decide against the vaccine at this point. It is so important that we conduct our personal assessment as Petula has done and make an informed decision of getting the vaccine or not. Alma reported that her sister is waiting for Johnson and Johnson (J&J) to get the one injection only. **Paulette**, her other sister, and homebound Mother are also awaiting the J&J. Their Mother is on the list with Fulton County Health Department for homebound residents.

Doris reported on the Alzheimer's webinar she attended by the **Alzheimer's Association of Georgia**. She was very impressed and learned a lot. At their website (alz.org), you can find a Doctor's Checklist of signs and symptoms for Alzheimer's Disease. There, they have defined a difference between dementia and Alzheimer's. There is also a list of the **10 Warning Signs of Alzheimer's**. We sent a list of those 10 Warning Signs to all members. Here are 5 of them: 1. Memory loss that disrupts daily life; 2. Challenges in planning or solving problems; 3. Difficulty completing familiar tasks; 4. Confusion with time or place; and 5. trouble understanding visual images and spatial relationships.

As a part of our efforts to increase awareness among local myeloma patients and caregivers about our Support Groups, we worked with a student group from the Rollins School of Public Health, Emory University. This was an Evaluation Course for them. Their project is to assist Community-based Organizations in assessing some aspect of their work. For us, the goal is to assess the effectiveness of our outreach efforts, especially for African Americans with myeloma – the group at highest risk for getting myeloma and for not receiving optimal therapy for their myeloma. We say a HUGE THANK YOU to those 11 people who provided their insights through participation in a Focus Group on March 23. **Sandy and Bernard** reported on their experience. They were asked their opinion about the importance of diversity. They reviewed IMF educational materials that we disseminate on signs and symptoms and questions to ask your provider. They also reviewed the Celgene/BMS publication called Standing in the GAAP (targeting African Americans). They spoke about the importance of knowing the kind of treatment available, the importance of early diagnosis, trust issues, and preconceived notions of mistrust. They had a lively discussion. We will look to share the report in our next meeting.

Myeloma Awareness Month. We had a sharing of how people are observing the 31 days of resilience for MAM. **Petula** has been sharing her 31 days on Instagram. She is doing more reading on her Kindle and other activities that distract her from any problem issues. That is what resilience is about. **Gloria** is a librarian in Fayette County – she is actually Alma's librarian! The County libraries have lots of resources and very liberal check-out policies during COVID. They have curbside service, movies, and offer a 15 book check out limit for three weeks. **Doris** has been participating in an online meditation Course – 21 days of the Book of John. Doris also shared that her son's Health Care Provider (HCP) tested her son for MM, after hearing that she (Doris) has

MM. Members are sharing information about myeloma through their personal and professional networks. We are placing new flyers at Emory, Northside Hospital office at Camp Creek, and other locations. We will email the latest flyer to members for them to distribute. The 31 ways to achieve resilience include practices like breath, drink more water, meditate, dance to your favorite song – all on the list of things we can do for MAM and beyond.

LLS has expanded its services to include paying for ECGs, PET/CT scans, Stem cell harvesting, and labs. Alma reminds us that we have to keep records and make a submission every 90 days. Once you get into a routine, it is well worth the financial support you get. LLS pays for insurance premiums, including Medicare, and for co-pays and medications. **Alma** reports there are also cards that should come in the mail.

Recent medical challenges. **Alma and Emma** have both gone through some unique medical challenges in recent months and shared some of those experiences with the group. As reported before, Alma has been participating in the Clinical Trial (CT) for the drug Iberdomide or CC220 for over a year now. In December 2020, she went to the Emergency Room at Emory and was hospitalized for a month – part of that time trying to come up with a diagnosis (She had a fungus-related pneumonia that may have come from being more immune-compromised than usual and/or from increased Dex with the CT therapy). This would be very frightening and difficult under any circumstances, but was even worse during COVID, where no visitors are allowed to be present for support and to watch over procedures. When she was to be discharged from the hospital, Alma made it clear that she was ready to go home. The staff told her she was not well enough to go home, and that she would have to go to a Rehab facility. As a result of low oxygen during her illness and long-term confinement to bed, Alma was no longer able to walk – barely with a walker. The Social Worker came to her after a few days and said she could recuperate at home, and would have Physical, Occupational, and Speech therapists visit her at home.

Q: Gloria-Why they had not offered home therapy earlier? **A:** Alma could not say, especially since she had made it clear to everyone that she wanted to go home.

Q: (Gail) What about the COVID-safety practices of the therapists – if all had been vaccinated? **A:** Everyone wore gloves, masks, foot covers, and were conscious of social distancing. All were not vaccinated, and one reported he did not plan to get the vaccine. Alma is doing much better now.

Emma had a confluence of decisions to make about her therapy. She was first faced with an intense pain under her chest bone. After some time and fears that it might be breast cancer, that was ruled out. Her sisters have had breast cancer, and this was a real fear. At the same time, she was having problems with Revlimid side effects, and was not satisfied with responses from her usual providers. She sought a second opinion from the Mayo clinic – and they agreed with the course of therapy recommended. She was told she would need radiation to help resolve the bone pain issue in her chest. At the time she went for the initial radiation, she was told this was part of a Clinical Trial. On top of all these issues, transportation to her appointments became a real problem – compounded by the fact that she lives more than 25 miles from the appointment. Emma is a solution-oriented person and sought answers and support from a variety of sources. She checked with the staff Social Worker, with the Outreach leadership at LLS, with the Cancer LLS Support Group in Fayette County, and with our Support Group. Fortunately, she could afford to seek a

second opinion by traveling to the Mayo Clinic. (COVID may have facilitated telehealth second opinions – no travel needed). She found that clear communication was absent from her interactions with the provider, with maybe a lack of respect for her as an equal partner in her treatment decisions. She knows a lot about her disease and is capable of being involved with treatment options.

Emma was impressed with the M-Power Initiative and Webinar on African Americans and Myeloma (Charlotte, NC), and thought the presentations were excellent. Reflecting on her own experiences, she felt that with CTs, a lot of information comes at you all at once. As she was trying to read and understand all the pages and language for her proposed CT, she recognized first-hand how overwhelming this could be. Perhaps there can be a more digestible “bite” of information offered – even before recruitment for a CT begins. For example, the statistics and information on Blacks and myeloma and CTs during the M-Power presentations were helpful. Maybe a checklist of things to consider before participation in any CT would be helpful, as well. We should continue to work towards these solutions.

The transportation would have been over \$100/day, and companies wanted a contract for a minimum number of days. COVID has contributed to fewer transportation services being provided. Alma offered one resource that her family had used in the past. The company was Logistics (866.588.5122). Emma would try them and report back on her progress.

Finally, **Pat C.** asked if we could have someone come to present from the *All of Us* research project. This is an NIH-funded project seeking to recruit over 1 million people of diverse backgrounds to participate and to advance our gene therapy research. Pat shared that she is a firm believer in CTs and will participate whenever it makes sense. Petula shared that she also has joined the *All of Us* project. While she believes in CTs, her adverse response to different medications precludes many MM CTs. Gail will try to get them for our next meeting.

Announcements, Resources, Upcoming Events

- --COVID-19 – Vaccines. <https://myvaccinegeorgia.com/>; <https://dph.georgia.gov/covid-vaccine>; <https://www.fultoncountyga.gov/covid-19/covid-vaccine>
- --Covid-19 Vaccine – Frequently Asked Questions. <https://www.cdc.gov/coronavirus/2019-ncov/vaccines/faq.html>
- --IMF. Patient and Family Webinar. Saturday, March 13, and March 20 (Charlotte) archived at myeloma.org, click on IMF Videos at the top of the page.
- -IMF: [Living Well with Myeloma](#): Thursday, May 6 with Charise Gleason from Emory
- --LLS – Understanding Myeloma at lls.org on replay. Recent webinar Evaluation and-\$50 raffle results
- --LLS: Patient Co-Pay Assistance Fund open

- --LLS: now paying for ECGs, PET/CT scans, Stem cell harvesting, and labs
- --MMRF. <https://mmrfcurecloud.org/>. Personalized data from your free genome report.
- --MMRF: New Drug – Pepaxto – April 1. Will discuss side effects, unmet needs, and more.
- --Myeloma Crowd. African Americans and MM. Facebook page. Advocacy. Check emails. <https://www.myelomacrowd.org/>
- --Patient Power. <https://patientpower.info/> What if I become resistant to Revlimid? Craig Cole, MD
- --PEN: Is your myeloma treatment working? <https://powerfulpatients.org/2020/12/12/is-my-myeloma-treatment-working/>
- --Search for Clinical Trials? SparkCures - <https://sparkcures.com/>. (888) 828-2206. Includes Worksheets for CTs and more. Call IMF InfoLine for CTs in your area – 800-452-2873.
- --AMAZON Shopping? [Smile.amazon.com](https://smile.amazon.com/) – You can choose IMF, Atlanta Area MM SG, or a charity of your choice.

Respectfully submitted, Gail.