

Northside - IMF Workshop October 15, 2016

The IMF workshop provided insight and very important information about Myeloma and the latest treatment options. For those who missed it, there is one more workshop this year in the Southeast. It will be in Nashville on October 29. If you are able to be there, you will get to hear from Dr. Robert Kyle, Mayo Clinic, who has been studying Myeloma for almost 50 years. For more information and to register, go to Myeloma.org and click on Meetings.

The Northside group did not have a meeting on the regular day. Instead the IMF Regional Workshop took its place on October 15. It was an excellent experience and many said that they learned more than they expected. Dr. David Vesole from John Theurer Cancer Center in New Jersey spoke first about the basics of Myeloma. He gave us a different perspective on the history and definition of MM as well as understanding the different types. He noted that there are 30,000 new cases of MM each year and 12,600 deaths per year. They are seeing a slowly increasing incidence of MM and he discussed the risk factors for getting MM. We learned about MGUS, Smoldering Myeloma, and updated diagnosis criteria for MM. Importantly, he compared the overall survival rates based on staging and genetic status. Dr. Vesole took questions throughout his talks and clearly wanted to help educate all who attended.

Dr. Vesole's second talk was about treatment options for newly diagnosed and how to measure response levels. He covered the different options for those patients who are not able to have a transplant vs. patients who have a transplant early in the treatment cycle. He talked about Minimal Residual Disease (MRD) and how it will help track the residual disease when a patient is in remission and other tests cannot see any myeloma. The new drugs in the last 15 years have dramatically improved survival rates and the quality of life factors. He even talked about how "cure" is now part of the conversation and how it will be defined. Dr. Vesole reviewed several clinical trials and how the newly approved drugs are being tested in new combinations with previous drugs. There are so many new options, so it is important for the patients to work with their healthcare team to create a long term plan for treatment. The bottom line is that getting a better clinical response from the initial treatment helps extend remission and maintenance can extend remission even further. Some of the newest treatment involves CAR T Cells and Dr. Vesole explained them in an understandable way, including some of the open questions that need to be resolved for the best outcomes. His final slides covered treatment in the elderly and identified all the factors that must be considered for the treatment plan: frailty index, insurance coverage, goals of therapy, transplant eligibility, and duration of treatment on maintenance.

Dr. Kaufman from Emory spoke next about treatment choices to manage relapse. So many options are available, but there are key factors that may influence the plan. Here are some of the issues to consider. 1 - How long was your response to initial treatment? If more than six months, then repeating initial therapy may be an option. 2 - What is your genetic profile for risk? If high risk, that will influence choices. 3 - What were side effects of prior treatment? This will influence ongoing quality of life. 4 - Is another transplant an option? Length of remission from first transplant and the number of stem cells in storage should be considered. 5 - Are there other health conditions that need to be taken into consideration? Age and general health enter into the evaluation process. 6 - What personal preferences and lifestyle choices should be included in the discussion? Going back to work, traveling and family obligations, insurance coverage, oral vs. IV administration and other factors should be expressed to the healthcare team. 7 - Is the patient interested in a clinical trial and what is available? This is an important question to consider for treatment options.

Dr. Kaufman talked about the different classes of drugs and the newer generations of treatment within each class of drug. The first proteasome inhibitor (PI) was Velcade (Bortezomib) and this still works very well as the first line of treatment in combination with Revlimid (Lenalidomide) and Dex. It can also be used in relapse with consideration of how well it worked before. The second generation PI is Kyprolis (Carfilzomib). This can be used alone or in combination with dex or Rev/dex. There are many clinical trials with Kyprolis in combinations and at different dose levels. The latest generation of PI is Ninlaro (Ixazomib) which is an oral version. It was just approved in November 2015 and there are many clinical trials of Ninlaro in combination with other drugs or for maintenance. The other well-known class of drugs are the immunomodulatory drugs and their versions are: Thalidomide, Revlimid (Lenalidomide), and Pomalyst (Pomalidomide).

A new class of drugs called mono-clonal anti-bodies had two new treatments approved last year. Emluciti (Elotuzumab) and Darzalex (Daratumumab) were approved in November 2015. These are promising new drugs with lower side effects.

Dr. Kaufman closed his talk noting that there are so many new drugs that are being used in new combinations, so relapsed Myeloma is treatable. With so many drugs, expect to receive multiple lines of therapy, which may continue for an extended period of time. With each new drug comes the potential for additional combinations. Many promising new drugs and new combinations are in clinical development, so everyone should consider a clinical trial.

Charise Gleason then addressed questions that have been developed from support group members and answered by the IMF Nurse Leadership Board. The scope of her discussion covered treatment-related questions, side effects, self-care,

and clinical trials. How do you decide on treatment? Your healthcare team will explore options with you based on your past treatment successes, data from research, and patient preference. Since the patient input is a key component, you should be up-to-date on the new treatments and express your preference and barriers to certain types of treatment. For example, your ability to travel to the clinic for IV infusion; verifying insurance coverage, ongoing side effects or other health issues. Charise reviewed the different classes of Myeloma drugs and their common side effects. Sometimes there is overlap of symptoms from the Myeloma with side effects from the treatment. They all impact how you feel and your quality of life. She talked about the side effects of steroids (Dex) and working with your healthcare team to monitor the effect. Do not stop or adjust doses without discussing with your providers. Other side effects discussed were peripheral neuropathy, pain, diarrhea, fatigue, depression, anxiety, and others. She urged everyone, patients and caregivers to stay current on health screenings and vaccinations. Maintain a healthy lifestyle with good diet and exercise to improve quality of life. Also, get involved in activities with friends and family, which is especially important for caregivers.

Southside Multiple Myeloma Support Group Saturday, October 22, 2016

Doris opened the meeting with a moment of silence. There were 7 support group members present.

Next month's meeting on Saturday, November 26, Thanksgiving weekend, and will feature a discussion of the **Pre-ASH 2016: What Myeloma Patients & Caregivers Need to Know**, November 17th at 7pm EST. To register for the teleconference please call 1-800-452-2873.

Doris introduced the speakers. **Dr. James McCoy**, Vice Chair of the Department of Psychiatry at Morehouse School of Medicine and **Marlon Sims** committed vegans, presented information about plant based diets and chronic disease. Also, **Kendelle Miller, LCSW, ACM** (Certified Case Manager) came to the meeting to introduce herself to our group. **Ms. Miller** is Oncology Social Worker with Winship Cancer Institute replacing long term Social Worker, Alice Mullins; she works directly with Dr. Hefner.

Ms. Miller addressed the group first. She has been a licensed social worker for 21 years and an oncology social worker for the last eight years. Ms. Miller is a graduate of the University of Massachusetts at Amherst where she obtained a Bachelor of Science degree in Psychology in 1993. She went on to earn a Master of Social Work degree in 1995 from New York University School of Social Work where she focused on behavioral health therapy. Her father died of cancer when she was 9 years old; she believes that is the reason she went into social work. She knows from her own experience that people with a cancer diagnosis need to talk to someone about what they are going through. An individual experiencing cancer may feel their life has been turned upside down. Often they have to stop work which creates financial issues. Ms. Miller counsels patients on social emotional issues and can assist with securing financial assistance. She loves her work and works alongside the medical team. Ms. Miller distributed her business card and a list of financial resources. Ms. Miller provides clinical social work for patients with hematological malignancies and who are treated at the Bone Marrow and Stem Cell Transplant Center at Winship. You can reach her by calling (404) 778-5535 or kendelle.miller@emoryhealthcare.org.

The support group then heard from **Dr. James McCoy**. He attended medical school in Texas and spent the first two years of his residency at Howard University. He specialized in thoracic surgery. He then went back to medical school to become a psychiatrist, so that he is both a surgeon and a psychiatrist.

For the last 20 years **Dr. McCoy's** diet included fruits, vegetables, chicken and fish; he considered himself a healthy eater. All that changed on June 19, 2016 when he attended a retreat at the Upper Columbus Conference in Spokane, Washington, the administrative office for the 132 Seventh Day Adventists Churches in the United States. During the retreat they focused on devotion, exercise and eating healthy. They discussed increasing one's vitamin D levels, fasting, consuming vegetable and fruit juice, and avoiding dairy, meat and fish. The goal is to consume 80 percent raw vegetables and 20 percent lightly cooked veggies. He reports that now this is how he lives his life.

As a cardiologist, **Dr. McCoy** knows firsthand what a person looks like if their diet isn't healthy. He discussed the "**Seventh Day Adventists' Eight Laws of Health**". They are 1. **Eat nutritiously** (many choose a plant-based diet). 2. **Exercise** regularly and often to improve your body, mind and spirit. 3. **Drink plenty of water**. 4. Spend time in **sunlight**. 5. **Practice temperance**: Use good things moderately; avoid bad things. 6. **Breathe in pure air**, and do it properly. 7. **Rest** well, remembering that the best rest follows labor. 8. **Trust in divine power** as you make choices and seek inner peace.

Upon arriving, Dr. McCoy distributed to support group members a booklet entitled "**Care for the Care Provider-Coping with Critical Incident Stress (Trauma Care)**" by **Johnathan R Ward, M.Div.**, He called the booklet a good

blueprint for humans, health care workers, and those dealing with significant health issues. The booklet lays out the six dimensions of wellness which are occupational, physical, social, intellectual, spiritual, and emotional. It also discusses the benefit of resiliency, or protective factors to ward off stress. Making connections, reading about things important to you, problem solving, goal setting skills, social skills, pursuing hobbies and interests all help one become resilient. Dr. McCoy cited the importance of taking care of our brain and body together.

Dr. McCoy reports that health studies of Seventh Day Adventists show that they have fewer incidents of cancer and heart disease than the general public. He suggests that people “go raw” and not cook their food which kills much of the vitamins. He also encourages people engage in regular exercise. You don’t have to work out like a gymnast, but a healthy person who lies in bed all day will waste away.

Dr. McCoy invited his colleague Marlon Sims to talk to the support group. Marlon is 62 years old and has been a martial arts instructor since he was 34. At the age of 13 he decided he didn’t like meat and started juicing. He said he learned the doctor who cured Magic Johnson of Aids did so by having him go raw.

While out of the country, Marlon injured himself. He visited a doctor who recommended surgery to repair the bone. The surgery would require he stay in the hospital to heal, so he turned down the surgery and wrapped up his leg. What ultimately happened is that the injury healed by itself. Marlon credits his healing to his lifestyle – exercise, juicing of raw foods and getting 9 to 10 hours of sleep a night. He brought to the meeting a bottle of his raw juice drinks for support members to sample and stressed the importance of consuming raw plant life for optimal health.

Support group members gave a brief update on their health status. **Janet** was diagnosed in 2012. She had a stem cell transplant. Eight months ago she was diagnosed with Hodgkin’s Lymphoma. **Teonna** has undergone treatment with Kyprolis, Pomalyst, Dex and is preparing for a stem cell transplant. **Gloria** was diagnosed in 2009. She had a stem cell transplant in 2010. She is under the care of Dr. Kaufman at Winship. **Alma** is off all medications. She recently had a petscan and is waiting for results. **Larry** was diagnosed in 2013 after a car accident; he went through treatment with Velcade, Revlimid and Dex. He had a stem cell transplant and is now in Larry is in stringent complete remission. **Kimberly** was diagnosed in 2008; she went through treatment with Velcade, Revlimid and Dex, then a stem cell transplant. She is in a stringent complete remission. **Doris** was diagnosed in 2006 and founded the SSMM Support Group. She was diagnosed via a regular physical with her primary care doctor, was referred to an oncologist, had a bone biopsy and was diagnosed with MM. She was treated with Thalidomide, Velcade and Dex. She chose not to have a SCT. She had been in remission for 9 years; earlier this year she began treatment with 25 mg Revlimid and 2 ½ mg Dex.

Announcements/Resources/Upcoming Meetings

- **IMF - CAR-T Therapy. Archived.** Chimeric antigen receptors (CARs) help T-cells recognize and destroy cancer cells. Vocabulary - Immunotherapy, Precision Medicine, Personalized Medicine. Daratumumab, Elotuzumab, and newer Pembrolizumab (not approved but shows promise).
- **MMRF. Kathy Guisti and former CEO of AOL/Time Warner, Richard Parsons, featured in Fortune Magazine, “Technology – the Newest Weapon Against MM. Richard Parsons was diagnosed with MM in 2014, and joined the CoMMPass study. This is a study that follows myeloma patients through their journey to relapse, collecting data for genomic profile. This data goes into the public domain for the benefit of researchers, doctors, and patients. This is genomic sequencing for myeloma.**
- **Telephone Support Groups.** CancerCare's telephone and online support groups are free and professionally facilitated for people living with cancer and their loved ones. To join a telephone support group, contact us at 1-800-813-HOPE (4673). To join an online support group, please register through our website at www.cancercare.org
- **IMF - Smart Patients** is an online peer-to-peer program – get daily emails from patients and caregivers regarding their MM treatment journey. They share experiences from preparation for SCT to hints on increasing energy to discussions on new medications, side effects, and more. <http://www.smartpatients.com/imf>.

Question: MM Vocabulary for today: Which Myeloma Drugs are in the Monoclonal Antibody Class?

Answer: Daratumumab/Darzalex; Elotuzumab/Emplificiti

Multiple Myeloma Classes of Drugs/Therapies:

1. Proteasome Inhibitors - Bortezomib/Velcade; Carfilzomib/Kyprolis; Ninlaro/Ixazomib
2. Immunomodulating Drugs – Thalidomide, Lenalidomide/Revlimid; Pomalidomide/Pomalyst
3. Monoclonal Antibodies - Daratumumab/Darzalex; Elotuzumab/Emplificiti
4. Histone Deacetylase - Panobinostat/Farydak

*New agents - Farydak, Darzalex, Ninlaro, and Emplificiti

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.