

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes Northside Virtual MM Support Group February 5, 2022

Business & News

Thank you to **Nancy B.** who hosted the meeting with approximately 30 attendees. Nancy's presentation clarified the comprehensive and complex American Society of Hematology (ASH) summary reviews from both Emory and Dr. Durie from the International Myeloma Foundation (IMF). Nancy also provided helpful tips and short demos to help us navigate the IMF website, which is a trusted information source for multiple myeloma (MM) patients and caregivers, and a great wealth of thorough, and current material.

Nancy has a special request for the group: If there is anyone who has been on, or is currently on a bispecific antibody clinical trial, please contact Nancy via the newsletter email address (aammsg@gmail.com) to inform her of your experience.

Meeting Presentation

The meeting objective was to make more sense of the previous ASH discussions in terms to help you better understand what it means for you. Emerging myeloma treatments can be complex to understand. We will try to make sense of the overall direction of specialized therapy and ongoing research.

The IMF website, <https://myeloma.org> is an excellent myeloma resource. There is so much information that it can be overwhelming, so it is advised that you read it slowly to digest the information in small pieces, then read some more to put the pieces together. This will help you to understand the information more thoroughly. The IMF site includes videos (some are very short so that you can stop, replay, etc.), blogs, publications, ongoing research, and support.

The IMF's network is huge, far-reaching and collaborates globally with a variety of myeloma groups:

- International Myeloma Working Group (**IMWG**) has over 250 members from 36 countries.
- Black Swan Research Initiative (**BSRI**) conducts numerous research studies to find a cure.
- Asian Myeloma Network (**AMN**) participates in eight Asian countries with 104 MM experts.
- Global Myeloma Action Network (**GMAN**) is represented in 41 organizations in 38 countries.

Myeloma research is conducted globally in Australia, South America, Europe, Asia, and particularly in Iceland. All of these international groups work together to help each other. Dr. Durie contacts the experts on myeloma from around the world to collaborate on newest treatments, clinical trials and COVID to update the IMF website with up-to-date information from a global perspective.

There have been major advances with the **IMF Black Swan Research Initiative (BSRI)**. There are two types of testing for **Minimal Residual Disease (MRD)**. One is called flow and the other one is called sequencing. Bone Marrow biopsy is currently conducted to determine MRD. Dr. Durie has sponsored research and investment for the flow version.

There is also varying levels of MRD depth of response:

- 10 to the minus six is one out of 1,000,000

- 10 to the minus five is one out of 100,000.

MRD at 10 to the minus six is more sensitive as it looks at a million bone marrow cells to find one MM cell. 10 to the minus five is less sensitive, but still provides valuable information. MRD testing will also indicate positive or negative status. A patient who achieves a MRD negative status, which means no MM cells are found in 100,000 or 1 million bone marrow cells indicates a longer remission which is very important. Researchers are trying to develop a blood test to determine MRD status rather than continuing to use a bone marrow biopsy. Immune system monitoring and molecular testing is also being performed. Currently two trials (CESAR and ASCENT) are treating patients with high-risk smoldering myeloma **SMM**. Smoldering MM patients who were already MRD-negative have participated in the ASCENT trial with improved results.

The **International Myeloma Working Group (IMWG)** sets global myeloma guidelines for doctors so that patients can get the best standard of care worldwide. A recent junior grant yielded research that resulted in a discovery of an RNA molecule that with further investigation may lead to the development of a new therapy.

The **iSTOPMM study** in Iceland has tested 75,000 people for smoldering MM (SMM) over five years. Dr. Sigurdur Kristinsson is leading the study with Binding Site and is making a lot of progress. There are six abstracts from the iSTOPMM study available on the IMF website. Some highlights from the study include:

- High prevalence of SMM in their population
- Many diverse outcomes from the 75,000 study participants
- Patients with MGUS had no increased COVID risk

The **Asian Myeloma Network (AMN)** is looking at patients with newly diagnosed MM using three versus four drug regimens for induction therapy in MM patients and considering whether or not the patient is stem cell transplant (SCT) eligible or not. For SCT *eligible* patients, studies are looking at the difference of having a SCT versus CAR T therapy and the importance of the timing of both. The antibody drug conjugate Blenrep is being used. If that fails, the patient can go to a bispecific therapy, SCT and/or CAR T therapy (possibly more than once). For SCT *ineligible* patients at relapse, patients are being treated with antibody drug conjugate, Blenrep, followed by a bispecific antibody, and then CAR T therapy. AMN is trying to determine the best approaches with and without SCT in the mixture of treatments.

Links to further information on IMF website

Click the link [Top Multiple Myeloma Abstracts Presented at ASH 2021](#) for a short 6-minute overview. IMF Chief Medical Officer Dr. Joseph Mikhael discusses the top Myeloma Abstracts presented at ASH 2021 covering five categories and important trends in myeloma:

- A new look at early disease: MGUS & Smoldering MM (SMM)
- Minimal residual disease monitoring
- Frontline therapy with four drug combinations
- Immune therapies, including CAR T-cell therapies and Bispecifics
- Emerging new treatments on myeloma

The “**The Best of ASH**” video from Dr. Durie is available here [Best of ASH 2021 Webinar \(myeloma.org\)](#) which highlights the topics on myeloma from 879 abstracts.

Additional ASH Highlights in myeloma treatments

Daratumumab added as a 4th drug to standard RVD therapy is yielding improved results in providing deeper and longer remission. Daratumumab is being used for newly diagnosed patients and also in the relapse setting.

Immune Therapy – BCMA Therapy Comparisons of bispecific antibodies, antibody drug conjugate, and CAR T-cell therapy with advantages and disadvantages referenced on “**The Best of ASH**” video is available here [Best of ASH 2021 Webinar \(myeloma.org\)](https://myeloma.org/best-of-ash-2021-webinar) which highlights the topics on myeloma from 879 abstracts.

CARTITUDE – 1 Follow-Up study has found that if a patient obtains MRD negative status for only six months, it still makes a significant difference in their outcome.

Triple Class Refractory has so many new options when drugs become refractory. Older drugs like Cytosan can be mixed with newer drugs and a new synergistic effect occurs with improved results for patients.

Myeloma Drug Classes Chart

The chart below shows drug name, their generations, and classes. Data collected in myeloma studies have proven that if a patient fails on a drug’s earlier version, the later version could still work for them.

General Business

Jeff reported doing well on **Venetoclax** clinical trial. He has reduced his dosage of Dex from 40 mg/week to 20 mg/week due to experiencing hot flashes. He is also taking **Carfilzomib** and subcutaneous **Daratumumab** every four weeks. Jeff is also participating in a clinical trial at Emory related to Covid and MM patients. **Dana D.** had **CAR T-cell therapy** and was PFS without MM drugs for three years. One of Dana’s side effects from CAR T-cell therapy was having to receive platelets weekly and blood every three weeks since his bone marrow does not produce cells well anymore. Dana relapsed last spring and then started **Blenrep** at the end of summer. Each time a patient is to receive Blenrep they must pass an eye exam first. Dana did not pass the eye exam after completing the fourth round and has been off the drug since early December. Dana mentioned that Blenrep was very effective for him, and he plans to continue with it again. He now receives platelets and blood more frequently than before – platelets twice a week and blood every week to 10 days. This sparked a conversation about how important it is for those who can donate blood and platelets to do so, especially now when our national supplies are so very low.

Marilyn has smoldering MM but is not currently in treatment reported having an unusual experience to warn the group to be careful of getting mosquito bites. She got a mosquito bite last July that resulted in developing West Nile encephalitis. She had a severe reaction and quickly went from being very active to being unable to walk or move well at all. Marilyn is better now but still in physical therapy and said that she lost about six months of active lifestyle while recovering. Her doctors think her severe reaction was due to having MM, even though it is stable, and the effects it can have on the immune system. **Nancy** commented that MM patients are more susceptible to so many things because their immune system is compromised. She knows of other patients who have their MM under control yet frequently get lung or respiratory infections or issues with healing from a simple cut or burn. Some have found help in getting **IVIG** through their oncologists, which boosts the immune system. **Rhea P.** has also experienced some unusual symptoms. About a month ago she suddenly developed swelling on one side of her body - left foot, knee, lower leg, and hand, which comes and goes. She had a CAT scan, and her oncologist has referred her to an arthritis doctor. Rhea wondered if anyone else has experienced anything like this. **Chuck** commented that he had a constant swelling in his arm that was due to a blood clot, likely from Revlimid. He was put on blood thinners, and it took about 3 months to subside. He has also had swelling that comes and goes in his arms and legs that is due to fluid retention. Swelling in limbs can also be related to the heart. Jim and Nancy both recommended keeping

good records to review with doctors and push them to get the issue resolved quickly. When something is not right, you need to be able to help your doctors help you and a journal of all the facts related to the issue can be key in getting the right help more quickly.

Jim M. shared that he relapsed and began getting **Selinexor** (weekly) four weeks ago. Side effects are mainly nausea that he controls with anti-nausea medication. He also started with **Carfilzomib** with 3 weeks on/1 week off cycles on the main side effects of fatigue and a hoarse voice. His relapse was discovered through a bone marrow biopsy that showed MM cells at the top of his left hip, where he was also experiencing pain. A PET scan also showed MM cells in his left femur and left rib. He has had eight rounds of radiation. Jim monitors his kappa light chain and identified that he was relapsing months ago when he noticed a trend that matched a previous relapse and hip pain. The PA that he was working with at the time did not follow up on his concerns. Jim acknowledged that he has a very supportive wife and kids who accompany him to all his appointments and the infusion center. He has also changed to a new PA who is very attentive. When Jim completes the four planned cycles of his current treatment (approximately May timeframe), he will consider another stem cell transplant (SCT) and possibly treatment with **Daratumumab** again (on which he previously relapsed but can try again in 6-12 months post relapse), or **Elotuzumab**. The good news is that Jim's current treatment is working, and his treatment-related diabetes is under control. He has lost some weight which is not of concern, but if he decides to have another SCT he will try to gain some weight first. **Gail M.** mentioned that the FDA has approved the use of **Prophylaxis** for COVID protection which is available for free at Emory for patients who are eligible. Emory has emailed a survey to patients to determine eligibility, but you might have to request it. Also, Emory is now recommending MM patients get their second COVID booster (fourth vaccine) at 4 to 6 months after the first booster (third vaccine). Gail also spoke on the **Promise study** being conducted by the MMRF researching patient MM to genetic components. African American males who have a close relative with MM have a 10% greater chance of having MGUS or smoldering MM. **Sandy W.** added that when there is any kind of immune-compromised issue found in blood or urine, it should be discussed with blood relatives because there may be an increased risk for an immune-related disease. Family members should be aware of the signs and symptoms of the disease. Enroll in the Promise study at: <https://enroll.promisestudy.org>. **Lory M.** is about to begin new treatment with **Pomalyst, Elotuzumab, and Dex** after being on well-tolerated *Daratumumab* for nearly six years. Since she had a good experience with Daratumumab, she is not as concerned about starting Elotuzumab, but has concerns about beginning Pomalyst and Dex and potential side effects. **Gail** commented that she has taken *Pomalyst* for several years without experiencing serious side effects. She also suggested that patients bring the chart with MM drug names and classes with them to doctors and pharmacists when they are discussing new treatment options and making decisions. <https://www.myeloma.org/multiple-myeloma-drugs>. **Nancy** reminded us that we have a very strong voice with our treatment decisions when we are empowered with knowledge and education about our options. This education is ongoing because the options change so frequently.

Submitted by Wendy R

Meeting Minutes
Southside Virtual MM Support Group
February 22 & 26, 2022

Business and News:

Recent Meeting: March 26, 2022. *Guest Speaker, Jewel Crawford, MD* – Herbalist and medical doctor to talk about the benefits and precautions in using herbs for healing. Notes will be posted on the next newsletter. **Discussion topic:** *What are Your Actions for Myeloma Awareness Month?*

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Group Discussion:

February was a busy month for increasing awareness and knowledge about myeloma. In recognition of Black History Month, the myeloma topics emphasized the disparities, inequities, and biology differences in Black, Whites, and other racial and ethnic groups. Our first “Dinner with a Doc” event was held on Tuesday, February 22 with guest speaker **Dr. Wendy Baer**. Our scheduled fourth Saturday meeting was adjusted to a one-hour meeting to hear from patients and caregivers. The second hour hosted our first “**For Men Only**” meeting to provide our male members a space to freely discuss their concerns with myeloma.

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Dinner with a Doc.

Dr. Wendy Baer, Oncology Psychiatrist, shared general statistics from the *American Cancer Society* (ACS) on the number of cancer diagnoses and deaths from cancer. With so many advances in cancer therapies, cancer is becoming a chronic disease, like diabetes and high blood pressure. Dr. Baer emphasized the importance to *Live Well Now* – to enjoy life now, no matter what may happen in the future. Many patients will live a long time with their cancer. Cancer causes distress. Not only from the diagnosis, but how it complicates life issues. Concerns on housing, transportation, medical insurance, family matters, emotional issues, physical problems, and Spiritual/religious issues may be made worse when diagnosed with cancer. Cancer anguish can interfere with your ability to cope with feelings of hopelessness, anxiety, and sadness.

There are healthcare professionals (social workers, nutritionists, cardiologists, navigators, and psychiatrists) available to support you with the stressors that a cancer diagnosis creates. Learn about services of palliative care, and how to ask for these services if they are not offered. For good mental health and a healthy lifestyle, return to exercise safely as soon as possible. Address any issues of intimacy, anxiety/depression and remember to get adequate sleep. 20 to 30% of all cancer patients have serious emotional or behavioral issues that require the services of a psychiatrist.

Ask for help if you experience any of the following.

- **Clinical Depression:** anhedonia is the inability to feel pleasure, whether social (avoiding other people) or physical (lost pleasure in hugs, the taste of food, or sex). Can be helped by medication or talk therapy.
- **Chemo Brain:** memory is affected, takes longer to do things, multitasking abilities suffer, causes fatigue. Play brain games, get enough sleep, review medication interactions.
- **Schizophrenia:** serious mental illness.
- **Fatigue:** caused by chemo, radiation, pain, anemia, deconditioning, or medications. Request a mental health diagnosis. Dr. Baer mentioned “Toot and Puddle” as a children’s book and TV series and a resource to help with reflections on surviving life’s challenges.
- **Therapy for dying:** For patients and families, there is a concern of being a burden. Inquire on end-of-life information, coping strategies, financial concerns. Patients may avoid discussing.
- **Talking Therapy:** decrease stress, increase communication, improve quality of life (QOL). Helps with problem solving, coping strategies, and overall wellness.
- **Supportive oncology:** Integrative Oncology – includes acupuncture for pain, neuropathy.
- **Art therapy** is used as well. Research Society of Integrative Medicine
- **Psychotropic drug therapy:** Antidepressants (neuropathy, hot flashes, appetite, and sleep drugs); Antipsychotics (nausea, appetite, sleep); Benzodiazepines (anxiety, sleep, nausea); Stimulants (fatigue)

- **In survivorship**, there is continuous worry about recurrence, what can you control? Look for reliable resources, support groups and services, integrative care, and exercise programs. According to Dr. Baer, the highest prevalence of suicide is in older men.

Group Question: How does one find the resources for mental health? **Response:** Begin with the Social Worker or Navigator at your healthcare facility. Talk with your physician. Emory Winship Family Resources Center can provide information. **Message for all:** Live well now. Notice the small things around you. Even children's lives have new challenges.

Dinner with a Doc Resources:

>**Suicide Number.** 800.273.TALK (8255). Website: <http://www.suicidepreventionlifeline.org>

>**Smoking:** 1.800.Quit Now; smokefree.gov; Winship Tobacco cessation have new challenges.

>**Emory Winship Integrative Medicine (Dr. Omer Kukek):**

<https://winshipcancer.emory.edu/patient-care/living-with-cancer/supportive-and-palliative-care.html>

>**Resources for Mental Health services.** WellStar, Northside, Ridgeview

>**Therapyden.com** Bob shared a website to find a therapist without insurance. Therapists for individuals, families, adolescents, children, and other special categories. Thanks, Bob!

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Southside Group discussion:

Doris M. opened the meeting with a moment of silence. Southside group meets virtually. Each meeting starts with members introducing themselves with their time of diagnosis, current status, and an interesting fact about themselves. **Vermell** shared that she had been invited to the Support Group by her patient, **Lonnie W.** and has remained a dedicated member/advisor to the group beyond her retirement from the VA Hospital. She has medical challenges of her own and is navigating the healthcare system. **Portia S.** is a caregiver by profession. She supports the group through her friendship with **Doris.** Her church, Edgefield Baptist Church in Fayetteville, has an annual program supporting all cancers called, "Every Color Matters" (cancer ribbon colors). Donations received provide \$300 annual grants for survivors who apply. **Carolyn H.** was diagnosed in 2006. She has not had an ASCT by choice. She has been on a number of clinical trials. Carolyn is being treated at Emory and has been on Daratumumab for 7 years. Dara is causing blood pressure spikes for her. She attends both north and southside groups regularly. **Barbara** was diagnosed in 2020 after noticing pain in 2018 and received an ASCT in May 2021. She is retired from the Department of Revenue. Her Church means a lot and along with Toastmasters. Barbara has been married 48 years, with two children and five grandchildren. **Ted** was diagnosed in 2019 and is being treated at Emory by Dr. Kauffman. He has not had a SCT and is on Dara for maintenance. One of his biggest joys is road trips with wife, Mattie.

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For Men Only – The Men's Voices

Eight men had their first opportunity to have a conversation about how myeloma has impacted their lives – mind, body, and spirit. They were encouraged to set their own rules about time, dates, and frequency of meetings. The meeting was the result of hearing different kinds of concern from men's' voices as they went through their journey. Meetings will be Tuesday evenings at 6:00 PM prior to the fourth Saturday meeting of the month. They will meet via Zoom until further notice. All men are welcome to attend.

Respectively submitted, Gail