

June 2017

**Northside Multiple Myeloma Support Group Meeting  
June 3, 2017**

**Business**

Nancy B. led the meeting. The Board of Directors met prior to the June meeting. The group's new brochure has been completed and printed. Thank you to Tim's wife Margaret for the donation to support the printing. Assistance with updating the web page is needed (mmsg.org). If you know anyone who can help redesign the AAMMSG web page, please contact Nancy B. There are funds available to support payment for the website redesign work. A financial advisor will speak at the July meeting. Please note that there will be no meeting on Saturday, 9/2/17, which is Labor Day weekend. Instead, the September meeting will be held on 9/9/17, and in celebration of the group's 20 year anniversary, the meeting will be held at a local restaurant, The 57th Fighter Group, in the form of a luncheon (at no cost for members). Details with a request for a head count will be provided as the event date gets closer.

**Discussion & Presentation**

The group has been together for nearly 20 years and Nancy and Sandy have been members from the start. The changes in advanced knowledge and therapies for multiple myeloma (MM) have been dramatic in the past 20 years but are also complicated and fast-moving. For this reason it is very important to stay educated so that you are always aware of your best options and can share your knowledge with your medical team to discover the best solutions for you. Remember that your education is an ongoing process due to the very fast changes in what we all know and understand. There are many free and easily accessed resources to stay informed so that you are empowered to make good decisions. The MMRF is focused on MM research. The LLS is a good source, although not focused specifically on MM. The IMF formed in 1990 and is specific to MM patients. Its purpose is to provide education, support, research, and advocacy. These categories present in many different ways such as the availability of 150 support groups in the U.S. with five Regional Directors organized by zone (Nancy is one of the five Directors). Research shows that people who are involved in support groups have better outcomes. Also, free publications that can be mailed to you - i.e. "Myeloma Today" and "Myeloma Minute" (weekly email). Register on the IMF website to receive these publications. The IMF website contains other types of information such as conference details, videos, forums, IMF TV, and blogs. A powerful search engine is available to help you find exactly what you are looking for. Nancy presented information on Black Swan Research and Immune Therapy. The discussion included: "How do we stop the cycle i.e. the return of the disease after remission?" i.e. you can't kill what you can't find. The Minimal Residual Disease (MRD) test is available now to find the disease below the surface - i.e. the rare "black swan", in this case the small number of cancer cells that remain during and after treatment that cannot be identified with other tests. Studies prove that if a patient is MRD negative, then they will stay in remission longer. Immunotherapy is a type of treatment that boosts the body's natural defenses to fight the cancer. It uses substances made by the body or in a laboratory to improve or restore immune system function. One example of a way that immunotherapy drugs affect cancer cells

is by removing the antibodies that cloak the cancer cell, allowing the patient's natural killer cells to do their job of killing cancer cells. A publication that is available from the IMF's website and the group's library entitled "Understanding the Immune System in Myeloma" explains how immunotherapy works. Nancy also provided a walkthrough review of the IMF's website. Some questions and answers follow:

Q: How is the IMF involved with patient advocacy?

A: Insurance coverage for IV-administered drugs vs. orally-administered drugs should not have dramatic cost differences for the patient. The IMF has led the oral drug parity activity. Now 43 states have drug parity laws that were led by patient advocates. Jim M. played a significant role as an advocate for the state of Georgia. Also, the Advocacy team is tracking the changes to healthcare coverage and reduction of funding for important cancer research.

Q: Is the MRD test a standard test for patients in remission?

A: Not yet, however MRD testing is rolling out now to a lot more labs. If you are in remission, remember to request the MRD test when you have a bone marrow biopsy test. The MRD test was created in Spain and currently a MRD blood test is replacing the current bone marrow biopsy test in Spain.

Q: Is MRD testing being used in clinical trials?

A: Yes, especially for when the trial requires a relapse to complete; because disease relapse can be identified so much faster with the MRD test. The clinical trial life cycle is significantly shortened when MRD testing is used.

To learn more about the IMF resources, go to [Myeloma.org](http://Myeloma.org) and scroll down to the four strategies:

- Education – IMF TV features "Ask Dr. Durie" short videos on various topics; 10 Steps to Better Care guides you along the Myeloma journey; publications are available online or call the InfoLine to order a New Patient Packet and be sure that they include Immune System booklet. Check out the IMF Publications (when you click on Education and Publications on the main page). Of particular interest is the Understanding Series booklet on the Immune System. It has a great drawing of a mono-clonal anti-body linking to the antibodies on a Myeloma cell so the immune system can identify and kill the Myeloma. Also, under IMF TV is the link to the Living Well Teleconferences and informative videos from the Medical Meetings, like ASCO and ASH.

- Support – There is a US map of all the support groups so patients can find the one closest to them. We all know how meaningful a group is on this journey! If someone is not able to get to a group, the Smart Patients forum is a great place to learn from other patients about treatments and challenges. You are also able to email the InfoLine from a link provided.

- Research – Learn more about the Black Swan Research Initiative that is working toward a cure and advancing the testing for MRD.

- Advocacy – Click on the Advocacy Action Center to find out what you can do to advance drug parity at the Federal level, learn about the new healthcare laws, and speak out for research funding to cure cancer.

Member Updates

Members at the meeting provided updates.

Becky is doing well.

Frank is 9 months post stem cell transplant, back on 10 mg. Revlimid, and doing well.

Marilyn, who has smoldering myeloma is doing well, but has experienced anemia.

Both Bob and Lory are doing well and in complete remission. Bob is taking 10 mg. Revlimid.

Donna is 1 year post stem cell transplant, on Revlimid maintenance, and doing well.

Jim M. is doing well, just stopped Zometa treatments, and has been in complete remission for 7 years.

Dana is taking Carfilzomib and Dex and doing well.

Sandy B. has been on Revlimid since February. She has stopped epidurals to treat the pain in her back and legs and has a spinal cord implant scheduled to help manage pain. Sandy also mentioned that she has neuropathy pain in her hands and feet but she can manage that. Sandy reported on some members who did not attend the meeting.

Monique F. stopped taking Velcade and started taking Revlimid in February. She has had challenges with femur fractures and pneumonia.

Vanessa F. has experienced GI difficulties when getting off drugs.

Both Mary and Cappa did not attend the meeting because they were traveling. Mary J. had lesions successfully minimized and Cappa is well.

- Submitted by Wendy R.

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Southside Multiple Myeloma Support Group  
June 24, 2017

Doris opened the meeting leading the group in a moment of silence. There were 15 members present; no new members but we were excited to welcome several members that we had not seen in some time.

Next month's meeting is canceled so that members can attend the LLS conference

Business: The annual Macy's Shop for a Cause campaign has changed from a coupon sale to an online/social media-focused campaign. It requires non-profit organizations who participant to maintain and enhance a web page and use social media to reach perspective donors by engaging them through special promotions. For this reason members present decided not to participate this year. The selling of Macy's discount coupons for \$5.00 each has traditionally been our biggest annual fund raiser. We have typically been able to raise \$350-\$450 per year. Those funds were used to pay for postage, greeting cards, printer cartridges, paper (agendas,

sign-in sheets), and mileage for group travel to member serves, etc. The group decided to brainstorm on other ways to meet annual expenses.

#### Member Updates

Carole had a stem cell transplant last fall and says she is doing well. She was on a regimen of Revlimid (10mg) for maintenance until labs showed her white blood count and platelets were going down. She is now on 5mg of Revlimid and is being monitored weekly. Carole has run the Peachtree Road Race each year since 1988 and plans to run it this year. Her doctor at Kaiser, whom she really likes, is leaving and she is in search for another.

Teonna was diagnosed in April 2016 with high risk MM and had a stem cell transplant in December 2016. She had a clinical complete remission. Teonna has been working part time and hopes to go back full time soon. Her doctor has cleared her to run, something she did routinely before her diagnosis. Teonna is on a maintenance regimen of Dex, Pomalyst (2mg) and Kyprolis.

Jameca was diagnosed with MM at the age 26 in 2003/2004. She has been in remission for 13 years and is not on a maintenance regimen. She is fighting arthritis and tendinitis along with some back pain. She says she is taking over 10 medications. A few years ago she moved to North Carolina to take a job; recently, she has had to stop her job because of side effects of the disease and medications (her "New Normal"). She says the blessing is that she is learning a lot about Social Security Disability as she is trying to get back on disability – it is a real challenge.

Ethel was diagnosed with MM in February 2015 and had a Stem Cell Transplant (SCT) on July 20 of the same year. She was in a car accident on October 28, 2016 and injured 3-4 disks in her back. She has pain but not sure if pain is from accident or myeloma. Chiropractor would not treat her because of her myeloma. Ethel is on Revlimid (10mg) for maintenance and Klor-Con (a prescription potassium supplement).

Barbara was diagnosed with MM in July 2014 while at Fort Stewart Military Base. She had been in pain and undiagnosed for some time. Barbara had pain while at the base, so severe that she could not get out of bed. When she went to the military doctor he diagnosed her immediately with kidney failure and told her she had "some myeloma in her blood." She was medevacked to a hospital in Augusta where she was in treatment for 2-3 months. Barbara says even though she is in remission, she has bouts of weakness, and fatigue; she has gained weight and sometimes has very little energy. She is on a regimen of Dex, Revlimid (10mg), and Ninlaro for maintenance.

Gloria was diagnosed in 2009 and had a stem cell transplant in 2010. She says it was a challenge to get the diagnosis. When she was finally diagnosed she had kidney failure and was on dialysis for 4 months. She is still adjusting to not having her old life style; Gloria says she cannot do as much as she did before and it is sometimes difficult to convey this since she does not look like she is ill.

Meriel apologized to Larry for chastising him for not going to the doctor when he was not feeling well in spite of his wife's instruction. (Larry ended up in the hospital 3 weeks with pneumonia and sepsis.) She said she was recently in pain all over her body and since she had a scheduled appointment in 3-4 days, she waited until then to seek treatment even though her doctor told her to go to the emergency room. Meriel said she had a kidney infection and developed a blood clot. She says it could have all been prevented if she had sought treatment when she realized something was wrong. The kidney infection was treated with antibiotics but

she is now on a blood thinner. Merieal cautioned us all to listen to our bodies and not wait to seek treatment if something is wrong.

Alma says it was also a challenge to get her diagnosis. She had a series of missed diagnoses and even was discharged from the hospital with an extremely elevated calcium level. She also had kidney failure. Alma says if it had not been for her sister intervening on her behalf due to continued pain and abnormal blood chemistry, the outcome could have been even worse for her. Alma follows her Freelite levels for disease progression, and says her Freelite is now stable. She is on a maintenance regimen of Daratumumab, Dex (20mg) and Pomalyst (2mg).

This was Geraldine's first meeting since her father's passing and a car accident that totaled her car. She is a Kaiser/Northside patient and is on Daratumumab after her oncologist noticed her numbers were going up. Geraldine said the first treatment with Dara was grueling; all of the side effects she experienced resulted in her hospitalization as she continued the infusion. She had chills, diarrhea, excess mucus, and other side effects; it was an 8 hour infusion treatment. Her next infusion took only 3 hours and went a lot smoother. She said today is the first day she has not had a headache and she stopped feeling dizzy. Her regimen now includes Velcade, Dex and Dara.

Larry is back at Emory with Dr. Kaufman. He is on Revlimid (25mg), Dex (40 mg/week) and Dara (3hr infusion). He is going back on Zometa every 3 months.

Janice was determined to be in remission in November 2016; in January 2017, her oncologist noticed her numbers were going up (para protein now at .05). They are watching; but for now, no treatment. Earlier she had side effects from Pomalyst and Dex which created problems with Atrial Fibrillation (AFib or AF), so she is now on Warfarin (Coumadin) to avoid blood clots. She is off Zometa but will be starting a different bisphosphonate – Pamidronate (Aredia).

In 2011, while visiting in Florida Dorothy had flu like symptoms that took her to a doctor. As part of her health assessment the doctor took blood; once lab results were returned, he noticed a spike in the M protein. He tracked her down in Atlanta and with her permission sent lab work to her primary care doctor pointing out his concern. She was referred to an oncologist who told her she had smoldering myeloma. Dorothy goes every 6 months to have her status assessed. For now there is no progression and is not currently in treatment. She says she does have some back pain from time to time. She expressed her gratitude to the group for helping her understand her myeloma and her status and to Doris for her tenacity in getting her to come back to the meeting.

Doris was diagnosed in 2005 after her primary care physician identified an M-spike in her lab work. She founded the group in 2006. Doris says she has experienced tightness in her chest and she says she may also need to see an orthopedist. Doris is on Revlimid (15mg), and Dex (2 mg), and Zometa. Doris has never had a Stem Cell Transplant. Doris cautioned us to be aware that the drugs taken by MM patients are very powerful drugs and affect the body in many ways. She says watch your body, be aware of changes and report them to your doctor.

Reflections from the 2017 Celebrating Our Caregivers Forum

Jameca lead the group in a discussion outlining takeaways from the 2017 Caregivers Forum. She said as a patient she attended the "New Normal" segment which was extremely meaningful to her. First be grateful we are here. Realize that some did not make it through the diagnosis and treatment. We have been blessed. Change your mind set. Things are different -- you may not be able to do some of the things you did before. She said her takeaways include:

(1) Keep a Medical Journal-record how you are feeling; she said she is on 10 medications and has some reactions,

(2) Be prepared for side effects; she says she has developed a tool kit that includes an array of strategies that help her to feel comfortable. She says, quality of life is in your hands (you know your limits-don't take on too much,

- (3) Don't shy away from a need to talk to someone. Mental health is something that many continue to shy away from discussing. She said having to give up her job and move back home was devastating to her. She was excited to gain employment and move to North Carolina for her first independent experience away from home. Having to move back so soon was mentally stressful to her and she sought counsel. It is time to put YOURSELF First and learn to say no.

Carol shared she had to make some real adjustments; she was retired from law enforcement just four months before her diagnosis and was therefore the one who was accustomed to being in authority. Not being in control was a real adjustment and she did seek counsel from Palliative/Supportive Care provided by Kaiser.

Remember to lend your thoughts and Prayers please for our members who may be struggling physically, mentally, and emotionally.

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.