

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Northside Meeting

June 1, 2019

Movement with Myeloma

Our presenters introduced themselves:

- Tony Suarez, PT, DPT, OCS Clinic Director for PT Solutions Amsterdam Avenue, Midtown Atlanta location. He has two dogs
- Molly Lay, NETA, ANWA, NIA, nationally-certified Personal Trainer and fitness leader with over 35 years of experience. She has two cats.

Tony began with a chair rise/sit test for everyone: Counting how many times we could stand up/sit down in one minute [honor system]. We had to take note of how “winded” we were at that moment. Then he had everyone challenge their balance with a simple one-legged stand which became complex and difficult when we closed our eyes.

After determining how many in the group were patients and how many were caregivers, he talked about how exercise during and after treatments is safe. If we, patients and caregivers alike, are not exercising then why not? Some discussion about barriers to exercise: Too fatigued, diarrhea and other side effects, no stamina, fear of falling, don't want to, can't leave patient alone, no facility close to home. He reinforced that with exercise, even a small amount in your own home, you will have LESS fatigue, less anxiety and possibly lessen the side effects from therapy. Check out Silver Sneaker Program near you. Work with your healthcare professionals to help design an exercise program or refer you to physical therapy.

After getting clearance from your oncologist, the exercise he recommends is 150 minutes/week of moderate intensity or 30 minutes five days per week. We then discussed what “moderate intensity” feels like and, after giving us a formula to use to calculate our individual maximum heart rate count, he brought it down to “If you are exercising and having difficulty talking, that is moderate.” We all practiced finding our heart beat in our wrist or in our neck. Molly indicated that our resting heart rates are an indicator of our fitness levels and told us how to get a valid resting heart rate [RHR]: Before getting out of bed, count your heart beats for one full minute and record. Do this for three consecutive mornings and average them out for your true RHR.

Tony encouraged everyone to engage in strength training 2-3 times a week and demonstrated some flexibility and balance exercises that can be done to complement the strength work. One for balance was standing on an unstable surface such as a cushion, fingertips on a wall for safety, then lift one leg and hold it up. To enhance the work, close your eyes. The Romberg Balance Test is used for DUI: Feet together,

close your eyes. Tony said two of the following three functions are necessary to maintain balance: vision, vestibular function [inner ear] and proprioception [knowing how your limbs are oriented in space]. He said that practicing balance will increase your ability to balance.

The muscles of the hip and pelvic region are important for balance and for most exercise. A volunteer from the group [Samantha] came forward and demonstrated the “clam” [many in the group moaned, saying “I hate clams!”] and the bridge with the extended leg pattern. Also, at Tony’s direction, she demonstrated Single Leg Raises and, using a band, holding it in front at chest level and pulling the band out to the side for upper body work. He suggested 8-12 reps each with palms up and palms down.

Molly then talked about the different forms of exercise we could pursue: Swimming, Tai Chi, Qi Gong, Ageless Grace™, Nia™, Tai Chi Fan Form, and Yoga. All of these options are available in the Metro Atlanta area. She then had everyone stand [including Arthur] and lead us in some Qi Gong movements, emphasizing that Qi Gong is about breath. This was followed by some Tai Chi moves emphasizing that Tai Chi is about movement and balance. She also demonstrated the benefits of the Tai Chi Fan Form using her large, red fan. Molly then discussed the importance of doing movement that is reciprocal to keep our brains plastic and keep us stable when walking. Nordic Pole Walking is one of those modalities and she demonstrated the reciprocal movements required to effectively Nordic Walk using a pole in each hand. Left foot moves forward/right arm moves forward. Molly suggested everyone get a playball [available in most five-and-dime or drug stores], a dowel with rubber chair tips on each end and an exercise band and you’ll have a full gym at home. Stay aware of how you are feeling during exercise and afterwards and listen to your body.

Tony then talked about the benefits of physical therapy and the importance of bringing a good physical therapist into your life. He passed out an article “Exercising with Cancer” from *Exercise is Medicine* which had photos of the exercises that were demonstrated, some information on his clinic and his personal contact information. One of the individuals in the group said he [Tony] had been to his daughter’s PT when she was recovering from knee replacement surgery and she responded perfectly and is doing very well on her new knee. There were others in the group who testified to the increase in flexibility and reduction in fatigue they experienced with physical therapy.

The presenters’ take-home message was “Exercise is *safe* for you so just do something active that you enjoy every week.”

When asked whether the group would like more programs like this and, possibly, this same one again, the consensus was “Yes!”

Submitted by Molly and Jim

Southside Myeloma Support Group

June 22, 2019

Doris opened the meeting with a moment of silence. There were three new members. Patricia, Veronica, and Gerri. The agenda for the meeting included a presentation from a representative of the **Social Security Administration** and a discussion of **Cancer Plans** for every cancer survivor.

Veronica was diagnosed with multiple myeloma in May 2019 after finding it painful to walk for two years. Veronica is being treated at Kaiser Permanente and has completed the first cycle of Velcade (injected), Revlimid, and dexamethasone (VRd). She learned that myeloma is incurable. Several members shared with Veronica, her mother, and supporter aspects of their own myeloma journey survivorship after diagnosis – from several months to more than 15 years. They shared their own experiences in response to questions and concerns and that though myeloma is incurable, it is largely controllable. There was more discussion about the financing of myeloma treatment, including the Patient Access Network (PAN) and LLS.

Samantha visited with the group and also attends the Northside Support group and was diagnosed in June 2018. She saw a chiropractor for some symptoms she was having and was left with 18 rib fractures. Her myeloma journey has included Stage 3 kidney failure and dialysis. She went through the VRd regimen, which placed her in remission. She is not interested in having a Stem Cell Transplant (SCT). Samantha will emphasize a healthy diet and regular exercise to remain healthy.

We had a representative from the Social Security Administration (SSA). She said it's important that we understand all our options. Though there are some employers who do not pay into Social Security, 95% of them do. Three handouts included a simplified chart explaining Social Security benefits, a schedule for payments of Social Security benefits, and a Medicare 101 document.

An important document that she encouraged us to order a copy or pick it up -- **Understanding your benefits**" booklet. There are three types of benefits: **Social Security for Retirement; Social Security Disability (SSD), and Social Security Income (SSI)**.

You are generally eligible for **Social Security in Retirement** if you have worked (taxable income) at least 10 years over your lifetime. The amount you receive is based on the average of your highest income for 35 years of work. For **SSD**, you must have worked for five of the last 10 years. **SSI** is a last resort benefit for those with low income or low resources. The maximum benefit is \$771/month.

You should get your statement for accurate planning. Currently, no one under age 60 years will receive automatic statements in the mail. You may elect to start to receive Social Security at age 62 at which time you will receive 75% of your benefits for the rest of your life. For every month past age 66 for retirement offers an 8% bonus. You will receive the highest average over 35 years of work. The 8% increases end at age 70. For those 18 years and older, as of February 2019, you do not have to visit the social Security office to replace your Social Security card. You will need to set up an account on the website, you will need your driver's license information. Most people are encouraged to establish an online account. They have worked to

become more efficient and reduce the amount of time anyone must spend in the social security office. www.socialsecurity.gov.

Your ability to earn income and receive Social Security. When you are 66 years of age, whether disabled or not, you are considered retired and you may earn as much money as you want with no penalties. The Senior Citizen's Right to Work Act of the 1990s gives seniors the ability to earn unlimited funds. The Social Security Administration and **Medicare** are separate agencies with separate rules. For Medicare the age of eligibility is still 65 years. There is no retirement health insurance at age 62 should you decide to retire. Those on Medicare must have the new Medicare card, red, white, and blue. These cards were mailed out June-September 2018. Make sure you have the new card as doctors will not take the old ones. They are mailed from CMS (Center for Medicare and Medicaid Services), Baltimore, MD. Some have discarded these new cards in error.

Through your online SS account, you can determine how much you will receive each month – from your date of disability. To receive SS disability, you must have a work history that includes having worked five of the past 10 years. Over age 66, there is no SS disability status; you are considered in retirement status.

For disability applications, it helps if you will document the physical or mental disability. At one time, Multiple Myeloma (MM) was on the list of expedited diseases –also called compassionate allowances --for quicker approval. In checking, our presenter did not see MM on that list. For terminal disease, where one is not expected to live more than 6 months, it is possible to get a one-day approval. For example, pancreatic cancer, Stage 4 is on the list. If you file a claim with the state, you can apply by phone, face-to-face, or online.

The Department of Labor conducts research for applicants. They are able to get all medical records electronically. Decisions on disability can take as long as 4-5 months to get a response, so it is important to file as soon as you think you might need it, then plan your finances accordingly. Keep your mailing address current in the database.

A spouse or children (biological or adopted) under age 18 may also receive disability benefits if you are disabled. If you are approved, you can receive payments from as far back as one year. If you still work, and make more than \$11,220 gross for the year, your claim is denied immediately because they determine you are engaged in "substantial gainful activity."

The process for disability benefits (based on one's earnings) include: a letter paid out after a five-month waiting period by law. Calculations for payments start on the first day of the month. You must live the entire month in order to receive benefits. Benefits are calculated based on the amount of your earnings, can range from \$160 to \$2300. Payment date is based on the day you were born, so that payments are staggered throughout the month. Example: those born on the 1-10 day of the month are paid the first Wednesday of the month, from 11 – 20 – the second Wednesday of the month, and the last 10 days of the month are paid the third Wednesday of the month. SSI is paid on the 1st day of the month. You may be eligible to receive Disability and SSI at the time.

In order to receive Medicare insurance with your disability payment, you must receive 24 disability checks before Medicare kicks in. If you have a positive diagnosis of Lou Gehring's Disease or you are on dialysis/kidney transplant, there may be exceptions.

Medicare has two different kinds of insurance. Those who receive Supplemental Security Income (SSI is based on low income/low resources) will receive Medicaid automatically. If you earn more than \$737/month, you will not qualify. This is paid on the 1st day of the month. You will get Medicaid automatically if your income is less than \$2000/month, you have a poor work history, or you have children under the age of 18.

Grandparents raising grandchildren can receive social security benefits. Aunties, cousins raising grandchildren might be eligible for benefits. In Georgia, the Kinship Coordinators of DFACs (Department of Family and Children Services) is the agency that oversees this process. It can be a temporary arrangement.

Another important document that you should get when considering disability applications is **“What you need to know about Social Security Disability.”** The review of the application does not depend on what your doctor says, but rather on the Social Security review. Other factors include being under age 66, and whether you are retired. If you are on disability, you can go back to work, but you may not earn more than \$900/month initially. After 9 months, you may average \$1220/month.

Hours for Social Security Offices are Monday, Tuesday, Thursday, and Friday from 9 AM – 4 PM. Wednesdays from 9 AM – 12 noon. Contact information: 800.772.1213 or www.socialsecurity.gov.

Cancer Survivorship Care Plans. In 2006 the Institute of Medicine issued a report recommending that every cancer patient receive an individualized survivorship care plan that includes guidelines for monitoring and maintaining their health. In response to that report, many groups have now developed various types of "care plans" to help improve the quality of care of survivors as they move beyond their cancer treatment (American Cancer Society). Care for people with myeloma or other cancers does not end when active treatment has finished. Your healthcare team will continue to be sure the cancer has not returned. Being a cancer survivor – anyone who has ever been diagnosed with cancer – might mean a wide range of services, like physical therapy, pain management, nutritional planning, and/or emotional counseling. The American Society of Clinical Oncology (ASCO), CDC, and the American Cancer Society have determined that each cancer survivor should have a cancer survivorship plan. In addition to the diagnosis and treatment, cancer plans should include family cancer risks, where treatment was received and from whom and managing any late and long-term side effects. Some stated side effects of medications include secondary cancers. There are other potential signs and symptoms that seem nonspecific initially, but even months and years in the future might have some relationship to your diagnosis and treatment. The ASCO Survivorship Care Plans should be updated regularly. Ask your healthcare team for your Cancer Survivorship Plan, but build your own if they do not provide one. Look for ASCO Survivorship Plans at: <https://www.cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-and-survivorship-care-plans>

Announcements/Upcoming Events

- The Leukemia and Lymphoma Society sponsored Blood Conference for 2019 will be on September 7 at the Renaissance Waverly, Galleria off Cobb Parkway.
- **The Promise Study** is seeking African American adults who are 45-75 years of age and are first-degree relatives (parents, sibling, or child) of patients with myeloma. They will get free screenings in an effort to find better treatments and an eventual cure for myeloma. For more information: 617.582.8544, Email: promisestudy@partners.org or website: www.promisestudy.org.
- **IMF – 10th Annual IMWF Summit/TeleConference series from Amsterdam. Making Sense of Treatment. Debates and discussions about trends in treatment.** ASCO, EHA/IMWG. June 27, 7 PM ET. www.myeloma.org

- **MMRF- Webinar Series. 6: Monoclonal antibodies and vaccines: Emerging myeloma treatments** July 10. **MRD/Blood Biopsy**, May 15; **ASCO Highlights** - June 18, 2019. REGISTER at www.themmr.org
- **MMRF. MyDRUG™ Platform Trial** — the first trial of its kind in multiple myeloma. MyDRUG assigns patients to treatment arms based on their genomic mutations. Four of the treatments are being tested for the first time ever in multiple myeloma. This clinical trial will test several different drugs on different genomic types. **Myeloma – Developing Regimens Using Genomics.**

Respectfully submitted, Gail