Northside Meeting Notes - March 2014

Business & Announcements

Nancy led the meeting; over 50 members attended. **March** is **Myeloma Awareness Month**. To help with this effort, flyers are available for group supporters to place in social settings and public places such as work offices, restaurants, stores, churches, schools, etc. Word of mouth is also a great way to spread awareness. There has been much in the news lately about Tom Brokaw's myeloma diagnosis which can be used as a conversation starter. The more that myeloma becomes a disease that is recognized by the general population, the more support it will receive. Also to promote myeloma awareness, support group leaders and members are working with local towns and counties to proclaim March as Myeloma Awareness Month. Already **Doris**, Southside group leader, has obtained proclamations from the city of Atlanta, Riverdale, East Point, Fayetteville, and Lithonia; and **Jim** group advocate, has obtained the proclamation from Cobb County. **Carolyn** has a proclamation from the City of Dunwoody. If you are able to work with your local government, please let **Nancy** know if the proclamation is passed; and when and where the ceremony will take place. Prior to the meeting, the Board met to discuss programs. The April meeting will be an open discussion/knowledge sharing forum with discussion revolving around news, treatments, side effects, etc. Please be aware that there will be no regular meeting on May 3rd. Instead, members are urged to attend the IMF-sponsored Patient & Family seminar which will take place in Atlanta on Friday May 16th – Saturday May 17th. More details can be found at Myeloma.org and click on Meetings on the red bar at the top. Note that the price is discounted if you register by April 15th.

Guest Speaker

Thank you to **Dr. Lonial** from Emory who joined the meeting to discuss autologous stem cell transplant and other myeloma treatments. Dr. Lonial opened by thanking the group for the caring messages that he received when he was recovering from his recent injuries. His entire family was very appreciative of the outpouring of well wishes. While the presentation was not in the form of an entire Q&A session, the following notes are grouped as such.

Is a complete remission (CR) necessary going into a stem cell transplant (SCT)? CR is defined as no detection of protein. Partial remission (PR) is defined as a 50% reduction of protein. At least a PR going into SCT is OK, but a CR is better. For the patient, a PR going into a SCT will likely mean more chemotherapy pre-SCT with more side effects and will probably be more difficult to collect stem cells. If a patient does not achieve a CR via standard induction RVD therapy, it does not mean that a SCT should be avoided and is not indicative of the post SCT response. Where a transplant helps is at the lowest level of minimal residual disease (MRD). The benefit of SCT combined with maintenance therapy is the ability to eliminate the low-level MRD. **What is the chance of not surviving an autologous SCT?** With an autologous SCT there is no associated graph vs. host disease as happens in an allogeneic (donor) SCT, there is less than 1% chance of dying from a autologous SCT, and there is value to volume, i.e. "the more you do, the better you get", so it makes sense to have a SCT performed at a facility that does a lot of SCTs. **When is the best time to have a SCT?** The timing for a SCT is still being studied and varies by individual. If the goal is to achieve a negative MRD state as soon as possible then a SCT immediately following induction therapy makes sense. There are three situations when it may make sense to avoid an immediate SCT: 1) for low or standard risk myeloma, 2) when achieving good results with RVD induction therapy, and 3) when there are no side effects or toxicity experienced with RVD induction therapy. **What is the latest in non-SCT treatment?** Antibodies are new treatments that will provide big changes in the way that drugs can be tailored to individuals, providing specific drugs to target specific protein types rather than drugs targeting all cells. For example, Elotuzumab targets

CS1 protein. Daratumumab targets CD38 and CD138 proteins. **How are antibody drugs administered?** Antibody drugs are administered by an IV infusion. They may also be combined with other drugs, which can make other drugs more tolerable. For example, some who are not able to tolerate Revlimid can tolerate Revlimid when combined with an antibody treatment. Also, Revlimid appears to activate the antibody to make it more effective and lengthen the response time. The dosage of antibodies is currently aligned with the amount of myeloma present – the more myeloma in the body, the more anitibody necessary to treat. Infusion site reactions are common at the start, as your body is initially less tolerant to the new protein being delivered. This side effect dissipates as your body adjusts. **What is the value of clinical trials (CTs)?** CTs got us to where we are in myeloma treatment. Just ten years ago, someone diagnosed with myeloma was estimated to have only 2.5 – 3 years average survival time. Now, a myeloma patient is estimated to have over 7 years average survival time. It is estimated that with the addition of each new drug studied in CTs and approved that estimated survival time is increased by one year. **What is new relative to myeloma and genetics?** The understanding of how genetics plays a role in myeloma continues to evolve. It is now evident that there is a link between myeloma, lymphoma, and CLL. If one family member has one of these diseases, then it is more likely that another family member may also get the disease, although it is considered to be low-risk likelihood. **What is the average maintenance dosage of Revlimid?** 10-15 mg., depending on side effects and efficacy. **Is Revlimid used to treat Myelodysplasia (MDS)?** If MDS is low risk, then data shows that Revlimid can help. If MDS is high risk, there is no data that supports the use of Revlimid. If MDS and myeloma are both present, and MDS is caused by the myeloma treatment, then Revlimid probably will not help. When the MDS is treatment caused, it is usually high risk and there is less data in support of Revlimid as an effective treatment. **What is the risk of getting a secondary cancer to myeloma patients?** With the use of any chemotherapy there is a risk of developing a secondary cancer. In using maintenance therapy to control myeloma there is a greater risk in secondary cancers than without the use of maintenance therapy, however the risk of getting relapsed myeloma is of greater concern. **Is Amyloidosis a consequence of myeloma therapy?** No, it is the result of a "sticky" light chain that can become attached to organs. Each patient has unique light chains so this condition cannot be anticipated. The key to treating Amyloidosis is to make the protein go away or to treat to a very good response and prevent further damage. The presence of Amyloidosis makes all myeloma treatments harder from that point on. Intolerance to drugs can be a sign of early Amyloidosis. **How has the standard of care for newly diagnosed patients changed?** New patients are being sequenced now and MRD negative tests are being conducted early. This is an evolving process using flow cytometry and sequencing, but is occurring now. **What is the percentage of mutations in myeloma patients?** NRAS mutations = 40%, KRAS mutations = 30%, BRAF mutations = 4%. These types of mutations have to be specifically looked for, unlike the translocation chromosome mutation. Currently there are 20 common mutations in myeloma, but not treatments for all of them. It is unlikely that a single drug will be the most effective for patients with mutations due to the complexity of the disease.

Submitted by Wendy R

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Southside Multiple Myeloma Support Group Meeting -- March 22, 2014

Present: 24 Members and Supporters, including 8 members of the **MADIOC** youth group (Making a Difference in our Community)

Gail opened the meeting with a guided relaxation exercise.
The agenda for the day was to provide updates on Myeloma Awareness Month (MAM) and patient updates. Doris touted the success of our 2014 Multiple Myeloma Awareness Month and "Tell One Person about Myeloma" campaign led by **Alma** There were about 8 proclamations signed in the Atlanta Metropolitan area (Atlanta, Dunwoody, College Park, East Point, Fairburn, Fayetteville, Forest Park, and Riverdale). This was a result of the hard work, collaboration, cooperation, and participation from all members of the Sorthside and Southside Atlanta groups. We started to collect stories from the membership, and made a major start to modifications on our website. **Vena** and **William** spearheaded our efforts in a health fair at Greenbriar, during which we met at least three MM patients. **Brenda, Doris,** and **Gail** attended the meeting of Concerned Black Clergy on March 31. This was a meeting that our beloved member, **Arthur**, tried to schedule before he became very ill.
At most of the meetings we attended, there were very few present who had ever heard of multiple myeloma (MM). In the Atlanta City Council meeting, Councilman Ivory Lee Young reported that he has been diagnosed with MM, and Keisha Lance Bottoms (representative from Doris' district) announced that her grandmother died from complications of MM. We were given a few minutes in most meetings to make comments and accept questions from the group. In some instances, articles appeared in local publications regarding the proclamations. Including the postcards (about 400), we can say we reached over 1,000 people directly during MAM, and many more indirectly. Kudos to all for a successful MAM.

The MADIOC ("Making a Difference in Our Community") group is comprised of youth ages 10-18. They attended the meeting to learn more about MM and more about the Support Group. Members directed their comments to the youth, who might one day be the scientists, the doctors, caregivers, or friends of MM patients. Members described how myeloma affected them and its impact on their lives. Doris invited the group to attend. **Pat** said her path to diagnosis included pain in right knee, calcium in her urine, a misdiagnosis of HIV, and being told she had 3 years to live. She was diagnosed in 2005. She talked about how painful bone marrow biopsies were for her…and the importance of learning as much as possible about any health problem you have. She was diagnosed in 2005; **Darcel** was diagnosed in 2012. Went to Zumba class, came home and slipped in bathtub, and broke her collarbone. She had a stem cell transplant (SCT) in January 2013, has had many painful bone marrow biopsies, and has been in remission since November 2013. The group emphasized the importance of cancer patients getting sufficient sleep, eat healthy, exercise, and maintain general health. They should maintain relationship with primary care doctors, as they continue through the cancer journey. **Mischa** reported that she had no symptoms, was diagnosed during regular physical exam, and is a survivor. MM usually is a concern for older African American men, but she was diagnosed at age 50. She was healthy, worked out regularly. She is doing well after a SCT; **Pat** was first misdiagnosed in October 2012 – treated for arthritis. The doctor started to see signs of anemia. She had severe leg and back pain, and eventually had a bone marrow biopsy, which confirmed the MM diagnosis. She had a SCT in June 2013, and is now on maintenance therapy with Revlimid and Zometa. **Pat's** journey started with a mass in her right hip—she had a fractured hip. She had radiation therapy to shrink the mass. She's now on Zometa each quarter to strengthen her bones. **Thomas** is a disabled Vietnam Vet – as a result of MM. He went to the ER with massive chest pains. They said he had a strained muscle. After X-rays the radiologist saw diseased areas in his ribs and pelvis. He was diagnosed in 2010. He now has rods for his femur (thigh bone), and is confined to a wheelchair. The steroids and chemo have further weakened his immune system and has frequent infections. He has an assistant to help him with daily transportation and other needs. He advised that one should always be in touch with their body; **Vena** has been in remission since

2007. **Brenda** was a caregiver to her husband, who fought MM courageously for 15 months. He was athletic, ran marathons, and through a routine physical exam found he was anemic. She is a Social Worker by training. Dr. Lonial at Winship Cancer Center said we are 10 years out from a cure. Cure comes with new medicines being discovered to destroy MM. Drug research is costly. He stated the Atlanta metropolitan area is contributing to the discoveries because so many are willing to participate on Clinical Trials; **Loretta**. had smoldering MM for 6- 7 years. She is now on newer drugs – carfilzomib and panobinostat. You just have to pray and keep it moving. **Doris** was diagnosed in 2004 just before her 65th birthday and with a routine physical. She had too much protein in her urine. She had never heard of MM and did not want to take drugs because she did not feel sick. Her IgG was up to 4,000 and a member of the north side Atlanta Support group encouraged her to take the meds. She was on Thalidomide for a period, but no longer. She is in remission and has harvested her cells in case she needs a SCT in the future.

Announcements

Patient and Family Seminar, in Atlanta, May 16-17, 2013. The Support Group will pay 50% of what members pay to attend the event (Subsequent to the meeting, members were informed that IMF has 60 scholarships available to attend the seminar for FREE – those wanting to attend need to call the IMF immediately at **1.800.452.2873 (CURE);**

Georgia passed an Oral Parity law. It is not what we desired -- $100 cap on cancer drugs. The law was for $200 cap – it's a start give some relief to patients. It goes into effect January 2015.

We encourage all members to write their personal story of their journey with MM. This applies to both patients and caregivers. We can share stories on the website, have stories ready for legislators when information is needed, IMF is also soliciting stories for their website.

Respectfully submitted by Gail