

## Northside Meeting Notes - May 2014

**No Northside Group meeting was held. Members were urged to attend the International Myeloma Foundation Patient and Family Seminar.**

### IMF Patient & Family Seminar Notes

On May 16 and 17, 2014, the International Myeloma Foundation (IMF) hosted a Patient & Family Seminar in Atlanta, Georgia. The 2-day seminar, which was attended by over 150 patients, caregivers, and family members, provided an invaluable forum for learning the latest about multiple myeloma and its treatment, for spending time in community with other support group members, and for making new connections among other patients and caregivers in Atlanta and beyond.

The seminar included presentations by renowned myeloma experts on a variety of topics including the biology of myeloma, current treatment approaches, side effect management, psychosocial issues, and novel therapies. The interactive nature of the seminar provided ample opportunity for attendees to have questions answered and hear expert perspectives on a variety of issues such as the role of stem cell transplantation, the optimal use of maintenance therapy, and supportive care topics.

The seminar opened with an “Ask-the-Expert” discussion with Brian G. M. Durie, MD, of Cedars-Sinai Medical Center in Los Angeles, California, and Jonathan L. Kaufman, MD, of Emory Winship Cancer Institute. A survey of the audience found that about half of patients in attendance had been diagnosed with multiple myeloma more than five years ago and some had been living with myeloma much longer—more than 20 years in some cases. These excellent outcomes serve as a testament to the dramatic advances that continue to be made in the management of myeloma.

In a session on side effect management, IMF representative Judy Webb discussed symptoms that can be associated with myeloma and its treatment. Ms. Webb provided practical suggestions for preventing and managing various side effects and emphasized the importance of reporting side effects early in order to improve response outcomes and maximize quality-of-life. Attendees were reminded that the IMF Infoline (800.452.CURE) is an excellent source of information for patients and caregivers seeking information about side effects and other issues related to living with myeloma.

Rudi Hrcic, MD, of The Binding Site Inc. provided an overview of the Freelite® test, a laboratory test that measures the amount of myeloma protein components in the blood. The Freeline® test is useful at diagnosis, for monitoring response to treatment, and for monitoring for relapse. By explaining the biology behind the Freelite® test and showing how the test is performed, Dr. Hrcic provided great insight on this important tool in myeloma management.

A highlight of the seminar was an inspiring talk by Mike Katz, an Executive Board member of the IMF and a 23-year multiple myeloma survivor. Mr. Katz’s positive outlook, determination, and persistence shone through as he provided encouragement for fellow myeloma survivors. Among his tips, Mr. Katz discussed the importance of advocating for oneself whether that means pursuing a second opinion, speaking up about side effects of pain, or not giving up when told ‘no’ by appointment schedulers, insurance companies, or others when something is needed. Finally, he emphasized that when patients and caregivers are able, they should reach out to help others going through the same issues.

Several sessions focused on the diagnosis and treatment of myeloma. In his “Myeloma 101” session, Dr. Durie provided an overview of myeloma biology, symptoms, diagnosis, and staging. In a session

on initial therapy, Leonard T. Heffner, Jr, MD, of Emory Winship Cancer Institute, discussed the various treatments options available for frontline therapy, emphasizing the importance of individualizing care based on each patient's unique circumstances. In a session on novel therapies, Sagar Lonial, MD, of Emory Winship Cancer Institute provided an exciting update on the wide range of novel therapies being developed and tested in myeloma. Dr. Lonial explained that increasingly, myeloma treatment will be individualized based on the specific molecular characteristics present in each patient. Some of the molecular characteristics identified in patients with myeloma have also been detected in patients with other types of cancers. "This opens us up to using drugs originally developed for other cancers," explained Dr. Lonial. As more targeted therapies continue to be developed, the future of personalized medicine is becoming more of a reality.

Another popular topic at the seminar was the issue of bone health, which was discussed by Matthew Drake, MD, PhD, of the Mayo Clinic in Rochester, Minnesota. Dr. Drake discussed the current treatments of myeloma bone disease and potential complications that can occur. Hot topics that were discussed among the faculty included the optimal duration of bisphosphonate therapy and the optimal infusion time of zoledronic acid (Zometa). Dr. Drake encouraged patients to engage in safe exercise to strengthen bones and to take precautions to protect the bones, such as reducing the risk for falls and bending from the knees when lifting objects from the ground.

IMF president Susie Novis and IMF co-founder Dr. Durie provided an update to the group on the IMF's innovative research project called the Black Swan Research Initiative. Through this initiative, the IMF has spearheaded an effort to standardize the measurement of minimal residual disease (MRD) in myeloma. Although MRD measurement does not yet have a role in clinical practice, it will be a crucial component of evaluating new therapies for myeloma in the future, as therapies become more effective and we step closer to a cure for myeloma.

--Respectfully submitted by Melinda T.

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### **Southside Multiple Myeloma Support Group Meeting -- Meeting May 24, 2014**

**Doris** opened the meeting with a moment of silence. There were 12 present for the meeting.

The meeting opened with discussion about low participation in the support group and poor turn-out from AA MM patients and family seminar. Among possible barriers we discussed: possibility that some may not have transportation and support to get back and forth to meetings; some may be too ill to participate, many may still work and Saturday may be the only time they have to rest and possibly there are still large numbers of members that are not aware of the support group. We will continue to work to address these barriers. There was also discussion regarding fund raising activities and that such events could serve to provide exposure and awareness of MM support group. Suggestions included a Fitness event that could include some safe movement for most – including a walk, Tai Chi, Yoga demonstrations and /or some low-impact movement, and a gospel concert. We decided not to participate as a group in Light the Night this year – and proceed with plans for the fundraiser for early Spring 2015. We had no volunteers to lead in this effort.

**Selina** shared Millennium was looking for Atlanta MM patients and caregivers to tell their story; go to Millennium [pharmaceuticals.org/mymyeloma](http://pharmaceuticals.org/mymyeloma). Click on SHARE; then click on Stories. You can see patient and caregiver's stories and add yours. **Selina and Patricia**, two of *our* members are featured.

**Discussion Regarding Recent Patient and Family Seminar:** Members discussed their impressions of the seminar. **Pat** shared she was extremely impressed with the seminar and gained a lot of information. She said she had a transplant last June at age 75, and is in remission. Since March

she has been on Revlimid for maintenance (7 days on and 7 days off). She shared her empathy for those in other countries who after a certain age were not eligible for BMT/SCTs due to age restrictions. Before diagnosis, was in good shape and engaged in regular exercise – had no diabetes, hypertension, etc.. **Selina**- she attended the breakout session with Dr. Drake on Management of Bone Disease and thought it was very helpful. Selina said she had Kyphoplasty. During that session he presented exercises one could do safely if you had that procedure and discussed suggested supplements including use of Vitamin D and C supplements. **Pat** -wonderful seminar; questions from audience were good -- we need to become more educated about MM. She said the Free Lite presentation seems to be a bit too technical –still a bit confusing. Members shared that **Vermell** did an excellent presentation during the April meeting as part of the Lab Values presentation and Free Lite was part of that presentation. It was suggested that Vermell S. do a presentation specifically on Free Lite. **Gail** used a picture on a Millennium flyer of the Immunoglobulin (Ig) or antibody to help with the visualization. She reviewed the information in the May meeting minutes to help explain free light chain vs heavy chain, M-spike, etc. We should review this as often as possible until people are comfortable with the information.

**Pat** suggested we send a thank you note to IMF for the scholarships. **Paulette** said the electronic engagement (electronic personal response system )of the audience was impressive as it allowed participants to provide immediate responses to questions regarding their experiences through the MM treatment journey. She made note that not many patients in attendance said they had been treated with Carfilzomib—she said the IMF staff seemed surprised as well. Since it has been described as a drug with fewer side effects why haven't more had treatment with this newly approved treatment regimen in the Atlanta MM clinics? **Gail** said she was diagnosed in 2008 and had a Stem Cell Transplant in December of that year. She says her numbers are doing well. After 5 years, she is in remission and is not on any maintenance regimen. She said she has IgG Kappa MM but; when she had the bone marrow biopsy they did not do Cytogenetics so she is not aware of her specific chromosome (deletion or transfer). She said going forward as treatment becomes more patient specific this will become critical to determine their personalized treatment regimen. She is on Aredia (versus Zometa), quarterly and even though it takes 2-3 hours to administer she more comfortable with fewer side effects than Zometa. **Doris** shared she was so happy to see so many members attending the seminar but wished even more had been able to attend. She said she enjoyed the presentation from Dr. Durie as he discussed the Black Swan Research Initiative to develop the cure for myeloma.

### Member Updates

**Doris** shared that **Andrew** and **Lonnie** were in the hospital. Andrew has been in the hospital for more than 2 months, Lonnie was recently admitted to the VA hospital with lung cancer. Please keep them both in prayers.

### Announcements/Upcoming Meetings

- IMF - Veteran's Against Myeloma website – [www.veterans.myeloma.org](http://www.veterans.myeloma.org) -provides links to relevant Veterans Administration information, such as state veteran's assistance offices and national veterans service organizations.
- **Update from ASCO/EHA/IMWG** - June 26 @ 7PM. Register: [2014ASCOrecap.myeloma.org](http://2014ASCOrecap.myeloma.org)
- White Paper on Subcutaneous Velcade from the IMF Nurse Leadership board White is available on the IMF website: <http://bit.ly/1nhHKk5>
- <http://smartpatients.com/myeloma>-new platform replacing ACOR from myeloma.org- Mike Katz

Respectfully submitted by Paulette N. and Gail M