

July 2018

Northside Multiple Myeloma Support Group Meeting July 7, 2018

News and Updates

Thank you to **Nancy B.** who led the meeting. Approximately 20 people attended the first meeting at our new location. There is an offsite luncheon scheduled on **August 4th instead of the regular meeting.** The luncheon will be at the 57th Fighter Group Restaurant, 3829 Clairmont Rd, Atlanta, GA 30341. The luncheon is free and all members, family, and friends are invited to join but **you must RSVP to attend.** A separate email invitation has been sent to all members for their RSVP. **Becky** urged everyone to keep updated with colonoscopies, especially those taking Revlimid. She has received abnormal results from several colon tests and she is not certain that it is linked with taking Revlimid for six years, but believes that in her situation, it is likely.

Presentation

The month of August marks 20 years since **Nancy and Mike B.** joined the group. Much has changed for multiple myeloma (MM) patients in those 20 years due to the large amount of advanced research conducted. For example, there are 2-3 new MM drugs expected to be approved in the next year or so, which is amazing. Changes come quickly in the myeloma community and it's important to stay updated. Nancy demonstrated how to stay informed using the IMF website. Below are some of the navigational flows that were reviewed in the meeting.

From the IMF homepage, <https://myeloma.org>:

- Click "Education & Publications" / "IMF Publications" - where you can sign up for free publications such as "Myeloma Today" and "Myeloma Minute".
- Click "Education & Publications" / "IMF TV" - where you will find educational videos and a link to submit your questions to Dr. Durie.

Under "IMF TV", click on IMWG Conference Series – The IMWG sets standards for MM and consists of approximately 230 MM specialists from approximately 50 different countries. They had a recent conference of about 100 MM specialist to discuss the latest research and impact on patient treatment. The group reviewed the video on Minimal Residual Disease (MED) testing.

There are many articles and videos available on the website, many of which can be viewed in less than 10 minutes. Numerous questions were answered during the website review and discussion:

Q: Why is MM so popular for researchers?

A: The IMF and MMRF have made MM a global concern. With so much that has been discovered, and is still to be discovered, it is an interesting and successful path for researchers. Researchers can now visualize a cure and they understand where we need to go to get there. They are now learning how to get there.

Q: Why is so much of the research being conducted in other countries outside of the US? **A:** There are several reasons. When Europe conducts CTs, many patients want to participate because it is an opportunity for them to get new drugs that their insurance will not cover

otherwise. This participation level positively impacts the research. Also, the US travel ban has affected foreign researchers from coming to the US and so those affected by the ban will find work in other countries.

Q: What is MRD? **A:** Minimal Residual Disease (MRD) refers to the small number of cancer cells that still exist when a patient is considered to be in remission and is the major cause of relapse in MM patients.

Q: Is MRD-negative (-) the same thing as complete remission (CR)? **A:** No. MRD-negative (-) means that no MRD was found via MRD testing. We now know that patients who attain this status show the best outcomes.

Q: Can a patient be considered to be in CR and also be MRD-positive (+)? Minimal Residual Disease (MRD) refers to the small number of cancer cells that still exist when a patient is considered to be in remission and is the major cause of relapse in MM patients.

Q: Can a patient be considered to be in CR and also be MRD-positive (+)? **A:** Yes

Q: How is MRD found? **A:** The IMF has developed a test to find and measure MRD in patients. The MRD test can find one MM cell in a million cells. The current MRD test is performed via a bone marrow biopsy. Researchers in Spain and France are finding a way to test for MRD via a blood test, which would be easier and more accurate and is expected to be available in a couple of years.

Q: Why is MRD testing not a standard? **A:** The IMF is trying to make MRD testing a universal standard but it is still in clinical trials.

Q: How can I get MRD tested? **A:** If you are in remission you can request that the test be performed via a bone marrow biopsy.

Q: How can MRD knowledge help us? **A:** Doctors still need more data from the MRD trials to change current standard treatment practices but knowing if MRD exists will help us determine paths for treatments in the future. For example: if a patient is in CR and MRD-negative (-) then their treatment recommendations may not change; however, if they are in CR and MRD-positive (+) then treatment recommendations may change in an effort to get them to a MRD-negative (-) state.

Q: How are MRD test results used in practice today? **A:** Top MM specialists agree that it is critical to perform the MRD tests, but are cautious about making serious treatment decisions until more data is available and examined. The reason for this is that doctors do not want to over or under treat patients.

Q: How is MRD data being used by researchers? **A:** Researchers are using MRD data to find answers to questions such as:

- What can that one in a million MM cancer cell tell us? What can we learn from that surviving cell?
- When can a patient stop treatment entirely? When are they cured?
- Who should continue to be treated and what is the best treatment?

Nancy recommends that you review the other videos from the IMWG Conference. These videos feature Dr. Lonial along with Dr. Durie and Dr. Mikhael summarizing the conference discussions about how the research affects treatment decisions. From the IMF homepage, <https://myeloma.org>:

- Click "Education & Publications" at the top of the home page and then select "IMF TV" on the left side. Click on "IMWG Conference Series" to get to the videos. They are short videos, 8-15 minutes, and focus on specific topics. Scroll down and Load More to find the videos with the picture of the three doctors, recorded in Stockholm. Look for videos about: CAR T-cells; New Drugs; and Cost of Care.

Nancy noted that you may need to play each video more than once to comprehend fully the terminology, but it will enhance your understanding of treatments to come that you can

discuss with your Healthcare Team.
Submitted by Wendy R

**Southside Multiple Myeloma Support Group Meeting
July 28, 2018**

Doris opened the meeting with a moment of silence. There were 27 in attendance.

We welcomed two new patient members and a friend/supporter to the meeting.

Caroline E. was diagnosed in 2018, had an **autologous** Stem Cell Transplant (ASCT) at Emory Winship and is doing well.

Harriet had an **allogeneic** Stem Cell Transplant, using cells from her daughter. Harriet's daughter and husband were also present at the meeting. Several members attended the Georgia Blood Conference on July 21 sponsored by the Leukemia and Lymphoma Society (LLS). **Vermell** was part of the volunteer staff. There were many sponsors in attendance with lots of giveaways. Doris mentioned that Dr. Shapiro's session was inspiring and seemed to help release anxiety.

Patient Updates and Caregiver Updates

Gloria S. said her husband has MM. This was her first time attending and would like to learn more about MM. He was diagnosed 5 years ago.

Caroline said her platelets were low. She had bone biopsy and it was very painful. She is also concerned about neuropathy and was told to take B-6 vitamins. Larry said one presenter at the Georgia Blood Conference said to soak your feet in warm vinegar water.

Emma S. was diagnosed in 2017 when she had pain on her side and back. She was told that she had arthritis. A CT scan showed MM. She is now on 5 mg Revlimid and pain medication. Vermell recommended a pain management doctor because Emma is concerned she is becoming addicted to the drug. Emma has two sisters and husband who are her support system. After chemo, Emma is now in remission.

Jameca was diagnosed 2003 and had a stem cell transplant. She was in the hospital for 3 months. She is not on any maintenance therapy and feeling calmer. Jameca recommends pain management CBT, Cognitive Behavior Therapy, and trying for non-pharmaceutical means for controlling pain. (*It is*

important that you not suffer in pain. Please work with your doctor to be sure you are as comfortable as possible. Do not be distracted by the opioid epidemic. While there is a legitimate crisis on drug abuse, those who have pain should use all resources available to them, including non-pharma and pharmaceuticals)

Don G was diagnosed April 2015 and had Revlimid. He had a SCT in March 2018 at BMT Northside Hospital -- he is now in remission.

Larry L was diagnosed in July 2012. He was in car accident and was at Emory for 2-3 weeks (*Larry is currently on Daratumumab*). Larry says he does not feel sick.

Annie W was diagnosed October 2012. She did the Peachtree Road race, was walking everyday 5-6 miles. She felt sharp pains in her back, which turned out to be 3 fractures. Annie had the SCT and back surgery. She was told in 2013 that she was cancer free and has been taken off Revlimid.

Janet S. was diagnosed in 2012 and had SCT 2013 at Northside Hospital. Janet has had a spike in her myeloma protein in the last nine months and is on new treatment.

Alma R. was diagnosed 2006. In the beginning, she suffered from dehydration and back pain. She had SCT two years later and currently taking medication. **Vena D.** was diagnosed 2007 and is in remission for MM. In 2016, she was diagnosed with stage 4 lung cancer, lesions on lung and spread to liver, and is being treated with Optiva and Retalin. **Debra** (support group's nurse support/oncology nurse) encouraged everyone once again to "know your body." Medical tests and trained medical professionals can provide invaluable information on your health status. If you are in tune with your body, you can be the first to know when there are any changes to your body.

Selena B. was diagnosed 2010 – it started with back pain. Her system shut down and she went into a coma. She had SCT and now has secondary cancer -- ovarian cancer.

Doris M. told her story – she was diagnosed in 2004 is being treated with Revlimid is doing well.

Announcements

- Doris reminded the group of our breakfast meeting on August 25th being sponsored by Takeda. Last chance to sign up with Paulette at ppmneely@gmail.com or call Doris at 404-346-1372.

Doris also told the group about assistance for free rides to their doctors. **Free rides for cancer patients. Lyft partnering with American Cancer Society**

through its Road to Recovery Program. Call 1.877.277.2345. You must call at least three days before appointment.

· **Light the Night 2018. Joshua Woods** of LLS. He is the Campaign Manager for Light the Night Fundraiser Walk. The walk will be at Piedmont Park Oct. 6th. Light the Night walk is the largest walk in the country. Please be at the park at 5:30 p.m. and the walk will start at 6:30 p. m. Anyone who donates \$100.00 will receive a tee shirt and Chick-Fil-A sandwich. Doris has set up website for Support Group donations

<http://www.lightthenight.org/events/Atlanta>

Larry asked the question regarding transportation, Joshua said it would be best to ride MARTA or Uber due to limited parking space.

Joshua said LLS has been around since 1949 has donated \$1.2 billion for research for cancer. Joshua can be reached Joshua.Woods @LLS.org. or call 404-720-7817.

Please keep the Goodwin family in prayer, Mrs. Jerri Cain Goodwin passed away in June.

Paulette and Gail are in Texas attending the annual IMF Support Group Leaders' Summit.

Notes were Respectfully submitted by
Vermell and Selena

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Southside Multiple Myeloma Support Group – Southside group meets at 10:00 on the fourth Saturday of each month in second floor Meeting Room at the Macy's on Greenbriar Pkwy. Doris Morgan 404-346-1372; dorismorgana@aol.com , Gail McCray 770-996-4964; mccrayg@aol.com web site: ssatlanta.support.myeloma.org

Northside Meetings: 9/1; 10/6

Meets 11:00 AM on the 1st Saturday of each month

New location starting in July ----

Shallowford Presbyterian Church

2375 Shallowford Rd.

Atlanta, GA 30345

mmsg.org, email: aammsg-2@comcast.net

For additional information, contact.

Nancy Bruno 404-374-9020;
Sandy Brown 470-514-5330

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.

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