

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Northside Meeting

July 6, 2019

IMF believes in empowering patients through support groups and education. The support groups help patients understand the effects of treatment and know that they are not alone. When a patient is first diagnosed, the information comes at you like “drinking from a fire hose”. It can be overwhelming, but the group helps patients understand the terminology and treatment. To see so many patients who have been through a transplant and doing well is so helpful to new patients. Now, as the treatments are advancing, the different options are more challenging to understand. The IMF provides education through its web site, publications, and workshops. There will be a two-day Patient and Family Seminar in Charlotte, NC, September 6-7. There will be six doctors speaking on various myeloma topics. Some of the most current information from IMF is available after the ASH (American Society of Hematology) and ASCO (American Society of Clinical Oncologists) conferences. At ASH, abstracts are presented on research projects. Each abstract states the objective of the research, the method, results, and a conclusion. At ASH in 2018, there were 939 abstracts just for myeloma! Dr. Durie and his team selected the 100 that they thought were most important and he summarized them during the Best of ASH teleconference, which is available at <https://www.myeloma.org/videos/best-ash-2018-teleconference> ASCO is held in June and there were over 200 abstracts presented for myeloma. Dr. Durie summarized the important topics at <https://www.myeloma.org/videos/post-asco-eha-imwg-2019> At both ASH and ASCO, the IMF posts videos of myeloma experts talking about what they think are the most important research that will impact patients in the future. These are available on www.myeloma.org and click on IMF TV. These are important teleconferences and videos to watch and learn, but sometimes the terminology can get confusing. To help understand the drugs and research, Nancy talked about the drug classes. She showed a chart of drug classes and the multiple generations in each class: Immunomodulatory Agents (IMiDs):

1. Thalidomide (Thalomid®)
2. Lenalidomide (Revlimid®)
3. Pomalidomide (Pomalyst®)

Proteasome Inhibitors (PI):

1. Bortezomib (Velcade®)
2. Carfilzomib (Kyprolis®)
3. Ixazomib (Ninlaro®)

Monoclonal Antibodies (Mab):

1. Elotuzumab (Empliciti®)

2. Daratumumab (Darzalex®)

Cytotoxic Chemotherapies and Steroids:

- Melphalan
- Cyclophosphamide (Cytoxan®)
- Bendamustine (Treanda®)
- Doxorubicin (Doxil®)
- Dexamethasone (Decadron®) and others
- Methylprednisolone (Medrol®)

New Therapies in trials:

- CAR T therapies
- BiTEs
- Anti-body-Drug Conjugates

Notes that lists with numbers are multiple generations within a drug class and all the generic names end in the same letters. That is the biggest clue to the drugs that the doctors are talking about. Most patients are treated with Revlimid and Velcade when they are first diagnosed. If you look at the chart, they both have newer versions within that drug class. For many patients who relapse on one drug, they can use the next version (if there have not be any adverse reactions) and it may bring the myeloma under control. For example, Doris took thalidomide for 2-3 years as was in remission for ten years. When her myeloma relapsed, she is now taking Lenalidomide (Revlimid) and the myeloma is back under control. The generic name of both drugs end in “mide”. It is important to be familiar with the generic names that the doctors use in talking about treatments.

Carolyn talked about clinical trials. She was on Phase I clinical trial of elotuzumab for five and a half years. She said that there is still one person who started with her in 2009 and is still on it and doing well. Therefore, the clinical trial cannot close since one person is still on it. If you are on a clinical trial, you can get off whenever you want, but if it is working then you can stay on it for as long as it works. In a clinical trial, the cost of the drugs are covered and any testing that is non-standard. The standard tests, that you would normally have if you were not on a trial, are usually not covered.

Nancy then did an overview of immune therapy in myeloma and used the IMF booklet “Understanding the Immune System in Myeloma”. This booklet has a great diagram showing how both elotuzumab and daratumumab work to kill myeloma. It can be found at - https://www.myeloma.org/sites/default/files/resource/u-immune_0.pdf The researchers are very excited about the immune therapy and how well it is working with very few side effects. A couple of people who were in the room are on immune therapy and have no side effects. With this level of effectiveness and good quality of life, many researchers are working to create new versions of immune therapy to continue this success. One of the new classes of immunotherapy drugs are BiTEs – Bispecific T-cell Engagers. These attach to the myeloma cells and engage the T-cells to kill the myeloma. You can see the diagram on the Best of ASH 2018 video from Dr. Durie as posted on the IMF web site. The video shows good results in

Phase I clinical trials. There are also many trials for CAR T therapy. Dana had CAR T therapy last October and had pneumonia in January. He says he is doing fine and we are glad to see him at the meeting, but his blood counts have not recovered to normal levels. He had to get platelets about once per week and monthly blood transfusion to boost his immune system. Nancy showed videos from both Dr. Mikhael and Dr. Richardson about a Phase III clinical trial in a new immune therapy, Isatuximab, that is showing great results and may be approved by the FDA. This video is at <https://www.myeloma.org/imf-tv?category=29&page=5> Listen to Dr. Rajkumar's video "Top 5 Multiple Myeloma Clinical Studies Presented at ASCO 2019". When you get to the video you can read the text (below his picture) and see the drug names to note the last letters of those names. On the same page above, Dr. Lonial talks about new drugs, one ends in "mab" and the other ends in "mide". Dr Lonial also talks about an antibody-drug conjugate (ADC) which means it is an antibody targeting the myeloma, but on the back of the antibody is a piece of chemo that is delivered directly to the myeloma cell as opposed to giving systemic chemotherapy which damages good cells. There is very exciting research going on around the world. The research is reported at ASH in December and at ASCO in June. New research and updates on clinical trials are tracked every six months at these conferences and there are hundreds of projects going on at once. That is why it is important to get to a myeloma expert for the latest treatment plan. A general oncologist cannot keep up. The IMF, MMRF, and LLS provide teleconferences to help keep you informed. Participate as often as you can to get used to the terminology and know that there are so many new options in the works. Nancy also noted on Dr. Rajkumar's video that research is advancing on smoldering multiple myeloma (SMM) to find which patients are a high risk to have damaging myeloma within 12 to 18 months. The IMWG (International Myeloma Working Group) has defined new criteria for high-risk SMM patients that should consider treatment.

The group was strongly urged to listen to some of these videos and note the points on good quality of life, which means low side effects so the drug can be given long term, much like diabetes or high blood pressure treatment. Most of the videos are only five minutes. Listen and learn to stop the video to back up and replay key points. For long-term survival, staying on a low level of treatment can keep the myeloma under control, but the patient must tell the doctor about any side effects so the dose can be adjusted for continued therapy. The videos can be found at www.myeloma.org and click on IMF TV at the top of the screen.

Patient updates: Sandy B. was unable to attend due to infection caused by dental work. She spent several days in the hospital getting IV antibiotics and is recovering at home. She hopes to see us at the next meeting. Nancy received a note from Gene T. (along with a donation to the group) that Gene is doing great. Gene has had myeloma for 13 years and feels the best he has in 13 years. He is on Darzalex and has no side effects. In 2006, he was given three years to live and is grateful to have so many years watching his family grow with 17 grandchildren and 4 great grandchildren!

Our next meeting will be August 3 and will be our annual luncheon.

Southside Myeloma Support Group

July 27, 2019

Rebecca Wallace from Leukemia and Lymphoma Society, 2019 Light the Night Event Details and the Blood Conference. The meeting was led by members Vermell S. and Deborah T. Both Doris and Gail were traveling.

Both Vermell (retired) and Deborah are nurses with a longtime career at the VA Hospital, working with Myeloma patients and have supported the group almost since its inception. The topic was: Patient-Doctor Communication and Imaging Tests (X-rays, MRIs, and CT scans, etc.) – When, what, and why.”

There were three new members in attendance. Veronica H., Marcia W., and Tracy O.

There was a lively discussion about the importance of clear communications between patient and provider. There was an emphasis on patients knowing their bodies and having or building the confidence to speak up. You should know your body better than anyone else, and it is important to share with your healthcare provider when something does not feel right. Share any side effects. All medications have some side effects. Medications can be changed or adjusted to ha sure they are not creating a long-term problem that might be avoided.

Vermell led a discussion on the purpose of imaging tests in myeloma treatment. It is important for patients who are over 65 and use Medicare to know that Medicare limits the number of screening MRIs they will pay for with myeloma.

Patients and caregivers were able to ask questions of special concern to them. The new patients were able to discuss concerns with the speakers.

Announcements/Resources/Upcoming Meetings

- **Request from Pat Conley.** Include/Read letter. Her church is requesting donations for their annual cancer event – for all cancers. Our support group, in conjunction with the IMF, has been a recipient several years of their generosity.
- **IMF – Making Sense of Treatment. Debates and discussions about trends in treatment.** Post-ASCO, EHA/IMWG. REPLAY. <https://www.myeloma.org/videos/post-asco-eha-imwg-2019>
- **MMRF- Webinar Series. 6: Monoclonal antibodies and Vaccines: Emerging myeloma treatments** – Archived from July 10.
- **LLS – Light the Night.** .Saturday, October 5, 2019. Piedmont Park. Donations can be with the Support Group, as an individual, or start your own group.
- **Advocacy. Your VOICE is important.** When you receive notices – from IMF, ACS, or LLS to write to your congress representatives, please do. Many issues concern us like pre-existing conditions, and cancer medication parity. www.advocacy.myeloma.org
- **IMF – Jameca** had a very nice article on the importance of small fundraisers. Every little bit helps.

- **IMF Fundraiser. \$50 raffle tickets for a 10-day Luxury vacation in Hawaii. Only 1,000 tickets will be sold.** <https://www.myeloma.org/hawaii2019>
- **IMF** – Amazon donates 0.5% of all purchases you make to the IMF when: You shop at smile.amazon.com, AND You designate the International Myeloma Foundation as your preferred charity. All donations are made at no added cost to you! It's that simple

Respectfully Submitted,

Geraldine and Gai