

July 2015 Northside Meeting Notes

Business & Announcements

Joe B. led the meeting. There were no new attendees at the July meeting. **Jeannie** reminded us that the September 5th meeting will be held at the [57th Fighter Group](#) restaurant. This marks the 4th annual Labor Day weekend special meeting event. This will not be a typical meeting, but rather more of a social event in place of the meeting, but at a different location (same location as last year), and will be sponsored by Takeda Pharmaceuticals. Friends and family are invited and encouraged to attend. More details will be provided later and a head count prior to the event will be required.

Guest Speaker & Discussion

Thank you to **Tracy Bonds**, a Clinical Nurse Educator at Onyx Pharmaceuticals (now Amgen), who traveled from Jacksonville, FL to join the group to discuss survivorship and living well with multiple myeloma (MM). Tracy explained that she travels to 9 different locations including Puerto Rico to attend IMF and MMRF sponsored support groups to provide education and she also learns a lot from attending support group meetings. Tracy is a survivor of Hodgkin's disease for which she was treated 27 years ago, and so she understands through her own personal journey the necessity of a good survivorship care plan, and is also why she decided to become a nurse. Survivorship begins at the time of diagnosis and continues throughout your life. Survivorship issues and quality of life expectations continue to become more and more important as longevity increases and as we age. The longer we live the more likely we are to experience secondary side effects from treatments and the disease itself. A survivorship care plan for MM survivors must address the long term needs of bone and kidney health, mobility, sexual dysfunction, and general health maintenance including physical and emotional well-being. After age 40 health screenings naturally increase for everyone as screening and prevention become more important. Some issues especially common with MM survivors include blood clots, neuropathy, and kidney and sexual issues.

Bone Health: Approximately 90% of MM patients have evidence of a skeletal event which may be represented by bone pain, high blood calcium, broken/brittle bones, spinal cord compression, limited mobility, and decreased quality of life. Some supplements that can help include bisphosphonates, vitamin D, and calcium. Some pain management methods include kyphoplasty/vertebroplasty, radiation, and surgical fixation.

Kidney Health: Approximately 20-25% of MM patients have kidney issues at diagnosis, and approximately 50% will eventually develop kidney issues as time progresses, even if kidney issues do not present at diagnosis. The likelihood of experiencing kidney issues increases for those greater than 60 years old, and for African American males. Other contributing factors include being dehydrated and the use of contrast dyes in tests.

Mobility: Approximately 33% of older adults will experience a fall. Falls for MM patients can be affected by bone disease, side effects of MM therapies, increased age, and other medical conditions. Some contributing factors to immobility in older patients in general include sensory issues, age-related medical conditions, nutrition and hydration, and psychological outlook. It is very important to do things that make mobility easier for you such as asking for help, using special medical devices, etc. to make it easier and safer for you to keep moving.

Sexual Health: Approximately 43% of women and 31% of men report intimacy issues. Some things that affect sexual health include diabetes, hormones, steroids, and thyroid function. It is important to communicate issues to therapists and other healthcare professionals. Ask whoever you are most comfortable with to help you identify the cause – disease, medication, age, etc. to help address the problem.

Other: Other survival types of issues to consider include employment, financial, insurance, and disability.

Atlanta is a good location for MM patients. Studies show that triplet therapies (2 active drugs and a steroid) get the best results currently. With all of the research and collaboration we can now expect to learn of major changes for MM regimens every 6 months, so it is very important to stay educated.

Meeting Discussion

Some helpful tips were discussed during and after the presentation. Some ways to relieve cramps include drinking dill pickle juice, yellow mustard, and a bar of soap underneath bed covers. Fatigue, digestive issues, ringing ears, locking of jaw, and neuropathy are common issues with MM patients. Neuropathy and fatigue can be caused by MM alone and also many of the drugs used to treat MM. Some patients have reported that some supplements such as B vitamins and folic acid can help with neuropathy. Often patients who are getting good results with their current therapy but who suffer from neuropathy do better when reducing dosages or switching to a newer generation of their current drug regimen. To better manage fatigue try to get quality restful sleep, stay hydrated, get good nutrition, and stay active. Enjoy life and do as much as you can each day. Smaller more frequent meals can help with digestive and energy issues. Communicate your concerns of fatigue to your doctors so that they can help you manage it better by reducing drug dosages, times of day that you take your drugs, etc. For example, the timing that you take steroid medications can affect

sleep cycles. **Lori** reported that she takes Dex at night so that it kicks in during the next day and she can take advantage of the energy, rather than having it disrupt her sleep. Some members had personal updates to share: Several group members reported remission anniversaries – **Jim M.** Is celebrating 5 years remission post stem cell transplant and another member reported a 4 year remission. **Earnestine W.** joined the group after being away for many months. She is doing much better and explained that she is performing her own nocturnal dialysis and her creatinine levels are dramatically reduced to a much better level. **Molly** reported that the “**Mob & Bolly**” (a.k.a. Bob & Molly) team recently raised \$2,700 for MM (*thank you!*).

Submitted by Wendy

Southside Multiple Myeloma Support Group

Meeting Minutes July 2015

Gail called the meeting to order leading the group in guided breathing exercises and a moment of silence. Doris was attending the annual International Myeloma Foundation Summit for Support Group Leaders in Dallas, TX.

Our August 22nd meeting will feature Sandra Francois Atkinson who is a pharmacist with the Atlanta VA; she will answer some of the questions we have had regarding medications and treatment regimens for MM. Also, Nancy will update us on advances in the treatment of Multiple Myeloma and other information obtained from the IMF Summit for Support Group Leaders.

Member Updates: **Lenora** was diagnosed with smoldering Myeloma last year -- and turned a very young and active 81 last week. She said her community oncologist had scheduled her for chemotherapy. After doing her own research on the internet, she found that smoldering myeloma was a precursor to MM, and also found Emory Winship. She went there for a second opinion, spent 45 minutes with Dr. Heffner, one of the myeloma specialists there, and was advised not to proceed with the chemotherapy. Dr. Heffner tried to contact her original doctor on the spot, but was unable to reach him. They had spoken by the time she went to the first doctor for a follow-up visit. They all agreed she would not start chemotherapy. She said 8 years ago she was told she had stage 4 kidney disease – kidneys functioning at 14%; but went against the recommendation of the doctor and did not start dialysis. She has found that when she moved a lot – went to the gym, that she felt much better – and **Patt** agreed. Lenora has quite a testimonial in near death experiences over her lifetime – including a diagnosis of an ovarian tumor with pregnancy in 1963 and a brain tumor 40 years ago. **Vermell** (*Nurse Supporter*) stressed that *second opinions are standard practice these days – insurance companies will pay. Having a second look at serious diagnoses or treatment plans can help to reduce medical errors, unnecessary costs for therapy, and peace of mind for the patient. Smoldering or MGUS almost always progresses to active myeloma, but it's important to get specialists involved early to determine the best options.* **Patt** is on 15 mg Revlimid (Rev) for 21 days and quarterly infusion of Zometa (bisphosphonate - helps to preserve bones); **Larry** was diagnosed in October, 2013 and is on Kyprolis with Rev/Dex, and Zometa once per month. He receives treatment with Northside Hospital offices in Stockbridge/Lake Spivey (Dr. Spinola – oncologist) and Dr. Kaufman (Emory Winship). It took some work to get the oncologists work together, it was at the insistence of the patient – and for the patient’s convenience. The location (Lake Spivey) is much easier on Larry and his family – and the desired specialists are at Emory Winship. **Elizabeth** asked if others had experienced personality changes while on Dex. She was assured by the group that this was a common side effect, and many had the experience. Her son noticed the difference in her personality (e.g., snapping at family members), and asked Dr. Lonial about the issue. She is now on 12mg of Dex -- reducing dosage to find the right level for her. *Each person has different responses to medications. Dosages are dependent on a variety of factors, including severity of disease, type of disease, body weight, etc. The discussion was that any major or common side effects should be discussed with the patient by the providers – providers include the pharmacist. Patients also have a responsibility to ask about possible side effects of new medications AND to read the patient information sheet that comes from the pharmacy.* In recent months, **Elizabeth** has had two radiation treatments -- one for a tumor in her back and another for a tumor in her right leg. She now has pain in her neck and fears she does not have a tumor there. She receives treatment at Emory but also continues treatment with M D Anderson Cancer Center in Texas, where she was extremely impressed with their treatment approach. She has been on Zometa since 2007—now treated quarterly. She now has one kidney. *We talked about the importance of being followed by a myeloma specialist – in a Center for research and treatment, who can work with your local oncologist. It's easier for this to occur now, since so many records are electronic. Participants mentioned Cancer Treatment Centers of America (CTCA) – being impressed by their commercials and holistic approach to cancer treatment.* **Gail** offered that in her opinion, CTCAs were not

for the economically disadvantaged – their desired patients were those with great insurance or private pay. The one in the metro Atlanta area has many patients from out of state, and went back before the Georgia General Assembly to have the number of beds for Medicare patients decreased from their initial contract – (no balanced portfolio of paying patients as other hospitals must abide by). Other oncologists have complained about their cancer treatment plans, as well. CTCA facilities, in general, are not endorsed by the Georgia Clinical Oncologists organization (Gail has been GASCO member since 2009). **Question: How does one get the equipment needed to improve mobility and accessibility at low or no cost?** Elizabeth has a walker, canes, a wheelchair, motorized wheelchair, and home healthcare equipment. Some of the equipment is self-pay – but most is from insurance. Get the prescription from the primary care doctor – if you have problems get the Social Worker to help facilitate. There should be a list of companies that provide what is needed. Contact the **Division of Aging Services - Georgia.gov or 404.657.5258**. Also, ask the pharmacist. Then check with medical supply stores. **Selina** is now on 5mg of Revlimid, and so far is doing better. She reminded us that she was on a clinical trial that included her taking Rev daily for 3 years after her Stem Cell Transplant. She experienced many side effects, including muscle spasms and heart palpitations. She was asked to enroll in another clinical trial but refused because there was no reimbursement for mileage or parking. She drove from Newnan to Northside to participate in the previous trial (more than 60 miles round trip), and never missed an appointment, even during the gas crisis. She said she started on 20 mg of Revlimid but gradually decreased to 5mg due to her reaction to the drug. She now attends the Northside clinics in Stockbridge. **Alma** reminded the group that MM patients should make sure they know what markers the oncologist is following—is it your Free Lite Chain—Kappa, Lambda? Is it IgG, IgA?...they can be different for different patients – she follows her free lite chain values. Alma is in cycle 8 of a clinical trial Panobinostat/Pomalyst (like Revlimid), Daratumumab, and 20mg of Dex administered intravenously (IV).. She is doing much better at once a month versus once weekly...and dosage is down from 4mg to 2mg. She shared she thinks Dex may cause some Attention Deficit Disorder –she has had some trouble concentrating. The Dex seems to reduce effects of other drugs. Alma says she was taken off Zometa because she had dental issues: several teeth “popped out” – she had 2 root canals and she thinks problems are related to myeloma. She said she was in a lot of pain; but her dentist would not do work right away--she needed to be off Zometa for a while before she could have the work done. She has been off Zometa since January 2015. *This group has had many discussions in recent months about the bisphosphonates (Zometa and Aredia) and dental problems. Additionally, Vermell shared, her experience is that Aredia provided less stress on the Kidney than Zometa.* **Vena** says she is cancer free. She said she, too, has been taken off Zometa so she can have some dental procedures done. Vena spoke about her experience with Dex and expressed concern that her doctor did not prepare her for the potential side effects of Dex. She shared she was referred to mental health facility as an in-patient for a week as the result of Dex – she had racing thoughts and could not sleep. **Lonnie** reports he is on 10mg of Revlimid every other day and reminded us that we can always call the drug manufacturer and ask questions about medications. **Harold** is no longer on Revlimid after several years, but now is on Velcade –delivered subcutaneously. He also has Parkinson’s disease and the neuropathy in his feet has increased. The discussion was that Harold should ask *WHY* the medication was changed – and also Alma suggests, he ask what numbers or markers are followed for his myeloma? What are the target numbers for these markers?

After the very rich discussion on drug therapies, dosages, and treatment practices, we watched an archived video from the IMF series selected by **Paulette**. We watched about 10 minutes of a 16 minute webinar from the Nurse Leadership Board (IMF). The webcast seemed to underscore much of the discussion from the day. The webinar focused on MM treatment regimen side effects, and the importance of regular screenings, especially as more people are living longer with MM. Example: Dex can cause blurred vision and increase cataract formation. To view the webcast go to www.myeloma.org. Then click on **webcast** (found in gray on the left side of the screen). Then click Nurse Leadership Board Webcast. Page down and select **Long Term Survivorship Guidelines for MM Patients**. The video is less than 17 minutes long. Even though it was done in 2010 it is worth watching for all MM patients.

Announcements/Updates:

- **Shop for a Cause** - Macy's. \$5 per ticket all goes to non-profit agency. Event date - August 22 at Macy's nationwide. Get tickets from Paulette ppmneely@gmail.com OR Nancy - aammsg-2@comcast.net;
- **LLS - Updates on Myeloma - Savannah, GA.** S. Lonial and others. First Presbyterian Church. August 29. 8:30AM- 1PM. To register: 404.720.7838: LLS - "**Light the Night Burlington Ambassador Volunteers**, various locations ongoing. Contact: Sathya Narayan Chakravarthy: Sathya.Chakravarthy@lls.org or **404-720-7811**
- New drug filed by Takeda with FDA. **Ixazomib** (proteasome inhibitor) - for refractory/relapsed myeloma.

Checklist for MM Patients - Myeloma as a Chronic Disease (from Dr. Brian Durie) - Because Myeloma patients are surviving longer, additional care must be taken in some areas:

- ✓ **Watch for progressive reductions in white blood cell counts, hemoglobin (anemia), and/or platelets**
- ✓ Hidden infections in sinuses, teeth, kidneys, or bladder areas
- ✓ Discuss ongoing use of steroids with provider
- ✓ Discuss ongoing use of bisphosphonates (Aredia and Zometa) - risks include necrosis of the jaw (ONJ) or fracture of femur
- ✓ Hip damage (AVN - necrosis)
- ✓ Blood sugar levels can elevate and result in diabetes
- ✓ Normal monitoring, including colonoscopy
- ✓ Whole body PET/CT scan suggested annually. Not automatic from insurer, but provided by physician request. Monitors low-level myeloma, detects hidden infections or early detection of secondary cancers

Respectfully submitted by Gail and Paulette