May 2017

Northside Multiple Myeloma Support Group Meeting
May 6, 2017

Business and Announcements

Jim M. led the meeting. Approximately 40 people attended. The group's new brochure is in print. Assistance posting the monthly newsletter is needed; please contact Nancy B if you can help. The http://smartpatient.org website is a good source for positive information and is monitored by the IMF.

New Members

The group welcomed Larry, diagnosed with myeloma in October 2016. Larry recently had a stem cell transplant and was near the 100-day post-transplant mark on the meeting date. He mentioned that since the transplant he has been suffering with neuropathy, uses a cane, and feels feeble. Group members mentioned that this is a common problem from many of the drugs used to treat myeloma and that the neuropathy often subsides over time.

Guest Speaker

Thank you to Dr. Harvey, a pharmacist from Emory Winship Clinical Trials who joined the meeting. Dr. Harvey was recently in Washington DC to lobby congress for advocated research funding for Cancer. Doctors should be able to prescribe based upon what is right for the patient, and independent of insurance costs. An example is oral parity. The IMF has led the oral parity revolution. There are many new options for myeloma treatment and supportive care. New combinations and new drugs are in research in clinical trials. For example, Darzalex (Daratumumab) combined with other new drugs are being studied. Oral (tablet) *Selinexor, a SINE (Selective* Inhibitor of Nuclear Export*) receptor, blocks myeloma cells. New IMiDs such as CC-220 by Celgene and others are in the lab along with new antibodies such as* Isatuximab and others*. In addition,* new ways to use drugs that are already on the market are being discovered. Dr. Harvey answered many questions and some highlights follow.

Q: For a patient who used Revlimid, Velcade, and Dex for induction therapy and is currently on Revlimid for maintenance, what would be potential next steps if a relapse occurs?
A: There are many options. If a patient progresses while on the maintenance drug, then that drug would not be used to treat the relapsed disease. However, since the other induction therapies worked previously, they may be recommended if it has not been used for maintenance. A combined drug regimen would be likely because they work better than single agents (i.e. two or more drugs together work better than the sum of their parts). For example, Pomalyst, or Elotuzumab, Carfilzomib, and other drugs in a combined regimen may be prescribed.

Q: For a patient who is about to begin a combination therapy of Velcade, Dex, and Panobinostat and who has already used Velcade and Dex before, what can be expected with Panobinostat?
A: This regimen can be very effective. A likely side effect is fatigue, especially in the first 1-2 months. Diarrhea is a common side effect from the Panobinostat. With subcutaneous (vs.

intravenous) Velcade, there are less GI and neuropathy side effects. A recommendation to take Dex in the morning, then wait 30 minutes and take the Panobinostat because Dex can help prevent nausea and diarrhea. A low platelet count is associated with taking Panobinostat.

Q: What are some options for controlling diarrhea?
A: Over the counter Imodium, and prescriptions Lomotil, and Welchol. A group member mentioned that Welchol is also used to treat high cholesterol. If Welchol is not covered by your insurance, then Prevalite powder is another option.

Q: What can be done to combat drug-induced fatigue?
A: If using Dex, take it in the morning, not in the evening. Stay active, do not "live in the middle" – i.e. if you are tired, then sleep, otherwise move and be active. Do not continuously stay on the couch and watch TV. When it comes to managing fatigue, think in terms of black or white, not gray.

Q: How are initial dosages for treating active disease determined?
A: The default is to typically start with stronger doses early and then back off if necessary, depending on the patient's toleration. This approach is taken with the hope to treat the disease and get that under control as the top priority. Sometimes if the patient can get through the first 1-2 months, the side effects subside and/or the patient gets used to the drug and feels better.

Q: Is there a known correlation between heart disease and Revlimid?
A: No correlation has been identified. Revlimid can cause blood clots but patients on Revlimid take blood thinners.

Q: Why are dosages of the same drug different for treatment and remission?
A: For active disease treatment the goal is to use larger doses and as much as the patient can tolerate to shrink the disease in a shorter time. For maintenance, the goal is to take the drug long term to extend the remission, so a smaller dose is usually prescribed.

Q: Are combinations of drugs used for maintenance?
A: Not usually, but it's sometimes done for certain cytogenic high risk cases

Q: Do we know enough about the efficacy of Ninlaro to be used for maintenance vs. Revlimid?
A: Not yet, the standard is still Revlimid but Ninlaro as maintenance is under investigation.

Q: What is the difference between resistance and relapse?
A: Resistance is when a patient is being actively treated and the disease becomes worse. When a patient becomes resistant to a drug, the drug is no longer working for them. Relapse is when a patient has been in remission and the disease returns. Relapsed patients can consider prior effective drugs to treat the relapsed disease.

Q: As a patient diagnosed in September 2016, had induction R/V/D treatment and some radiation. Has had no maintenance and doing well since stopping treatment in February and

has stem cell transplant planned for July. Should I continue with plans for stem cell transplant, or should I just use Revlimid for maintenance? Or, is a combination of both a better choice?
A: Dr. Harvey mentioned that this question would have been answered differently just two years ago, but now clear data exists that shows that patients who have had a stem cell transplant and then used Revlimid for maintenance have done dramatically better than those who did not opt for a stem cell transplant.

Q: If the new healthcare bill is approved, will it affect Cancer research funding?
A: No, the part of the government that funds cancer research is different from the part that supports insurance.

Q: What factors are considered for a stem cell transplant?
A: Only patients with active myeloma (not MGUS or smoldering) are candidates. Age is less of an issue now; there used to be a cutoff age of 70, but that no longer exists. Health considerations include kidney, heart, lungs, and total general health.

Q: What are your thoughts on using Curcumin as a supplement for myeloma patients?
A: Curcumin looks very promising in the lab and it can cancel many different kinds of cancer cells. Curcumin is not well absorbed, so it generally does not interfere with treatments. It may have benefits that we do not know about yet. If you feel better taking it and it is not harmful to you, then you should take it, but let your medical team know that you are taking it.

Q: If a patient decides to take Curcumin, how do they know how much to take?
A: The FDA was created to keep U.S. citizens safe by regulating the safety of drugs. Supplements are not FDA regulated and a recommended standard has not been established.

Q: What is the monetary cost for a patient in a clinical trial?
A: There is no monetary cost to the patient to participate in a clinical trial and the cost of drugs is not considered for trials because the drug company pays. This question led to discussion of drug costs in general and Dr. Harvey mentioned that there is a lot of drug waste and there are plans to reduce this waste in process. A member mentioned that with the patient paying for Revlimid by the pill, she has been taking Revlimid every other day vs. every day (with her doctor's permission) to cut her expense in half.
Submitted by Wendy R.

****

Southside Multiple Myeloma Support Group
May 27, 2017

Be happy for this moment. This moment is your life. Omar Khayyam...

There are no ordinary moments. Dan Millman. The Way of the Peaceful Warrior.

Doris opened the meeting with a moment of silence. Please take a moment to devote thoughts and prayers for our members who may be struggling physically, mentally, and emotionally.

There was one new member. Kyle usually attends the Northside Support Group Meeting. He was diagnosed in 2005 near his 40th birthday with smoldering Myeloma. Once diagnosed, Kyle, a home builder, went back to school to study nursing so he could better understand his diagnosis. Eleven years later, just as he took the examination for his nursing license he had a blood clot; during treatment he was diagnosed with active Multiple Myeloma. Kyle went through induction treatment with Revlimid/Velcade/Dex, and had a stem cell transplant which resulted in a very good response. He is now on Ninlaro (2.3 mg), Revlimid (15 mg) and Dex (40 mg). Kyle is receiving treatment at Emory with Dr. Nooka and also sees Dr. Douglas Collins, a hematology/ oncologist (and past speaker to our group).

We welcomed Carol back; she had a stem cell transplant in August at Northside and had a complete response. Carol is now on 25 mg Revlimid for maintenance. She looks and is doing very well.

Gail was diagnosed in 2008; she went through induction therapy with Revlimid/Velcade and Dex and had a stem cell transplant in December, 2008. By April, 2009 she was in near complete remission. Since May, 2016 Gail has been treated with a regimen of Ninlaro 3mg (initially 4mg), Pomalyst 4mg, and Dex. Gail began treatment with 40 mg Dex which was gradually reduced to 4mg. As of June, 2017 she is no longer on Dex.

The Myeloma Support Groups in Atlanta held a successful event to acknowledge and say "Thank You" to Caregivers. On May 20th, about 60 caregivers and Myeloma patients came together for the first Caregiver's Forum and Appreciation Event. It was a joint effort of the Northside and Southside Myeloma Support groups. Thanks for the generous sponsorship of the Atlanta Leukemia Lymphoma Society and Takeda Pharmaceutical Company. We also owe the team of MM patients and caregivers who spent countless hours planning the event. They include Nancy, Doris, Alma, Vermell, Paulette, Kimberly, Sheryl, Tricia, and Gail who chaired the committee. Also, thanks to Larry, Leah and Pat for serving as hostess for this event.

Speaker: Nancy Bruno is the Southeast Regional Support Groups Director for International Myeloma Foundation (IMF); her topic: The Black Swan Research Initiative (BSRI) and Immunotherapy. Nancy has been involved in Myeloma since her husband Mike was diagnosed with MM in 1998; she was his care giver and joined the Northside Support group soon after. Nancy began leading that group in 2007. The IMF is the oldest and largest myeloma-specific foundation in the world. With more than 350,000 members in 140 countries, the IMF serves myeloma patients, family members and supporters as well as the medical community. The IMF provides a wide range of programs in the areas of Research, Education, Support, and Advocacy. Nancy began her presentation by showing us how to navigate Myeloma.org – the IMF website to find reliable Myeloma information. She encouraged us to take time to explore the website.

The Black Swan Research Initiative (BRSI) takes its name from the discovery of black swans in 1697, when it was assumed all swans were white. Just as people who had only seen white swans could not imagine the existence of black swans; until very recently, we could only imagine the possibility of finding a cure for MM in our lifetimes. Through the BRSI, we are getting closer to a cure for Myeloma. What is Minimal Residual Disease (MRD©)? When a

patient is diagnosed with MM, conventional wisdom thinks of it as one disease when in reality there are multiple diseases in one. There are many clones of multiple myeloma cells that are present in the same patient. Current treatments for myeloma target the dominant clones, but often leave behind some of the more resistant clones, which may lead to relapse down the line. These leftover cells are the Minimal Residual Disease, or MRD. Defining the Cure: MRD-Zero®. With a new understanding of myeloma at the molecular level, the IMF's Black Swan Research Initiative is developing ultra-sensitive tests to accurately measure Minimal Residual Disease and define its absence as a cure. Currently those ultra-sensitive tests rely on the bone marrow. There is hope that tests using blood to measure MRD are within the next one-two years.

The immune system is extremely complex and is made up of multiple mechanisms that work together to protect and defend the human body from extreme threats like bacteria, virus, toxins, and from internal threats such as cancer. During her presentation, Nancy likened the immune system to a fine Swiss watch, with many tiny moving parts working together seamlessly. Any change or malfunction in even one of those tiny parts will affect all the others. Myeloma suppresses the immune system as a whole, reducing the number of normal antibodies and affecting all the cells that patrol for attack abnormal cells. Immunotherapy treatment (monoclonal antibodies is one of the newest forms of myeloma treatment) is defined as a treatment that enhances the body's natural defenses to fight cancer. It works by having your own immune system attack cancer cells. The two immunotherapy drugs, approved since 2015, are Darzalex (Daratumamab –"Dara") and Empliciti (Elotuzumab – "Elo") for MM patients who have had at least two prior therapies. The immune system has two major components: (1) the innate response, made up of cellular proteins and killer cells and (2) the adaptive response, based on the ability of the immune system cells to recognize and attach to specific antigens on the surfaces of infected cells and tumor cells. The treatment of cancer with therapies that trigger cells in the immune system is vital and is a growing field of research. One of the more promising lines of research in hematologic cancers is an immunotherapy technique called chimeric antigen receptor (CAR) T-cell therapy. Nancy referenced an IMF publication "Understanding the Immune System in Myeloma" in her presentation. To find it go to Myeloma.org; click on the tab "Education and Publications", then IMF Publications, scroll down to find The Understanding Series, page down to find Understanding the Immune System and click to open. This booklet will help you understand immune system basics and provide details of drugs used to treat multiple myeloma. Nancy ended her presentation by showing a six minute video featuring Dr. Morie Gertz, myeloma researcher of 30 years and Chair of the Department of Medicine at the Mayo Clinic-Rochester. The summary of his comments on breakthrough presentations from the 58th Annual American Society of Hematology (ASH) meeting provided a strong sense of hope and encouragement. In this video, he says, "This year's ASH proves that we are moving very close to a cure for myeloma, having converted it to a chronic disease for which we should expect long-term survival for the majority of our patients." (To get to his presentation and others go to Myeloma.org; Click on IMF TV; Click on Medical Meetings; scroll down and click on "Load More" until you get to ASH 2016: Multiple Myeloma Overview - Dr. Morie Gertz December 4th 2016. Please take time to explore the IMF TV site as there is lots of useful information.

Announcements/Resources/Upcoming Meetings

· Piedmont Cancer Wellness: The Thomas F. Chapman Family Cancer Wellness Center is a non-profit entity located at 1800 Howell Mill Road; Suite 700, Atlanta. They offer free services and programs such as yoga, cooking demos, expressive classes, and counseling. You are welcome to participate whether or not you are a Piedmont cancer patient or caregiver/family member. For more information about programs and services, visit Piedmontcancerwellness.org or call 404-425-7944. Please register at least 48 hours prior to for cooking demos or other programs where a meal is provided.
·IMF: Living with Myeloma: Nutrition2017.myeloma.org (now archived) Speaker: Kylie Buchan, RD, CSO, LD; Kylie is a Registered and Licensed Dietitian and holds her CSO designation, Certified Specialist in Oncology Nutrition.
·MMRF – Webinar: Clinical advances in Immunotherapy. Monoclonal Antibodies: A New Type of Myeloma Drug. Now MMRF.org/webinars (aired June 14th 2017-now archived).
•LLS. New video - CAR T-cell Therapy: A Hopeful Emerging Option in Myeloma Treatment. www.LLS.org/educationvideos
•IMF. Check Archives for Webinar. This Free Webinar: Addressing Concerns on the Recent Lack of Funds for Co-Pay Assistance may be timely.
•Join SMART Patients - Conversations. https://www.smartpatients.com

To Locate Clinical Trials:
·IMF - Myeloma Matrix 2.0 - provides information on myeloma clinical trials. https://www.myeloma.org/matrix . Sponsored by SMART patients
·MMRF - https://www.themmrf.org/ pipeline-clinical-trials
· www.clinicaltrials.gov

Multiple Myeloma Classes of Drugs/Therapies:
1. Proteasome Inhibitors - Bortezomib/Velcade; Carfilzomib/Kyprolis; Ninlaro/Ixazomib
2. Immunomodulating - Thalidomide, Lenalidomide/Revlimid; Pomalidomide/Pomalyst
3. Monoclonal Antibodies/Immunotherapy - Daratumumab/Darzalex; Elotuzumab/Empliciti
4. Histone Deacetylase - Panobinostat/Farydak.

Today's Question: What is the new agent with a "V" for myeloma treatments? * New agent- Venetoclax - Venetoclax is an oral BCL-2 inhibitor that kills myeloma cells, especially for patients with an 11;14 chromosome translocation. A Precision Medicine Drug for relapsed or refractory myeloma. Often used with Velcade (Bortezomib) and Dexamethasone (Steroid).

Respectfully submitted by Paulette and Gail

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.