

February 2018

**Northside Multiple Myeloma Support Group Meeting
February 3, 2018**

News & Updates

Jim M. led the meeting; approximately 30 people attended. The notes from the January ASH Meeting at Emory are very informative but also complex. If anyone has questions about the content, please feel free to ask questions and discuss at meetings. Also, researching the terminology on the IMF website and wiki pages can be very helpful.

There are two new drugs that are being used as frontline therapies: 1) Venetoclax, and, 2) B-cell maturation antigen (BCMA) drug conjugate.

March is Multiple Myeloma Awareness month. This is a good time to drop off the group's brochure at your doctor's offices. You can learn more about March awareness activities on the IMF website/March MM Awareness page.

There are some great programs coming up. For the March meeting, Dr. Kimberly Curseen, Winship Supportive Care, will be the guest speaker. April will be open discussion for updates and discuss new treatments. In the May meeting, Dr. Harvey, Pharmacist and Director of Phase I clinical trials will be the guest speaker. This will be a good time to ask about clinical trials and ask how the new drugs work.

Carolyn H. has been getting IVIG (immunoglobulin booster) which is administered as a 3.5 hour IV and is working well for her.

Becky recommended a book, "[The Mission Is Remission](#)" by Pat Williams.

Meet Your Members

Jim M. has been married to Lisa for nearly 42 years! They met in high school but started dating later. Jim shared a humorous story about how when he began dating Lisa, his job was driving a garbage truck for a family-owned company. He would pick up Lisa for their date after work (in his garbage truck) in Lisa's nice neighborhood and then take her home after their date in the same truck. This continued, and they eventually married. After 43 years Jim still works for the same company in a different role. He has worked in Chicago, New Orleans, Jackson, and Nashville. He mentioned that from his experience he has a deep respect for garbage truck drivers as it is one of the most dangerous jobs, as well as for his company because they take all precautions to keep their drivers safe. From his experience he is reminded to think about where you've been and who has been there on the sidelines with you and to remember and appreciate them. This includes nurses, lab techs, other patients, etc. The meeting broke into separate patient and caregiver sessions before reconvening at the end.

Patient Discussion

We talked about a phase 2 trial at Emory. Very important to stay in touch with the coordinators for medication requests. Patients were urged to keep the communication lines open with your coordinator and doctor. Don't break your pills in half or open the capsules to reduce the strength. Talk with your doctor before making any changes.

IVIG is working to help build up the immune responses for several patients. The incidents of getting sick with colds, bronchitis, etc. are significantly reduced when on IVIG. It is difficult to get approval from the insurance companies, but your doctor and nurses will help with the approvals. Sepsis is another concern with a compromised immune system. Stay on top of fevers and report them right away. Watch your

blood test results for the neutrophil levels, which can be an indication of illness.

Please keep your regular doctor visits going while you are in treatment, on meds, or just watching your myeloma. Go to the dentist. Go to your internist regularly. Get your scans done as anyone healthy or not should – colonoscopies, prostate checks, gynecology tests – your oncologist is not the go to person for these. However, the oncologist can recommend someone if you ask. There are members of our group who are dealing with non-myeloma issues. We all need to remain as healthy as we can. Keep your appointments and keep them scheduled.

Caregiver Discussion

Molly led the caregiver session and we discussed how caregivers can take care of themselves by continuing to stay engaged with enjoyable activities to help reduce anxiety and other negative feelings. Meditation, yoga, walking, swimming, dancing, gardening, reading, journaling, pets, nature, and remaining social were mentioned as activities that help. We also discussed how keeping organized and prepared for crisis before it occurs helps reduce stress. Some examples include maintaining documented instructions for any dependencies (for all parties), including wills, finances, passwords, etc. Molly recommended some books that can help reframe the way we think about dealing with a serious medical condition, and she generously offered to let group members borrow any of the books: “[A Three Dog Life](#)” by Abigail Thomas. “[The Year of Magical Thinking](#)” by Joan Didion, “[Dream New Dreams](#)” by Jai Pausch, “[The Last Lecture](#)” by Randy Pausch, “[The Best Day the Worst Day](#)” by Donald Hall, and “[The Iceberg](#)” by Marion Coutts. Also recommended reading by several caregivers is “[A Lucky Life Interrupted](#)” by Tom Brokaw. Note: The links above are provided as a convenience for the reader to obtain more information about the books, not to promote purchases at Amazon. If the reader decides to purchase from the Amazon site, however, a reminder that purchasing from “smile.amazon.com” and designate donations to Atlanta Area Multiple Myeloma Support Group. Thanks!

Submitted by Wendy R.

Southside Multiple Myeloma Support Group Meeting February 17, 2018

Next Meeting: Saturday, March 24, 10:00 – noon, Topic – **The Role of a Plant-based Diet in Disease Prevention and Control.** Speaker: Jennifer Rooke, MD, MPH, FACOEM, FACPM, Medical Director, Optimal Health and Wellness Clinic, Morehouse Healthcare, Morehouse School of Medicine

Our February meeting was a luncheon at Piccadilly/Greenbriar, sponsored by Takeda pharmaceuticals and John Schwarz, representative. Our speaker was Deborah Cook, RN, BSN, OCN, a Takeda representative and cancer survivor. Many thanks to the Takeda team. There were 49 present, with no new members.

Deborah’s message focused on Survivorship – and what survivorship means. She has been in nursing for 42 years and is a two-time breast cancer survivor. There are “19 million survivors” in the United States. (*In Georgia, there are an estimated 410,700 cancer survivors, according to Georgia CORE**). A cancer survivor is anyone who has ever had a diagnosis of cancer,

throughout life.

In survivorship plans, keep it simple – have three goals to work on versus 10 goals. For example, personal health goals for exercise, improved nutrition, and reduced fatigue. As a survivor, you may have been recently diagnosed, be in remission for 6 months or 10 years, you may have relapsed. You are a survivor. Fatigue issues should be discussed with your provider. There may be many contributors to fatigue. Exercise may be a partial solution for both stress and fatigue. There are four categories of side effects.

Physical – long term and late term well-being. Pain/chronic pain. Sleep, strength, fatigue, and neuropathy;

Psychological – sadness, depression, fear (“has the cancer spread?”);

Social Well-being – able to maintain regular friendships;

Financial well-being may be considered here. Are you still able to work if you want? and,

Spiritual Well-being.

There are acute side effects immediate and long-term side effects (like peripheral neuropathy), and late term side effects. Late term effects may occur years later. An example of late effects of cancer treatment is heart problems. Some breast cancer survivors wear heavy sleeves to prevent swelling – this is a “new normal.” Metabolic problems, secondary cancers, cataracts, lymphedema, and sexuality (80 percent of all patients have some sexual issue) can all be long term or late effects of your cancer journey. Talk with your providers – doctors, nurses, nurse practitioners, etc. Some providers are better at discussing these issues than others. DO not stop with just one response.

In 2013, the National Comprehensive Cancer Network (NCCN), developed guidelines that medical professionals should follow. The purpose of these guidelines is “to improve the quality, effectiveness, and efficiency of oncology practice so patients can live better lives.” You should have a Cancer Plan that is provided by your oncologist – incorporated into one that you maintain for yourself.

Your plan should include any staging, cell types, what is going on with the rest of your body – managing dental issues, dermatology reports (any rash’s that may have come from medications – or not). Include lab tests, test results, and the interpretation of these tests. Include any side effects. Include all dates of events on your journey. This is important, because our bodies constantly undergo changes. We may have a long-term response to a drug – that we might be able to trace back, if we have the information recorded.

Include an overview of your own type of Myeloma, all the specialty providers you see or have seen – yoga therapists, dermatologists, nutritional needs, medications taken throughout your cancer journey.

Plans should include **physical** information – exercise and diet plans – weight gains/losses. They should include **psychological** changes – depression or anxiety. **Sexual intimacy** is an important part of survivorship – and you can get information from the sources below, including the American Cancer Society and the Leukemia and Lymphoma Society (LLS). **Financial issues** can also be a part of survivorship concerns, and we should not hesitate to ask for help. American Cancer Society has great guidelines for diet and exercise. LLS has a great 5-page document on sex and intimacy. There is a 24-page booklet to help guide you through developing your Survivor’s Plan. There are many features to this plan, including the *Journey Forward*. Some information is for your provider, some for electronic health records (EHR), and some for self-

care. You may customize the plan for your needs. Feel free to download, and complete on your computer OR copy and complete your Plan as a hard copy. http://mncanceralliance.org/wp-content/uploads/2013/07/SurvivorCarePlan3202012_Final.pdf.

There is a link on the ACS page to ASCO Survivorship plans -

<https://www.cancer.net/survivorship>. ASCO (American Society for Clinical Oncology. In Georgia, we have GASCO – Georgia Society for Clinical Oncology).

The Leukemia and Lymphoma Society has great information for cancer survivors. Be sure to attend any in-person or webinars hosted about Survivorship. <https://www.lls.org/managing-your-cancer/follow-up-care-and-survivorship>.

Georgia also features a Survivorship resource through Georgia CORE - <http://www.georgiacore.org/survivorship.aspx>.

Caregivers and Survivorship. Caregivers have many of the same issues as patients -- psychological and physical issues, and emotional issues. There is more stress, more fatigue, depression, weight gain or loss. Loved ones of a Survivor have all entered a New Normal. The finances of caregivers might be impacted. It is important again to address any sexual intimacy issues for caregivers.

Creating a Survivorship Care Plan is an ongoing process. Getting started may be difficult and making it a family or group project can be educational and enlightening for all concerned. One idea is to start with a 3 or 4 inch three-ring binder – with tabs to separate topics. Congratulations on being a Fighter – a Survivor!

Announcements

- **Tricia Hernandez** of the Leukemia and Lymphoma Society (LLS) was present to remind us of the many programs offered by LLS. She especially wanted to recruit at least 9-10 African American churches to participate in their 18 month-long Myeloma Sundays Program. This project is being conducted in Atlanta and Washington, D.C. in partnership with the National Black Church Initiative, and is designed to increase the awareness of MM in African American communities. The program is a three-minute presentation – followed by an information-sharing session for individuals. Several of those present volunteered to assist in this effort. Tricia also brought one-page handouts on the **Myeloma Link: Connecting African Americans to Information, Expert Care, and Support**, describing these efforts.
- Another new handout was a cookbook from Takeda. The cookbook will be distributed at our March meeting.
- March is **Myeloma Awareness Month**. The focus is on **Myeloma Warriors**. The IMF has created a form that includes the hematologist/oncologist and primary care providers of members. These completed forms will be submitted to Paul Hewitt (phewitt@myeloma.org). The IMF will send MM educational materials directly to providers.
- Cancer and the Public's Health: Strategies to Advance Health Equity. Annual Public Health Summit. Morehouse School of Medicine. April 3, 2018, 8:00 AM – 5 PM. Registration - \$125. <http://www.msm.edu/Education/ExtendedProfessionalEducation/publichealthconference.php>
. Please contact Gail if you want to go.
- IMF – New Tip Card -Early Warning Signs of Myeloma.
- CAR-T Cells. Dr. Durie – treatment is not a panacea for MRD sustainability. Continue to watch progress of treatment of myeloma.

- Searching for Myeloma Clinical Trials? Myeloma Matrix 2,0 makes it so much easier – more focused on MM needs.
 - Veterans Act passed in US Senate. Act allows licensed medical professionals working at Department of Veteran Affairs to treat patients remotely – e.g., rural clinics by telemedicine. Veterans E-Health and Telemedicine Support Act of 2017.
 - “RAISE” Family Caregivers Act passed on January 9th and awaits President’s signature. Provides assistance for relatives and partners who provide medical, household, and financial assistance to loved ones. Act will make it easier on Caregiver to coordinate care, get information, and resources for loved ones. *RAISE – Recognize, Assist, Include, Support, and Engage.*
- *Georgia CORE – Center for Oncology Research and Education.
www.georgiacore.org/survivorship.aspx

Respectfully Submitted by Gail