

# ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

## Meeting Minutes Northside Virtual MM Support Group July 9, 2022

### Business & News:

**Next Meeting:** Saturday, August 6, at 11:00 for open discussion. Long term survivors are welcome to attend and encourage the newer patients.

### Guest Speaker Presentation:

Thank you, Dirk Bender, for hosting this month's meeting. There were 25 members in attendance to hear Kim Burney, BSN, RN, MSNed, OCN - Oncology Clinical Educator with Janssen present **Shared Decision Making in Multiple Myeloma**. Kim has visited our group in the past with a positive message for MM patients and caregivers.

### **Guest Speaker**

Kim introduced her presentation with two key points in mind: understanding what shared decision-making is and the importance it can have in your myeloma journey. She is empowering you to engage in the shared decision-making process with your team and to learn how to apply the S.H.A.R.E. approach. Your myeloma decisions are made in a complex environment that includes the patient, caregiver, oncology team of doctors, nurses, and other departments such as infusion, transplant, radiology, pharmacy, etc. Engage everyone on the team in making decisions regarding the treatment plan. Let your healthcare team know what is important to you and to be sure everyone is on the same page with the same goals. Even though myeloma right now is not curable, there are plenty of treatments and resources available. Let the team know how you are doing physically, mentally, emotionally, and less commonly addressed, financially. Each of these details are important in the treatment decision making process. The mental battle is just as important as the physical battle and it is important to a relationship of trust with your healthcare team.

Shared decision-making is a collaborative process between you and the healthcare professionals

- Conversations occur with 2 or more participants
- Clearly communicate your feelings and understanding of the treatment plan
- Share your knowledge and understanding of key information and inquire about clinical expertise
- Discuss all facets of the topic details to come to a mutual agreement on the treatment plan

Developing trust relationships bolsters your confidence to discuss your goals and views as you navigate your disease and treatment options. There will be many conversations with different members over time based on where you are in the myeloma journey from initial diagnosis to active treatment, remission, and relapse. Goals and desires change with new treatments in moving forward and staying on plan. Most important is to stay fully engaged and involved and actively collaborate with your doctors and healthcare team. Clearly communicate with your doctor how you feel and comprehend the treatment plan. Express what you do and do not understand about the information and always ask questions for clarity.

## ***What are the Goals and Benefits of Shared Decision-Making?***

### *Intermediate Goal:*

- Better understanding of your therapy and treatment goals
- Increased confidence and understanding of treatment
- Active involvement and collaboration to decrease stress and anxiety in team decision-making

### *Long Term Benefits:*

- More satisfaction in treatment journey
- Greater understanding and importance in maintaining your treatment plan

### *Key Outcomes:*

- Your input and viewpoints build respect and trust in your care team
- You will attain a positive affect to your physical, mental, and emotional well-being
- Stick with the treatment decision with more positive outlook towards better outcomes

## **So how do you become more involved in the decision-making process?**

It is one way to ensure you are getting the best care possible. Play an active role in open discussion with your healthcare team. Do your research and write down questions and concerns before each appointment. Make sure you understand your diagnosis, treatment options and recovery to make informed decisions. Share your goals, lifestyle preferences and treatment choices with doctors and staff. Do not rush through the process. Take notes, ask questions, discuss concerns and sticking points to arrive at the best treatment plan together.

Putting shared decision-making in action can be challenging. Do not hesitate to speak. Go over the conversation in your mind ahead of time concerning diagnosis and treatment plans to reduce being overwhelmed and worried. Address language and cultural barriers that may hinder the conversations. Discuss differences in treatment goals and additional health issues you may have with your healthcare team. Although your provider may be limited in time, be sure to go over all the treatment options so your health team knows your specific needs. Work together to tackle any barriers you or the healthcare team may experience. Remember that everyone involved is an important stakeholder in the decision-making process. The healthcare team provides expertise in MM treatment, transplant, clinical data, and evidence-based research information. They have a clear understanding of each patient's specific needs, cultural differences, physical and emotional states. Patients and caregivers' needs are more personal. They include physical and mental health, transportation and financial concerns, lifestyle preferences and general health literacy. Patient goals may differ that of their doctor. Addressing the issues helps facilitate shared decision-making goals to a mutually agreed upon treatment plan that extends and maintains your quality of life.

Kim continued her presentation in taking a more active role in the treatment decision using the S.H.A.R.E. Model to demonstrate the importance of patients need to discuss their treatment plan with their health care team. Start by preparing a list of important questions to ask the doctor.

- What are all possible treatment options? Which ones are the most effective with positive results?
- How long is remission and will there be a relapse?
- How is the treatment plan delivered? What kinds of drugs are used? How long does it take and how often?
- Are there side effects and what should I do about them?

## **Using the S.H.A.R.E Model in shared decision -making?**

Patients handle the news of their myeloma diagnosis differently. It can be overwhelming, and time is needed to absorb the information. Using the SHARE model acronym will assist in the process.

**S = Seek.** Gather information and questions to ask the doctor to discuss your test results, symptoms, and any terms you do not understand. **H = Help.** Let the health team know any background information that may help in the diagnosis of your myeloma, background information, symptoms, level of understanding myeloma, treatment options. **A = Access.** Ask questions, voices your concerns. Let your doctors know what your personal values and preferences on the treatment plan are. **R = Reach.** Time to make a decision that is mutually acceptable to the patient, doctors, and family members. **E = Evaluate.** Keep in mind that there will be rough times ahead and not everyone will agree with your decision. It is ok to have a difference in opinion. Refer back to the SHARE Model to review and update the decision-making process throughout the myeloma journey.

Submitted by Sandy W.

## Meeting Minutes Southside Virtual MM Support Group July 23, 2022

### Business & News:

Southside support group met Saturday, July 23. There were 25 members in attendance and the meeting topic was Patient and Caregiver Voices and Updates. For Men Only MM Support Group Meeting was on Tuesday, July 26. Their discussion was on *Communication Styles*. Meeting notes will be included in next month's newsletter.

### Guest Speaker:

**The Southside group meeting welcomed** Tara Roy, MS, NP, the Patient Advocacy Liaison. from Takeda. The topic was **Risk Status in Multiple Myeloma**. Tara explored why *risk status* is important to making myeloma treatment decisions and how it is assessed, including contributing factors. In addition to her talk, Tara shared a special publication of CONQUER magazine article, [Risk Status in Multiple Myeloma: Personalizing Your Care](#).

Tara's presentation focused on ***why risk status assessment is important*** and ***how risk status is assessed***. The group was asked to compare the terms "**Risk factors**" versus "**Risk status**." *Risk factors* are those factors that increase a person's chance of developing a disease. For multiple myeloma (MM), those factors include age, gender, race/ethnicity along with obesity, having other plasma cell diseases, and family history. *Risk status* is defined by the categories of people living with myeloma to inform their prognosis and treatment. Categories include tumor biology: features of the tumor, how much the disease has spread, and kidney function. Generally, patients do not know their risk status, though most say they are interested to know if they have high-risk myeloma. The group survey showed that 42% of respondents knew that people with high-risk MM received a different treatment than those with standard risk; 15% said that patients were aware that they had high risk MM.

Tara presented a brief review of Myeloma 101 with interesting graphics explaining the function of platelets, red and white blood cells and plasma cells emphasizing that everybody's myeloma is different. Some features of differences include our medical history, how widespread is the myeloma and whether it is responding to therapy. The two risk categories include **standard risk and high-risk myeloma**. About 25% of people living with myeloma are classified in the high-risk category at initial diagnosis. A patient's risk status can help inform the kind of myeloma treatment that should be

considered, the timing and sequencing of your treatment, and what the disease prognosis is based on your risk category. Some factors that contribute to risk status are general health, how much disease is in the body, and the genetic features of the myeloma cells. Many attendees in the meeting noted that their providers never spoke to them about their risk status.

Many patients and caregivers were told that there are no cancer stages for myeloma. Others were told that their myeloma is Stage 1, 2, or 3, based on how serious the myeloma was at diagnosis. There are two staging systems used in diagnosing MM. The classic is the **Durie-Salmon Staging System** (named in part for Brian Durie of the IMF). This system considers CRAB symptoms: C= calcium levels, R= renal kidney function, A= Anemia (RBC counts) and B= presence of bone lesions, function. The **Revised International Staging System (RISS)** additionally considers higher beta-2-microglobulin, lower albumin, higher lactate dehydrogenase, and genetic abnormalities.

The genetic abnormalities of myeloma cancer cells can be different, even in the same person. Cytogenetics is an analysis of one's cells that can help your healthcare team better define your myeloma. Genetic abnormalities are not inherited and are also known as chromosomal abnormalities. They are not found in everyone who is living with myeloma.

Tara used graphics to define chromosomes, or long strands of DNA and protein that contain most of the genetic information. There are several different types of chromosomal abnormalities in MM, including: **structural abnormalities** (rearrangements of parts of the chromosomes, or the gain or loss of a part of a chromosome) and **Numerical abnormalities** (too many or too few chromosomes). Additional abnormalities include *translocation*, *deletion*, *duplication*, *hyper-diploid* (extra chromosomes), and *hypodiploid* (missing chromosomes). The pictures to demonstrate these abnormalities were very helpful in the explanations. There are specialized tests that can determine the level of risk. The *fluorescence in-situ hybridization (FISH)* analyzes chromosomes to look for abnormalities. FISH tests are considered to be very accurate and can find things too small to be seen with other cytogenetic testing. Newer testing for chromosomal abnormalities includes the *Next-generation sequencing (NGS)* panel, *Single nucleotide, or polymorphism (SNP) Array*, *Multiparameter flow cytometry*, and *Karyotyping*.

The human body has 23 sets of chromosomes for a total of 46. Half come from the mother, half from the father. Two of your chromosomes (X and Y) determine your gender at birth. **High risk chromosomal abnormalities associated with MM:** A deletion of all or part of chromosome 17 (**del 17p**); a deletion of all or part of chromosome 13p; a translocation of a part of chromosome 4 with a part of chromosome 14 [**t(4;14)**]; a translocation between parts of chromosomes 14 and 16 [**t(14;16)**]; a translocation between chromosomes 14 and 20 [**t(14;20)**]; deletions or duplications of part of chromosome 1 [(**1p**) (**1q**)].

Tara provided attendees with a list of **questions to ask your healthcare team** regarding your risk status.

- 1- Have cytogenetic tests been performed on my bone marrow? If so, which ones?
- 2- Was Minimal Residual Disease (MRD) testing performed on my bone marrow if/when restaging my disease at relapse?
- 3- Do I have high-risk multiple myeloma? If so, which cytogenetic abnormalities were identified and how is this influencing the therapy I am receiving?
- 4- Were these tests also performed when I relapsed?
- 5- When will you reassess my myeloma next?

Tara concluded her presentation by tasking each of us to talk with our healthcare team and families about our risk status. She encouraged us to work towards clear communication with our doctors and medical members and instill mutual trust to ensure a more satisfactory myeloma journey.

Respectfully submitted, Gail