

April 2017

**Northside Multiple Myeloma Support Group Meeting
April 1, 2017**

Business and Announcements

Jim M. led the meeting and approximately 20 people attended. Thank you to **Libba** who provided the refreshments.

New Members

The group welcomed three new members:

Peter F. was diagnosed in 2015 when he cracked vertebrae while moving. He had chemotherapy and a stem cell transplant at Emory in 2016 and has been on Revlimid for maintenance since then with good results. Peter also mentioned that he will be attending a MMRF conference in Dallas soon.

Jimmy R. was diagnosed in February 2015. Blood was found in a urine sample during a physical and further testing led to a myeloma diagnosis. Jimmy had a stem cell transplant in June 2015 and is in remission and doing great. He is on Revlimid for maintenance and is experiencing some peripheral neuropathy.

Allison M. was diagnosed with MGUS in 2008 and has been monitoring since that time.

Discussion

Don attended the meeting and shared laminated copies of **Madge's** favorite family recipes from her service. For those who missed the meeting, there are extra copies. Don mentioned how helpful the in-home hospice care (Hospice Atlanta) was for Madge and their family and he explained that Madge was comfortable and passed very peacefully surrounded by her family. Several others commented on their experience with hospice care for their family members and how grateful they were for the excellent care that they received.

Libba has had myeloma for 10 years and has been on Revlimid for five years. Her white blood cell and neutrophil counts were very low in January and she had pneumonia. She recently went to the emergency room and was diagnosed with a UTI and sepsis with bacteria in her blood, which is very serious and is fatal in 50% of the cases. She became immune compromised due to the Revlimid and has reduced her daily dosage from 10 mg. to 5 mg. She recommended that if you have an infection while on Revlimid that you order blood tests and monitor your numbers.

Beth reported that she is also on Revlimid and recently had pneumonia. She did not expect a pneumonia diagnosis because she did not have a cough, but a chest X-ray led to the diagnosis. Her doctor told her not to take Revlimid until the pneumonia was gone. She has been on a 15 mg / 21 day cycle and is well again. Others in the meeting were on Revlimid and some of the side effects were discussed. Diarrhea is a common side effect of Revlimid. Welchol was mentioned as a good remedy and/or Imodium AD to counteract the effects. Several members reported having low red, white, and/or neutrophil counts when taking Revlimid and they lowered their dosages as a result. If you have a fever of 100.5 or higher while on chemotherapy, then you should go to the emergency room. **Jim** experienced stomach distress when taking 10 mg. Revlimid, but is doing well after since lowering his dosage to 5 mg. He also mentioned that he travels a lot for business and carries a thermometer with him.

Barbara had a fever and cough in November and was diagnosed with Respiratory Syncytial Virus (RSV) and severe inflammation of the lungs. She endured six hour long daily in-hospital tent treatments for five days and no one could visit her while she was being treated.

Mary reported that she has myeloma in her spine and is currently getting injections of Pomalidomide and Carfilzomib into her spine. Her balance and brain function has been affected by these treatments. Peripheral neuropathy and balance issues were discussed as it is a common side effect of many of the myeloma treatments.

Jim reported having had very good results with acupuncture for peripheral neuropathy. Also suggested were ultraviolet light treatments, physical therapy, B-Complex and other supplements. **Libba** mentioned that Dr. Lonial at Emory has a list of supplements to help with neuropathy. Medications that have helped some in the group who have neuropathy include Neurontin, Lyrica, and Fentanyl. The meeting closed with some reminders: It is important to maintain not only your myeloma doctor appointments but all other doctor appointments. Also discussed was the need to be cautious during and after treatments with bisphosphonates and dental procedures. Planning is critical for any dental procedures that involve going below the gum line. Also discussed was how relapsed myeloma may present and behave differently than prior occurrences of the disease because it can return as a different type. Therefore, treatments that worked previously may not work in subsequent versions of the disease

Southside Multiple Myeloma Support Group
April 22, 2017

Doris led the group in a moment of silence. There were 22 present no new members. We did have several visitors.

We had an exciting mélange of visitors during our April meeting. Visitors included: **Natalie Hawks, MD**, Oncology Physician with the Atlanta Veterans Administration Hospital introduced by Debra Thompson (oncology nurse VA hospital and resource for our support group). **Debra** also reminded us that our support group had a table for the annual health fair downstairs in the Greenbriar Mall. The Health Fair is sponsored by the Atlanta chapter of the Delta Sigma Theta Sorority. **Shana Lightfoot** is the new Community Outreach Liaison with The Leukemia and Lymphoma Society (LLS). She is working on a special LLS project designed to increase the awareness of Multiple Myeloma in the African American community by working with the faith community. Her pilot project is working with identified African American church congregations' health ministers to ensure myeloma information is provided to church members. Last April, our support group worked with Tricia Hernandez, Senior Manager for Patient Access, LLS, to host a round table luncheon. From that successful round table event, strategies to increase awareness of multiple myeloma in the African American community were developed. These strategies were used to outline activities written in the grant for this pilot project. **Shana** is seeking volunteers to assist during her presentations in various churches. You can reach Shana 404-720-7836 or shana.lightfoot@lls.org.

We also had the pleasure of experiencing individualized massages provided by **Dr. Clark** and four of his massage students from the **School of Massage -- Everest Colleges, Institutes and**

Universities. The students received 9 months of training including some instruction in message therapy for cancer patients. Dr. Clark said it is important to share any concerns you may have with the masseur/masseuse before you begin. *They were fantastic.* The Everest Student Massage Clinic offers one hour massages for \$30. They offer Swedish Massages (for stress reduction) as well as Deep Tissue (for sore muscles, chronic pain). You can purchase gift certificates or schedule appointments for yourself. Doris was given a gift from her son and daughter in-law. Doris has enjoyed weekly massages by the students for several months and raves about her experiences. Their hours are Wednesday-Friday 2:30-5:00pm--to make an appointment dial **678-500-3456**. Everest is located behind Greenbriar Mall near Burlington Department Store.

During **the May 27th meeting** Nancy Bruno, Support Group Southeastern Regional Director, International Myeloma Foundation, will provide an update on **Black Swan Research Initiative and immune therapy**. We look forward to her presentation.

Today's Speaker: Melanie Richardson, LMSW, represented the Elder and Disability Law Firm of Victoria L Collier. Her topic: Estate and Long term Care Planning in a Nutshell—Protect Yourself, Your family and your finances.

She said there are four documents needed for Independence: **(1) Georgia Advanced Directive for Health Care (GADH)** **(2) Personal Care Choices Statement** **(3) Financial Power of Attorney** and **(4) Living Trust**. The **GADH** can be found on line and should be used to designate someone to advocate for your health needs and **desires** should you not be able to do so. **The Personal Care Choices Statement** provides your caregiver guidance for your very personal daily routines – for example, do you like to be warm or cool, do you like green beans or green peas, do you like to listen to jazz, classical or gospel music? Do you like to keep the TV on when sleeping? It is important to have a **Financial Power of Attorney** – depending on your assets you will simply need to add someone to your checking account or have someone who will have the ability to manage your estate, you may want to make gifts, or nominate someone to be a conservatory. **A Living Trust** can work in the place of a will and can avoid probate.

Their firm believes that every person is an individual who deserves respect and the highest quality of life possible, regardless of age or ability. They also believe you should not have to lose everything you have worked a life time to earn and can help preserve assets.

Protect yourself, your family and your finances. Their agency offered a free consultation with their client intake specialist to assess whether they can assist. They estimate that such a meeting is a \$400 value. **Melanie** can be reached at 404-370-0696. Their office is in downtown Decatur.

Congratulations! Doris Morgan and Carol Higgins received the Atlanta Area MM Support Groups - Spirit of Hope Award – 2017 presented by the Multiple Myeloma Research Foundation. The awards were presented during annual walk. Sunday, April 9th and given to one who inspires hope with their work and demonstrates extraordinary commitment to the MMRF." We are so proud of the work they have done. Well done!!

Several members attended the Multiple Myeloma Research Foundation (MMRF) Family and Patient Summit on April 8th at the Georgia Tech Hotel in Atlanta. **Karen** said one of the highlights of the event for her included hearing the story of a Multiple Myeloma Patient who during his time in the hospital for his Stem Cell transplant convinced the staff to allow him to

bring his bicycle into his room so he could get his exercise. He is an avid cyclist and climber. Other highlights included the many advances in treatments for Multiple Myeloma.

Announcements

- MMRF - Fortune Magazine named MMRF Founder Kathy Giusti one of 34 leaders who are driving progress in medicine and "the business of keeping us healthy." Coming from a variety of different areas in health care, other notable visionaries included Former Vice President Joe Biden, Bill and Melinda Gates, Arianna Huffington and Sean Parker... recognizes Kathy for her leadership and having "created what is without question the most successful patient advocacy model on the planet."

- International Myeloma Foundation: Myeloma.org** Check Archives for Webinars. This Free Webinars: Addressing Concerns on the Recent Lack of Funds for Co-Pay Assistance and other important information and updates.

- Join SMART Patients online Support Group (There are daily conversations with MM patients. <https://www.smartpatients.com>)

Clinical Trials-Definitions of phases

Phase 1 - see if experimental medicine is safe - Very few patients (n=10-30)

Phase 2 - see if treatment is effective (More patients - generally less than 200)

Phase 3 - see if treatment is safe and effective AND works better than currently available drugs (Large numbers of patients - several hundred to thousands)

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.themmr.org/pipeline-clinical-trials>

www.clinicaltrials.gov

Today's Question: Name three of the four classes of myeloma drugs.

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 - Daratumumab/Darzalex; Elotuzumab/Empliciti
4. Histone Deacetylase - Panobinostat/Farydak.

*Venetoclax – **A Precision Medicine** for patients with 11;14 translocation chromosomes. It is an oral BCL-2 inhibitor that kills myeloma cells. It is often used in a triplet with Bortezomib (Velcade) and Dex.

*New agent - Venetoclax

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.