

Northside Meeting Notes - March 2015

New Members

The group welcomed **Libby**, whose husband was diagnosed in October when he was hospitalized with acute kidney failure and a lesion on his hip bone was found. Libby mentioned that he had had symptoms including fatigue, anemia, and pain for years prior to the diagnosis.

Business & Announcements

Nancy led the meeting. March is **Myeloma Awareness Month (MAM)** and flyers were distributed to members (and also made available by email). Please distribute them in your community to help raise awareness; which can lead to earlier diagnosis and additional funding for better treatments and ultimately better quality of life for all who are affected by MM. The Board met prior to the March meeting and Nancy thanked those who serve on the committees that help to make the group work so well. The program committee is looking for ideas for guests to attend the meetings and educate the group. If there is a specific guest or subject that you would like to have included in a future program please let Nancy know. A Meditation & Massage Therapist will join the **April meeting**. The **May meeting** will be an open general discussion forum. Please remember to get on the mailing lists for these free and informative IMF-sponsored publications (sign up at www.myeloma.org or call the IMF Info line 800.452.2873): 1) “**Myeloma Today**” (hardcopy mailed quarterly) and 2) “**Myeloma Minute**” (emailed weekly on Fridays). The group’s **brochures** which are glossy, 2 color, and trifold need to be printed again which is expensive. **Vanessa** spoke about Emory’s Patient Family Advisor (PFA) program that she joined in December. The group is comprised of people who have been through any kind of major illness who are passionate about volunteering their time to provide feedback from patient experiences for improvement purposes. Vanessa cited examples such as now being able to schedule chemotherapy on weekends, new and redesigned chairs in the labs, and the redesign of the patient resource center. **Ed** mentioned that he is also on Emory’s Board of Advisors and there are approximately 174 Winship PFAs, where there is good leadership supporting a dynamic and results-driven program. If you have suggestions for improvement in care at Emory which go beyond the general patient satisfaction survey, please contact a PFA with your suggestions. Additional information can be found on the Emory Winship website.

Meeting Discussions

The meeting broke into separate meetings between patients and caregivers.

Caregiver session was led by **Don**. The survivorship rate of caregivers is of growing concern because there is now a huge population of caregivers. Since unmanaged stress can lead to illness and disease, a main component of the health of caregivers is the ability to reduce stress and anxiety to maintain health. There is much that can be done to reduce anxiety beyond the general nutritional diet, sleep, and exercise standards. Finding healthy positive distractions that can be incorporated into your life easily, and at any given time and place is key. Most, if not all that were discussed in the session came at little or no financial cost. Regaining focus and peace by regular meditation sessions

can be very rewarding. Also writing, gardening/reconnecting with nature, guided imagery, visualization, relaxation tapes, and Jon Kabat-Zinn Mindfulness Meditation phone apps were mentioned as good ways to accomplish anxiety reduction. One member mentioned that they liked to write and then meditate; i.e., do a complete “brain dump” on paper to clear their mind, in preparation of clear-headed, focused meditation. Meditation can be self-taught and there are a lot of good online resources. Trying something new that leads to self-fulfillment and getting out of a comfort zone in a positive way can be very effective. For example, staying educated, not only on MM but on topics that interest you. There are free resources available online including Massive Open Online Courses, “[MOOC](#)”, and “[Coursera](#)”. Don also recommended some helpful articles and distributed hardcopies at the meeting: “[Chronic Stress Puts You at Risk](#)”, “[Surviving Caregiving](#)”, and “[How to Boost Your Immune System](#)”.

The **Patient** session was led by **Dana**. He was diagnosed in 2000 and has had two stem cell transplants. He is now on a clinical trial and wanted to get the members first impression when someone mentions “Clinical Trial”. Some wondered if the MM has to be active to be in a clinical trial. There are trails for Smoldering MM. Do participants in clinical trials get placebos or treatment less than the current treatment? Patients on a clinical trial will not go without treatment. The trial group will be divided so some will get the standard treatment and others will get the new treatment. Placebos may be used so no one knows if they are getting the standard drug vs. the new drug. For example, a group could get Revlimid plus the new drug and the other half will get Revlimid plus a placebo. It is important for participants to fully understand what the options are on a clinical trial. The doctors and the research nurse will explain everything thoroughly and ensure that all questions are answered before proceeding and during the trail. It is most important to know that a patient can stop participating in the clinical trial at any time. Criteria may include newly diagnosed for some trials vs. relapsed MM patients in other trials. Generally, patients on a clinical trial get the best of care and those on a Phase I trial get VIP treatment! **Jim** said that the clinical trials are where patients can get the latest and greatest treatments. He was on a Phase I clinical trial for Vorinostat in 2010. In that group, there were 30 participants and 29 of them are still around. Jim said that he is MRD negative, but the doctors still don’t know what that means. MRD testing is still in clinical trials for the process to collect enough data and analysis so that the test results can be accurately interpreted for everyone. **Lory** has also had the MRD test as a baseline for when more data is available. Dana said that he was at the ASH (American Society of Hematology) conference in December in San Francisco. He was asked to speak to the researchers who were about to receive grants and the press was in attendance. He told that group at that meeting that everyone is in the same boat – whether you have cancer or not, you cannot predict when your time is up. So what do you do to live a full life? Remember the important things, not just things.

Submitted by Wendy and Nancy

Southside Meeting Notes, March, 2015

Doris opened meeting with a moment of silence. There were 26 present. Concurrent with our support group meeting was the Greenbriar Mall Expo: a Health Fair featuring over 36 vendors. Our Myeloma booth was organized by Alma in recognition of Myeloma month. The booth was supported by **Vermell, Portia, and Nancy** with **Alma and Doris** setting up the table.

April's speaker will be Taryn Tennyson RD LD, Piedmont Cancer Oncology Dietitian.

Today's Speaker: Tammy Rabern, APRN, MSN, is one of 15 Nurse Educators for Takeda -- the makers of Velcade. Tammy graduated from Emory University's School of Nursing with a specialty in oncology and she has worked with Myeloma patients since the early 1990s'. She left the clinical practice to become an educator in pharmacology. This was Tammy's second time speaking to our group and she shared her excitement on the advancement of Myeloma treatment over the years. Tammy says it is important for us to share MM information with those who are not familiar because early detection is important to prevent damage of organs. She said Myeloma is only 1% of the cancers, but the second most prevalent blood cancer, and went on to explain the biology of myeloma. She says it is important that we understand that Myeloma is cancer of the plasma cells. Plasma cells are white blood cells that produce disease-and infection-fighting antibodies/immunoglobulins in your body. Myeloma (cancer) cells prevent the normal production of antibodies, leaving your body's **immune system weakened** and susceptible to infection. The multiplication of myeloma cells also interferes with the normal production and function of red and white blood cells. An abnormally high amount of these dysfunctional antibodies in the bloodstream can cause **kidney damage**. Additionally, the myeloma cells commonly produce substances that cause bone destruction, leading to **bone pain and/or fractures**. Myeloma cells are produced in the bone marrow, the soft tissue inside your bones. Sometimes myeloma cells will travel through your blood stream and collect in other bones in your body. Because myeloma frequently occurs at many sites in the bone marrow, it is often referred to as multiple myeloma.

Tammy's message to **caregivers** is to take care of *you*. There were 8 caregivers present -- with some survivors who are also caregivers. Survivors and caregivers must be honest and have open communication about how they are feeling because they are going through the journey together. Survivors must remember caregivers love them and are going through the journey with them. They are also afraid of the unknown and may need to sit and just talk about what is happening. Caregivers and survivors should get away from each other and engage in social contacts that will take you away from the survivor. Support groups can be an atmosphere that will allow the caregiver to express concerns and identify ways of addressing concerns.

Question: With the passage of the Marijuana bill in Georgia (House Bill 1), how do you see the treatment of myeloma changing? **Answer:** Don't expect to see prescriptions for marijuana immediately. There are issues with knowing the dosage that should be prescribed -you may see doctors referring to pain specialists for Palliative Care. Synthetic forms of marijuana are currently offered to patients to improve appetite.

Tammy also shared that Takeda Oncology provides assistance for transportation. Contact them at (www.takedaoncology.com). Also, contact Tammy at 404-944-5960 or tammy.raburn@takeda.com.

New Members

There were **two new members**. **Lenora** was diagnosed earlier this month; she learned about the group by searching online. She shared she has a slow growing myeloma and is just learning about her disease. She shocked everyone by saying is 80 years old; she has had kidney disease since 2007—never on dialysis. **Barbara** was diagnosed in the middle of 2014; she is receiving treatment at Emory. She said she suffered for a long time because no one could determine why she was having pain in her back, leg and ankle. Barbara is feeling much better now. She expects to have a SCT next month.

Member Updates: **Loretta** has not been doing well; she had a tracheotomy due to severe breathing problems and also fell and broke her leg (Please reach out to her). **Yvonne** had surgery earlier this month (Yvonne is a SSMM Support caregiver). Her daughter also had surgery. (Keep them in prayer.) **Janet** was diagnosed 3 years ago; she had a SCT and is not receiving any treatment because she did not tolerate Velcade well. She is waiting to determine her next treatment options. **Geraldine** says this is her second time attending a meeting. She had lots of concerns that were addressed because of her coming to the meeting. She says she has come a long way since her last visit and is grateful for all of the support assistance she was provided. She shared that Alice prepared a letter for her that she hopes will provide sufficient documentation for her cousin to obtain a VISA to come to the US to become her caregiver. She is planning a SCT at Northside in May. **Geraldine** said she was having trouble identifying transportation and paying the \$500 co-pay. **Tammy** shared Takeda Oncology provides some transportation support and **Paulette** shared LLS provides up to \$10,000 for insurance premiums and co-pay. **Mariam** says she is doing well, she has SCT in 2011 is on Revlimid for maintenance and goes monthly blood tests. She also has some neuropathy. Three of **Doris'** sisters (**Marie, Frances, and Mary**) and her son (**Elliott**) were present to support her. **Alma** was diagnosed 9 years ago --she had SCT in 2008 and is currently on a clinical trial; **Elizabeth** was diagnosed with MM in 2007 and is planning for a SCT in July-- her cells were harvested in 2013. She said she just finished 10 rounds of radiation for tumors in her back. She shared recently had a biopsy and Dr. Lionel told her she had 17 P deletion She is preparing for PET Scan April 9th; **Larry** has a SCT in July 2013 and is doing very well; **Pat** had a SCT at age 75 in July 2013; she is on Revlimid for maintenance, has some neuropathy and experiences back pain; **Harold** says he is okay but has also been diagnosed with Parkinson's disease and has some neuropathy from the myeloma treatment; **Selina** was diagnosed with MM in 2009 and has a SCT in 2011. Selina had tumors in her back and went through the Kyphoplasty procedure to relieve back pain caused by vertebral compression fractures. She received treatment at Northside and also was on a clinical trial for 3 years. She goes monthly to have blood work done; **Lonnie** says he was diagnosed with MM in 2005 and is doing okay with MM. He was diagnosed in June of 2014 with lung cancer --“that was rough”. He says he is doing okay today; **Montine** says she became a member of the group to support her brother who passed from MM away last year. She says one of her cousins now has MM and is going through treatment.

Announcements:

•**MMRF** - Atlanta 5k. **Sunday, May 17 @9 am**. In Piedmont Park. Also, MMRF will offer a conference at Emory on May 16th at the Emory Center Hotel; this education session is free- Clinical Insights. When: Saturday, **May 16, 2015 8:30 AM - 9:30 AM Registration and Networking; 9:30 AM - 2:30 PM Program (Breakfast and Lunch included)- Where:** Emory Conference Center Hotel, 1615 Clifton Rd NE, Atlanta, GA 30329. To register contact Sara 203-652-0219 or www.themmr.org/Atlanta

- New from IMF: Updates on Myeloma Glossary. Download the PDF version. Acronyms, new drugs. www.myeloma.org Publication "Understanding MGUS and Smoldering Myeloma" Questions about Myeloma? Time sensitive - 800.452.2873 from 9AM -4PM PST
- Email-infoline@myeloma.org; askDrDurie@myeloma.org;
- Understanding Myeloma Risk Factors? Few are known, but age, gender, race, and environmental agents (chemicals) (e.g., work place, agriculture, 9/11).Source: American Cancer Society (ACS)
To close the meeting, **Doris** led the group reciting the Serenity Prayer. **Alma** also added a quote: "Some of the best days of our lives have not happened, relax and keep going".
www.Simplereminders.com

Respectfully Submitted by Paulette and Gail