

November 2018

Northside Multiple Myeloma Support Group Meeting November 3, 2018

Jim M. led the meeting. Jim started the meeting with having everyone introduce himself or herself with a little known fact about each of us. We have crafters, former Oncology nurse, librarian, schoolteachers, business professionals, cat lovers, journalists, psychologist, to name a few.

It was a great way to get the meeting going by getting to know more about who we are outside of the Myeloma journey.

We may continue this for each meeting – quick intros around the room. The group then split with the caregivers and patients meeting separately.

Caregivers – focused on palliative care and general care of the patient. Ed moderated the group.

Patients – side effects, therapies, and general information. Jim moderated the group.

One of our members' family members was undergoing serious surgery and we asked that we remember the family in our thoughts and prayers. Asked for anonymity.

Southside Multiple Myeloma Support Group Meeting November 24, 2018

The meeting was opened by **Doris** with a moment of silence. Our December meeting will be an interactive session on the Myeloma journey.

We had two new members **Luther** (patient) and his wife **Sandra**. Luther was diagnosed in September 2018. They are going to Northside for their myeloma care. We also welcomed back **Sandy** and **Joe** to the meeting. They introduced their son, who has moved back to Atlanta permanently from Manhattan. Sandy is a 29-year survivor of multiple myeloma. **Nancy** shared that when her husband was diagnosed in 1998, he was told he had two years to live. At that time there were very few drugs to choose from. He was on Thalidomide and had 7 years in remission from a transplant. He had a good quality of life for the most part. Since his passing in 2011, Nancy has been involved with the International Myeloma Foundation (IMF). **Jameca** was diagnosed in 2003 and was the youngest of the

group at diagnosis at age 27.

Since 2014, there have been 8 new drugs introduced. The research and treatment advances in myeloma continue to give patients and their families so much hope and quality of life. A strong message from Nancy and others who have been involved with myeloma over the years is the importance of communication with your doctor. Strongly communicate side effects. Use the vast number of resources – print and video/webinar -- that are available for free from the IMF at myeloma.org.

Nancy Bruno presented a program from the IMF web site. It was parts of the Best of ASH video from Dr, Durie in January 2018. This is important information about the research that was reported at ASH last year since the ASH program from this year will be providing updates on this research. Dr. Durie will have Best of ASH video on January 10

The American Society of Hematology (ASH) holds their conference every December. There are over 25,000 hematology oncologists from around the world attending. This is where the latest research on blood disorders is reviewed and reported. The myeloma sessions are very popular since there is so much research that is making a difference for patients. Every research project and clinical trial is summarized with an “abstract”. At ASH last year, there were 981 abstracts on just myeloma! Nearly one thousand research projects around the world on myeloma. This is exciting news for patients. Dr. Durie and his team reviewed the abstracts and reported on the 100 that they found most important.

The first was iSTOPMM, which is a project in Iceland to test all adults over the age of 40 to see if there is MGUS or SMM – early forms of myeloma. They found 4000 with signs of myeloma and some received treatment. This is called the “Cure” trial; to see if myeloma can be cured if treated early enough.

Another important research project is testing for MRD (Minimal Residual Disease). MRD is a very complex and sensitive test that can find myeloma when all current standard test show that the myeloma is undetectable. MRD can find one myeloma cell out of a million bone marrow cells. If this test does not find any myeloma cells, then the patient is considered MRD negative. Clinical data is showing that patients who achieve MRD negative status are staying in remission at much higher rates over a four-year timeframe. A clinical trial in France is gathering MM patients and tracking their MRD status through initial treatment. For those patients who are MRD negative, they will suspend Revlimid maintenance to see if they continue as MRD negative and stay in remission. At

the end of this video, Dr. Durie shows a drug chart by drug classes along with the new drugs in development and undergoing testing in clinical trials.

Another video that Nancy reviewed is the Best of ASCO/EHA/IMWG. These are conferences held in the summer where experts review myeloma research. ASCO is American Society of Clinical Oncologists. EHA is European Hematology Association and IMWG is the International Myeloma Working Group founded by the IMF to bring together about 100 myeloma experts from over 30 countries to evaluate research results and set the standards for treatment. The agenda for this teleconference are:

- Best outcomes and access
 - o Access treatment globally
 - o Frontline therapy of VRd is giving survival rates of 7-8 years
 - o Four drug combinations showing anticipated survival greater than 10 years
- Role of Mass Spectrometry
 - o Sensitive test for myeloma proteins that is inexpensive and available
- Imaging guidelines
 - o Helps to understand the different tests
- Status of MRD Testing and CURE Trials Update
 - o Update from ASH 2017
- New Therapies
 - o New drugs presented
- CRISPR Gene Editing.
 - o New and exciting treatment

There was not enough time to cover all the topics on this teleconference. It is strongly recommended that everyone view both of these videos to understand the research status for this year. The videos can be found on the IMF web site - <https://www.myeloma.org/>. Click on Education & Publications (under the Donate button at the top); click on IMF TV; and then select Living Well with Myeloma. There you will see recent conferences, include Nutrition impact on Side Effects. Scroll down for the ASCO and ASH videos. Be sure to register for Dr. Durie's Best of ASH to be held on January 10.

Nancy took some time to review the IMF publications, especially on how Immune therapy works and how Velcade works. Since Velcade works inside the myeloma cell, it is important to let your healthcare team know what supplements you are taking that may impact the effectiveness of Velcade. One of the guidelines is to not drink green tea on Velcade day.

It is important to note that the research shows that the standard of care should generally be four months VRd (Velcade, Revlimid, dexamethasone), harvesting of your cells, then an autologous stem cell transplant (ASCT). The research shows that those who get transplants tend to have better survival rates. You will have to be eligible for the transplant. Deborah (nurse at VA Hospital) shared that the eligible patient must be relatively healthy and must be compliant (attend all their appointments, etc.). The VA sends their myeloma patients to the VA Hospital in Nashville for transplants. The VA Hospital has a relationship with Vanderbilt University Hospital. She also advises any veterans to be sure not to use up all their finances before coming to the VA Hospital.

Remember that the treatment for myeloma is very individualized. Myeloma can be so different in different patients. Sandy has been in remission for 12 years. She started on Thalidomide in 1999. With side effects – you live with the advantages and the disadvantages. She has not had a transplant – and it took her 10 years to get into remission. Your myeloma journey will be very personalized, and hopefully well-informed.

Part of being well informed, Deborah says, is never leaving your doctor's office without answers to your questions. You should be told in simple terms about your disease, the medications, and what else you can do to help yourself (ex. Nutrition). Part of the basic understanding is knowing what kind of myeloma you have – IgG, IgA, kappa or lambda, and cytogenetics (must be tested during bone marrow biopsy). You should also know what your lab results say – and what they mean. What value is expected for your glucose, kidney function, free light chain, etc. Get a printout each time with your results and the normal range. After the meeting, Deborah sat with our new members and reviewed the lab tests with them. Sandra had an impressive notebook of details that she is keeping. There are great publications from IMF and Takeda on laboratory tests and their meanings. Jameca brought a display board of resources. The purpose is to help patients and families navigate their 'new normal.' The board had resources for various agencies and organizations that have more information on nutrition, legal services for disability, mental health, and more.

P.S. During the post meeting networking, **Carole** suggested that we develop a plan for members who do not have caregivers – no family members are close by to support. We ask that all members think about others, especially through the holidays. We should develop a formal plan after the holidays.

Announcements/Resources/Upcoming Meetings

IMF - Stand up to Cancer (SU2C). New project to model population study in Iceland. For Myeloma patients over age 45 and African-Americans -- with first

degree relatives Mother, Father, Sister, Brother) who have MM.

· **IMF. New – Diversity Communications Group.** All are urged to be involved. Send an email indicating your interest to diversity@myeloma.org.

· **LLS. Funding Updates.** There are two travel assistant programs for patients. Susan Lang Pay-It-Forward Patient Travel Assistance Program for Myeloma and the General Fund. Neither is accepting applications at this time. **Check back to see if more funds have become available.**

· **LLS. Patients and Caregivers may get one FREE Nutrition Consult.** (800) 955-4572 or provide your name for email.

Free rides for cancer patients. Lyft partnering with American Cancer Society through its Road to Recovery Program. Call 1.877.277.2345. Must call at least three days before appointment.

Respectfully submitted, Gail and Nancy

* * * * *

Southside Multiple Myeloma Support Group – Southside group meets at 10:00 on the fourth Saturday of each month in second floor Meeting Room at the Macy's on Greenbriar Pkwy. Doris Morgan 404-346-1372; dorismorgana@aol.com , Gail McCray 770-996-4964; mccrayg@aol.com web site: ssatlanta.support.myeloma.org

Southside Meetings: 12/22/2018; 1/26/2019

Northside Meetings: 1/5/2019 at Emory; 2/2/2019

Meets 11:00 AM on the 1st Saturday of each month
Shallowford Presbyterian Church
2375 Shallowford Rd.
Atlanta, GA 30345
mmsg.org, email: aammsg-2@comcast.net
For additional information, contact:
Nancy Bruno 404-374-9020;
Sandy Brown 470-514-5330

Please Note: Meeting notes are anecdotal only and not intended to replace advice from your doctor. Feel free to review the discussion topics with your healthcare team.