

## **October 2017**

### **Northside Multiple Myeloma Support Group Meeting October 7, 2017**

#### **New Members**

Welcome to Susan who joined the group for the first time. Susan was diagnosed with myeloma in November 2014 and had a stem cell transplant at Emory in 2015. She is in remission and doing well.

#### **Business**

Nancy B. led the meeting. Some news about upcoming meetings was discussed. The November meeting will be in the form of separate patient and caregiver sessions. The December meeting will be an annual holiday celebration. The January meeting will be held January 6, 2018, at Emory Winship, where doctors will present American Society of Hematology (ASH) results. More details will be provided at a later time. Thank you and congratulations to Lory M. and Ed S. who are leading the "[Lorymac Myeloma Team](#)" for an Emory Winship 5K walk/run for the sixth year in a row! Ed S. mentioned that it is a very well planned and exciting event. If you are interested it is not too late to support the team. Nancy B. reminded the group of upcoming IMF-sponsored educational webinars. Additional details will be provided in a separate communication. The webinars are recorded and available to replay from the IMF website.

#### **Guest Speaker**

Thank you to Amy Schrader, Executive Hematology Oncology Consultant, and Aaron Streufert, MSN, FNP, BMTCN, Clinical Nurse Consultant, both from Celgene, a global biopharmaceutical company (and producers of Revlimid), who attended the meeting and provided participants

with a Multiple Myeloma (MM) Knowledge Kit binder. The binder contains a summary of each of the MM publications that are available through Celgene, including: Multiple Myeloma Overview, Understanding Your Lab Test Results, Caregiving/Myeloma Central, Living With Multiple Myeloma, and Understanding and Communicating Your Needs. Extra binders are available in the group's library. The Celgene support website is called "Myeloma Central" and the address is: [www.MyelomaCentral.com](http://www.MyelomaCentral.com). The Celgene toll free phone number is: 1-888-771-0141. Aaron, a clinical nurse consultant and practitioner, presented information that was designed to empower patients to take an active role in their care for the best outcomes and quality of life. MM is a complex disease and a cancer of the plasma cell, a type of white blood cell produced in the bone marrow. The disease can cause bone and kidney problems that may be present at the time of diagnosis. The effects of MM are described using the "CRAB" acronym, which stands for: [C]alcium elevation, [R]enal insufficiency, [A]nemia, and [B]one abnormalities. A MM diagnosis has a physical and emotional impact. The symptoms of the disease itself and some of the treatments can cause discomfort. Some common side effects of treatments include gastrointestinal problems, peripheral neuropathy, fatigue, and myelosuppression. Preserving your quality of life is vital to your overall health, but at times can be very challenging. Managing the disease is the key to preserving your quality of life; the more that you can manage the disease, the better your quality of life will be. Managing the disease requires you to take a proactive role and not let the disease define you. Remember that MM is one part of your overall health and there are many things that you can control when you remain proactive in managing your health. Some things that will help you stay proactive include staying as healthy as possible, staying informed and involved with your care, asking questions and expressing concerns, taking advantage of any support that is available to you, and staying positive. With the frequent and rapid advances that are made in understanding and treating MM, education is an ongoing process; there is always more to learn. Stay educated to control the things that you can control. For those things beyond your control, find the proper

support. Discuss all issues (no matter how small or insignificant you think they are) with your medical team so that they can help you. Remember that you are not an inconvenience to your medical team; they are there to help you and want you to communicate with them honestly. Report any new issues immediately when they are more likely to be treated or corrected. For the best outcomes, remember to always remain vigilant about your overall health. Remember to include pharmacists as a part of your medical team. Inform everyone on your medical team of the drugs and supplements that you take and keep them all updated with any changes. Get the proper checkups and screenings that are required for your long-term health. If you have any financial issues, discuss them with your social worker; they can be very helpful and are “lifesavers”. Some of the questions and answers from the presentation follow.

Q: Drug companies create a lot of drugs, but why not a cure?

A: In general western medicine is good at treating, not curing diseases. There is still a lot about MM that we don't understand. We need to understand the cause of MM in order to cure it.

Q: How do pharmaceutical companies report/record side effects once the drug is brought to market (i.e. how are side effects tracked once the drug is in production)?

A: When patients report a drug side effect to their medical team (i.e. doctor, nurse, pharmacist, drug company representative, etc.) they are required by law to report it to the drug manufacturing company. The patient can report side effects directly to the drug manufacturer. The drug manufacturer updates the package insert up to 3-4 times a year in some cases, or accordingly based upon what has been reported. Note that MM patients are not always on a single agent, so it may be difficult to know which drug is causing the side effect.

Q: How can you make patients responsible for reporting issues that they think are not important?

A: This cannot be forced, but it is your right and your job to report issues.

Q: How can you know for certain if, after long-term use of a specific drug, it has caused a new issue that you've just begun to experience?

A: You can't always know and that is a reason why it is so important to continue with your general health checkups to establish baselines and report all updates and issues to all members of your medical team. They may know if others have reported the same issue when using a specific drug and may be able to understand the causes of new issues.

Q: Are there known heart complications associated with Revlimid use?

A: This is something that should be discussed with the medical information department at Celgene for the best response: 1-888-771-0141.

### **Member Updates**

Nancy B. reported that Tony M. is doing well post stem cell transplant. Dirk is planning for a stem cell transplant at Northside in early November, pending final tests. Dirk asked if anyone else in the group had experienced "heart ejection fraction" issues (Ejection fraction is a measurement of the percentage of blood leaving your heart each time it contracts). He explained that his was normal at the time of diagnosis but has changed since. He thought that it could be related to Velcade use. No one at the meeting mentioned having this type of issue. Someone mentioned diarrhea as a side effect of Revlimid and asked the group for ideas for managing. Several people mentioned using Welchol, which is a cholesterol lowering drug but is also prescribed for controlling diarrhea. Many said that it worked well for them and that they did not experience adverse side effects. It was also mentioned that it alleviates cramps and discomfort that Imodium does not do. Someone suggested asking for a free sample if you'd like to try it. Joe B. reported that Sandy is doing well since having the surgery to implant the *neurostimulator device to help control her pain. She has become more active as she recovers and Joe seemed very happy to report that she is cooking again!* Lory M. shared a helpful website: [www.drugs.com](http://www.drugs.com) where you can enter medications, supplements, foods, ingredients, etc. and use it to find interactions and ratings. There was some discussion about the definition of the word, "remission". Some members have noticed that doctors seem less

likely to use the word in general. Nancy mentioned that Minimal Residual Disease (MRD) testing is redefining how we define “remission”.

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## **Southside Multiple Myeloma Support Group**

**October 28, 2017**

The meeting was called to order with a silent moment of meditation. There were 26 members present, with two new members. Dr. Bernal had to reschedule. We hope to have him at our November meeting. We will get the word out when he is confirmed.

November is Caregiver Awareness Month. You can thank a Caregiver on the LLS homepage in 25 words or less. <http://www.lls.org/article/caregivers-thank-you-for-your-kindness>

### **New Members**

The group welcomed Todd B., who was diagnosed with Multiple Myeloma (MM) in 2015, and went through the RVd (Revlimid, Velcade, Dex) induction, and had a Stem Cell Transplant (SCT) in June 2015. He is being treated at Emory Winship with Dr. Lonial. He has been on Ninlaro/4mg for 1-1/2 years. He did experience a malignant melanoma (secondary cancer), which, fortunately, was caught early. His journey has included fatigue, and a bout with colitis with a 3-month round of prednisone.

We also welcomed Judy T. and her husband/Caregiver Calvin T. Judy was initially diagnosed with smoldering myeloma, and since June 2017 has had active MM. She is preparing for a SCT. She is being treated with Dr. Lonial at Emory Winship. She has experienced itching with Revlimid (Rev) – 25 mg, 14 days on – 14 days off. Chemotherapy has taken her taste buds. She asked the group to help her know what to expect during the transplant procedure. Several members strongly encouraged her to go through a formal orientation by Winship transplant team, to have meals prepared in advance, to be sure the environment is immune-system

friendly – for example, no children at first. Ethel D. volunteered to talk with them about other possible concerns surrounding the SCT process.

### **Members Update**

Teonna I. went through her SCT this past December (2016) and is in remission, is doing well, and back at work. She is on maintenance therapy with Rev/5mg for an indefinite period. Both Teonna and Todd have been diagnosed with high risk MM. We are looking forward to the time we have reliable tests for Minimal Residual Disease (MRD).

There was some discussion about therapy using combinations of Pomalyst/Dex and Ninlaro/Dex. The current research shows that triplets (3 drugs) are better for fighting myeloma than doublets (2 drugs).

V.W. is a patient at Grady and Emory Winship with Drs. Bernal and Kaufman. She is also being treated with Ixazomib/Ninlaro, Lyrica, and Morphine. She had a SCT in 2010. V was in a coma for 2-1/2 weeks. She had dental work while on chemo and developed sepsis. She also has a heart murmur. While being treated for MM, it is important that all dental work that is being considered below the gum (so not regular cleanings), be reported to the oncology staff. You must be sure to report your MM treatment status to the dentist.

Larry L, who also suffered through sepsis, reminded us how important it is for us all to clearly communicate with our providers about all medications, including over the counter (O-T-C) supplements, etc. Some drugs may have negative interactions with cancer drugs. Sometimes the effectiveness of these very expensive drugs might be compromised.

Vena is being treated for an aggressive, Stage 4 Lung cancer now with some liver involvement. Her MM is in remission – the lung cancer is requiring all her focus. Her white blood cell count (WBC) was consistently low, and she had to have several blood transfusions. She also had to inject herself with Neupogen to counteract neutropenia (low number of white blood cells), which compromises the immune system and increases the risk of infections. She has since started on Opdivo, and is doing much better. The Opdivo helps to build up the WBC count. No

more injections!

Some group members emphasized the importance of the information gained from the webinars. The most recent one on Nutrition (LLS) identified obesity as a risk factor for MM. We should eat clean, not processed foods (e.g., Fruits, vegetables, and whole grains -- less sugar) and lots of water. Most webinars can be viewed at your convenience in the website archives. Special thoughts and prayers go to each of our members, and especially those who might be in need of greater support now – and as we approach the holiday season.

### **Announcements, Resources, Webinars, etc.**

- Results of Phase III ENDEAVOR clinical trial:  
Head to head comparison of two proteasome inhibitors – Carfilzomib (Kyprolis) and Bortezomib (Velcade). Randomized trial of 929 patients from 27 countries, 198 hospitals were assigned to take Kyprolis and Dex or Velcade and Dex between 2012 -2014. The study was conducted with those who had relapsed. Results showed those on Kyprolis showed a clinically significant reduction in deaths versus the Velcade group. This suggests that Kyprolis should be the standard of care as a proteasome inhibitor.
  - Financial Support for MM Treatment – Without warning, on October 18, many copay assistance and other financial assistance programs have suspended their support. There is no indication about when or whether programs will resume. Programs include LLS, Patient Advocate Foundation, Healthwell Foundation, and CancerCare. Thanks to Kimberly (locally) and Jerry L. (IMF) for sharing this information. Patients are urged to reach out directly to pharmaceutical companies for assistance. The IMF is diligently staying on top of this and will keep our website up to date: <https://www.myeloma.org/article/co-pay-assistance-programs-update>
- For now, patients are advised to contact the financial aid programs of the drug manufacturers directly.
- o Celgene's (Thalomid, Revlimid, & Pomalyst) patient support web

portal: <https://www.celgenepatientsupport.com/>

o Takeda Financial Aid

Ninlaro 1Point Program: <https://www.ninlaro.com/cost>

Velcade Support: <http://www.velcade.com/paying-for-treatment/>

o Amgen Kyprolis

Amgen Assist 360 Program: <http://www.amgenassist360.com/patient/kyprolis-cost-nurse-ambassador-assistance/>

o Janssen Darzalex

Janssen CarePath Program: <https://www.darzalexhcp.com/cost-support/janssen-carepath#affordability>

· LLS Videos: MM: Managing Side Effects; Diagnosis and Treatment; Support for Patients and Caregivers – 8-10 minutes each

<http://www.lls.org/patient-education-videos/myeloma-diagnosis-treatment-side-effects-and-support>

· LLS Survivorship Series – <http://www.lls.org/webcasts>. Nutrition; Communication with your healthcare provider

o Release before December 20. Previously recorded. Navigating Financial Maze of Cancer. Joanna Fawzy Morales,

Esq. [https://event.webcasts.com/starthere.jsp?ei=1161167&tp\\_key=d948501561](https://event.webcasts.com/starthere.jsp?ei=1161167&tp_key=d948501561) .

Respectfully submitted by Gail M.

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**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.**