

# ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

The **Northside** meeting on **November 5** will feature a program about *Wellness and Stress Reduction*, with guest speaker Kelley Sidorowicz, certified in yoga and holistic health. With the upcoming stress of Holidays and family events, we must take heed that stress is not good for us. Kelley will talk about the impact of stress and how to mitigate it.

## Meeting Minutes Northside Virtual MM Support Group September 10, 2022

### Business & News

Thank you to **Dirk B.** who hosted the meeting with approximately 35 attendees. This month's meeting focused on "**Risks and the Importance of Vaccinations**" followed by an open group discussion.

### Speaker Presentation

Thank you to **Tara Roy**, Patient Advocacy Liaison, from **Takeda Pharmaceutical Company**, who joined the group to discuss "**Risks and the Importance of Vaccinations.**" Tara has been an oncology nurse for 33 years, with the majority of her time spent on taking care of patients with hematologic malignancies, and those who have had stem cell transplants and CAR-T therapies. The essence of Tara's presentation provided timely information to discuss with your healthcare team regarding vaccinations and prevention of infection in patients with multiple myeloma (MM). Your healthcare team is the most valuable resource for answering questions about your disease, your treatment, and your overall health and well-being. Her presentation included information about MM, an explanation of vaccines and the immune system, and guidelines for vaccinations for people with MM.

**Multiple myeloma** (MM) is a blood cancer that impairs the immune system and lowers the body's ability to fight infections. The risk for infection in MM patients is higher than for someone who does not have cancer. It is especially important to do all we can to protect ourselves against infection from influenza (flu), pneumonia, COVID, etc. with vaccines, as well as other preventative vaccines as needed. Blood consists of three types of cells: **red blood cells, white blood cells, and platelets**. Red blood cells ([RBC](#)) carry oxygen throughout the body to keep vital organs and tissues healthy. White blood cells ([WBC](#)) fight infection by producing antibody proteins that attack foreign organisms and platelets stop bleeding through the clotting process. These three cell types are produced in your bone marrow or "*the factory*." MM begins in a subgroup of five white blood cell types called **plasma cells** that normally produce antibodies to fight infection. In MM patients, these plasma cells become abnormal. Instead of making different types of antibodies, just one type of antibody or one type of protein, also known as monoclonal protein or M protein, is overproduced which weakens the rest of "the factory" resulting in an increased risk for infection. The disease itself, myeloma treatments, and the normal aging process are contributing factors to the risk for infections.

A study conducted in Sweden of approximately 10,000 MM patients concluded that the underlying cause of death was *infection in 22%* of these patients. Another study, called the [INSIGHT study](#) followed 4200 MM patients from 15 countries for 5 years and concluded that vaccines significantly reduce death rates from infections and can also prevent severe complications requiring hospitalizations, and ICU. Vaccinations have been around since 1796 and currently prevent 4-5 million deaths worldwide per year. Vaccines use the body's natural defenses to build up resistance to specific infections, which makes your immune system stronger. Vaccines train your immune system to create antibodies to attack infection causing an immune system

response that targets the invading germ so that the body can fight it. Vaccines are generally given by injection but can also be given by mouth or nasally.

An important question to ask anytime you get a vaccination, **“Is this a live vaccine?”** Live vaccines are not recommended for people who are immunocompromised. MM patients should avoid contact with anyone who has received the *intranasal flu vaccine* (often children) because this type of vaccine administered causes the virus to shed through the nose putting you at additional risk if you are in contact.

Development of different types of vaccines include:

- Inactivated vaccine – uses killed version of the germ that causes a disease
- Live-attenuated vaccine – uses a weakened form of the germ that causes a disease
  - People with weakened immune systems should NOT receive live vaccines
- Messenger RNA (mRNA) vaccine – makes proteins to trigger an immune response
  - Example: Pfizer and Moderna COVID-19 vaccines
- Conjugate, recombinant, polysaccharide vaccine – uses specific pieces of the germ
- Toxoid vaccine – uses a toxin made by the germ that causes a disease
- Viral vector vaccine – uses a modified version of a different virus to deliver protection
  - Example: J&J/Janssen COVID-19 vaccine

It is recommended that people should be vaccinated following the vaccination guidelines provided by the CDC. When talking with your healthcare team about your vaccinations ask them *“What guidelines are you following?”* to understand what schedule is being followed. Always check with your oncology team first before getting any kind of vaccination to make sure it is safe for you. Tara recommends keeping a journal to record your vaccinations including dates and times and to review your vaccination schedule with your healthcare team.

Organizations with vaccination guidelines include the following:

- **CDC-ACIP:** Advisory Committee Immunization Practices
- **EMN:** European Myeloma Network
- **IMF:** International Myeloma Foundation
- **NCCN:** National Comprehensive Cancer Network
- **WHO:** World Health Organization

Common FAQs regarding infection risk/vaccines for MM patients include:

**When should cancer patients not receive vaccines?**

- If not recommended by your healthcare team
- If it is a live vaccine
- Precaution: if recent exposure or active current infection
- If vaccine type is affected by underlying degree of immunocompromised status
- During chemotherapy or immunostimulatory therapy
- Vaccinations should be delayed for at least 3 months following HSCT or CART

What is **“herd immunity”**? Herd immunity occurs when a significant portion of a population becomes immune to an infectious disease, limiting further disease spread. It can be achieved either through infection and recovery and/or vaccination. Vaccination creates immunity without having to contract a disease. Herd immunity also protects those who are unable to be vaccinated because the disease spread within the population is very limited.

What is **vaccine hesitancy**? Vaccine hesitancy refers to delay in acceptance or refusal of vaccination despite availability of vaccination services.

Recommended vaccines for MM patients include:

- Influenza (Flu) vaccine – EMN, WHO, CDC, and NCCN recommends, annually via injection, not a live vaccine, timing of vaccinations with therapies that compromise immunity as appropriate
- Pneumonia vaccine – CDC, EMN, and NCCN recommends two types of pneumonia vaccines, both given via injection: pneumococcal conjugate and pneumococcal polysaccharide. Specifics of dosing schedule are dependent on age and prior vaccination for pneumonia.
- Varicella Zoster (Shingles) vaccine – NCCN and CDC have no recommendations for MM patients for the Shingrix vaccine. EMN recommends that MM patients receive the recombinant vaccine, 2 doses by injection, 2-6 months apart.
- COVID-19 Vaccine: CDC recommendations for immunocompromised patients include the following primary series and boosters:
  - Pfizer and Moderna mRNA vaccines – 3 primary doses and then 2 booster shots
  - People who received the first Covid-19 vaccine from Johnson & Johnson (J&J) Janssen should receive a second dose from Pfizer or Moderna along with booster from Pfizer or Moderna
  - People who have received the first dose of Johnson & Johnson (J&J) Janssen vaccine as well as a booster dose from J&J may now receive a second mRNA booster +vaccine
  - the current administration for MM patients is either the COVID-19 vaccine from Pfizer or the Moderna vaccination. New booster vaccines have recently been approved, so it is important to talk to your healthcare team on when you should receive the newer vaccine since it covers more strains of the COVID-19 virus.

### Group Discussion

We welcomed new member **Elaine P.** who joined the meeting for the first time. **Sandy B.** noted that there is a flu shot available for people 65+ years old, but you may need to request it since it is not automatically offered. **Lory M.** talked about the pneumonia vaccine being available as shot to your arm or subcutaneously. Lory opted for subcutaneously which was a good experience for her with no soreness. **Gloria B.** experiences severe cramps in her legs and feet at night and asks how others have managed this side effect from treatment. *Dave*, who is a runner, mentioned that he drinks tonic water to help with leg cramps. *Jeff W.* uses an extra blanket or towel over his calves to keep them warmer. *Anderson* was pleasantly surprised by a tip that he discovered on YouTube. Put a bar of soap at the foot of the bed under the sheets, which has worked for him. He also suggested removing socks to help. *Dirk B.* and *Marilyn* both said that standing up helps them. *Vanessa* recommended magnesium tablets, magnesium gel, and staying hydrated. She keeps a bottle of water at her bedside. A key cause for cramps is dehydration, so be sure to get well-hydrated at least two hours before going to bed. *Elaine* asked for advice with fluid retention in her legs. Several members recommended compression socks. *Marilyn* mentioned that there are compression socks with zippers that are easier to put on to remove soreness.

**Barbara W.** had a SCT in May 2021 and is in the process of getting re-vaccinated. She asked how others are socializing now that the mask mandate has been lifted. She has a desire to socialize more in person, especially to participate in exercise classes she attended pre COVID and pre SCT. Group suggestions varied with some members saying that they still stay in a lot and join online exercise classes. Others venture out but continue to wear a mask in public and avoid crowds. *Mary V.* commented that before visitors come to see her, they do an at-home COVID test pre visit and wear a mask while in her home. *Jeff W.* said that he likes to walk outdoors in public parks where he is around others but can maintain a safe distance and still socialize. Several people recommended the [\*Silver Sneakers\*](#) program, supported by several insurance plans including United Health Care

and Medicare. There is a variety of in-person classes with locations in Georgia. Contact them in advance and ask about which classes are not usually as crowded if you want to attend in person. Also inquire about outdoor classes where it is easier to stay distanced from others. **Nycole S.** had two recommendations: *Cancer Support Specialists*, <https://www.cscatlanta.org/> and classes through *Northside Hospital*, which are both free and very accommodating for people with cancer. There is a wide variety of classes including exercise, painting, nutrition, meal preparation, and a lot of activities.

There was discussion about the importance of knowing what type of MM you have, which can change over time. **Dirk B.** was diagnosed with IgA MM, but he now has IgG MM. Knowing your type allows you to conduct better targeted research and helps you and your doctors make better treatment decisions. Different treatments affect different types of MM. **Jeff W.** mentioned that Daratumumab can significantly improve IgG levels. **Nycole S.** referred to IMF brochures that helped her understand her type of MM.

Group discussion brought up the prevalence of MM in the African American population, which is significantly higher when compared to the rest of the population which was also a topic in a recent IMF newsletter. Some encouraging new research shows that once diagnosed, the African American population responds better to treatment outcomes than the general population. Despite higher rates of MM, African American patients tend to have less biologically aggressive disease. The need for more demographic representation is essential in MM research and ongoing treatment testing. Several members have experienced challenges in the workplace with co-workers who are not supportive of their special requests due to being immunocompromised. For example, a request to work behind the scenes to avoid the general public. Repeatedly explaining that they have myeloma that makes them immune-compromised, and although they may “look healthy” and “don’t look like they have cancer” that the risk is real and ongoing. This led to a discussion about how to rejoin the world where there are very few mask mandates or consideration for those who are immune compromised.

Submitted by Wendy R

## Meeting Minutes

### Southside Virtual MM Support Group

### September 24, 2022

#### **Business and News**

**Next Meeting:** Saturday, October 22, 2022.

**Program:** CBD Oil, Neuropathy, and other Uses. **Speaker:** Terrell Johnson. The family business produces CBD oil at a farm in South Georgia. The Patient and Caregiver Voices discussion will follow the presentation. **Deborah** called in to offer her continued support and assistance to us in whatever ways needed. She is a nurse for the VA Hospital and has over 40 years’ experience with myeloma patients. Deborah has been a good friend and patient advocate since its inception providing insightful presentations, medical information, and words of inspiration and encouragement to our AAMM Support Group.

**Reminder:** It is time to get your flu shot. The influenza season is here, and the CDC anticipates a higher rate of transmission this year. Also update any COVID boosters that may be due. COVID pandemic is NOT over. There are new subvariants continuing to emerge. The recently approved **bivalent COVID booster** vaccine provides additional immunity to the new subvariants to help reduce the symptoms from COVID infections and reduce the chance for complications or hospitalization. Also, be aware that long COVID or post-COVID can be serious enough to place you on disability for respiratory, cardiovascular, neurological, GI, and other complications.

## **Group Discussion**

**Doris** opened the meeting with a moment of silence. She shared patient updates from those she spoke with over the past month. **Carla M.** has had *CAR-T therapy* and reports she is doing well. She said this may be better than the Stem Cell Transplant (SCT) procedure. **Doris** also summarized her experiences at the annual *IMF Support Group Leaders Summit* in Phoenix, AZ. This year's summit was a hybrid in-person and virtual format gathering SG Leaders from across the country. IMF sponsors over 150 Support Groups in the United States and U.S. territories. The conference provided support group enrichment opportunities to share experiences among leaders, presentations from pharmaceutical companies on current drug therapies, and sessions from the IMF physician-scientists on the progress of myeloma treatments. The effort to increase support group diversity continues through the work of *M-Power*. IMF also produced a 90-second video promo for September Blood Cancer Awareness Month featuring our own Doris and other SG Leaders. Take a look: <https://www.myeloma.org/imf-videos/myeloma-blood-cancer-awareness-2022>

**Light the Night/LLS:** On September 24, Southside AAMM support group met 95% of this year's LLS fundraising goal. The Light the Night event scheduled for October 1 was postponed, due to Hurricane Ian. No new date has been set. As of October 15, 2022, we had exceeded our goal of \$3,000! Thank you to EVERYONE for your contributions to LLS. If you did not have a chance to donate for whatever reason, please talk to Doris, Paulette, or Gail and they will be sure to make your numbers count.

**"For Men Only" Support Group.** Ted and Anderson extended an enthusiastic invitation for men with myeloma and caregivers to join them on fourth Tuesday of the month at 6 pm for an hour. The group's mission purpose is for men to be able to talk about their experiences and challenges along the myeloma journey, and to discuss solutions to help them with the best possible experience. Ted shared that they have great discussions. Meeting topics on nutrition and plant-based diets (Jennifer Rooke, MD), neuropathy, and Understanding lab results and speaker recommendations have come from their discussions for the larger group meetings. The Social Worker at Emory has requested a flyer to advertise the "For Men Only" Group to her clients.

## **Patient and Caregiver Voices**

**Emma** has many challenges for more than a year which include poor communication with the medical staff about both treatment recommendations and clinical trials. She is a very involved patient who demands answers. Emma has sought second opinions because issues of respect and trust are now part of her relationships with her providers. She has two very caring sisters who are walking with her through this journey. Doris encouraged her to apply for LLS funds to help with the added financial burden of new therapies and appointments. Emma has been approved by LLS for transportation funds. Other members have received LLS support, and highly recommend keeping well organized records so to re-submit applications when the current grant expires.

**Doris** had a similar issue with her providers – communication, trust, and respect. Because her protein levels were increasing, Doris needed to consider a new therapy. Her myeloma doctor did not meet with her during the appointment. She was generally disappointed and considered changing treatment locations after almost 18 years. Doris was dissatisfied with the explanations given for the recommended therapy. She spoke with the Social Worker who contacted the staff. Doris was able to have a second consultation with a different provider who walked her through her options and the reasons for the recommended treatment options. The doctor and support staff all attended the conference to ease her concerns and any remaining hesitation. She is now satisfied she made the right choices in her new therapy.

**Glenn** shared that LLS.org has an Urgent [\*Financial Support Need\*](#) fund. Be sure to apply regularly throughout the year. The funding in different "need buckets" runs out over the calendar year. They are replenished as additional funds come in. Please let your Social Worker know if you have financial needs. There are many different sources to help. Glenn also talked about lab results and where to find them. It is important that each patient follow their labs with their

providers. It does not matter if you do not understand at the beginning. Ask your providers to note on your lab results which values are important to follow. Also, ask to define your myeloma type – IgG, IgA, etc., kappa or lambda, any gene abnormalities, high-risk symptoms, etc. Keep these in your notebook and follow the lab results for each visit.

**Anita** researched her own myeloma type specifics and found out there are two staging systems to determine the stage of one's myeloma – the *International Staging System* and the *Durie-Salmon*. She has Stage 3 myeloma (not like a solid tumor staging – breast or lung, for example). Her myeloma is IgA lambda, and extramedullary. *Great job, Anita!* She now asks for a printout of the flow chart of her lab results. Because myeloma is so different in each of us, we must find our own definitions, and follow up with your treatment plan and medication needs with your providers. This sparked a spirited discussion about understanding lab results. We will plan for more presentations on lab results as soon as possible. A follow-up email was sent to everyone on Understanding Lab results from several sources. [IMF Understanding Lab Reports](#) *Additional links and resource files are attached below.*

Additionally, **Glenn** shared that AARP reported that Revlimid is the 2<sup>nd</sup> highest expensive drug on the market at \$13,000. He was on the generic med for a while until it was no longer available. **Gail** shared that the recently passed Inflation Reduction Act that Medicare recipients' drug costs will be capped at \$2,000 each year.

**Advocacy Success.** President Biden signed a landmark law that makes healthcare more affordable for millions of patients allowing them to live longer, healthier lives. Under this law in 2023, Medicare Part D patient out-of-pocket prescription expenses will be capped at \$2,000, which can be paid incrementally over the year. Right now, many blood cancer patients pay over \$10,000 out-of-pocket each year for their treatments, with some paying over \$16,000 for a single drug, which is why this law is so critical! The law will also include *a three-year extension of tax credits that reduce premiums for those who buy health insurance through the HealthCare.gov market through December 2025.* These credits have dramatically lowered or even eliminated health insurance premiums for millions of consumers since 2021.

**Reflections.** In a previous meeting, we discussed **leg cramps**. Cramps, Muscle spasms, Charley Horses, Nocturnal leg cramps – What is the Cause? Some cancer therapies can create deficiencies in electrolytes potassium, calcium, and magnesium. Dehydration can also be a risk factor for leg cramps. Also, overuse – intensive exercise can cause muscle spasms. Source: *Cleveland Clinic*. Solutions: Stretch and massage the muscles; apply ice or heat; resist sitting for long periods of time; Walk around; monitor your lab results; drink lots of water each day. Gail will send a list of foods that are high in magnesium.

Respectively submitted, Gail