August 6, 2016 Northside Meeting

New Members
Stephen was diagnosed with smoldering Myeloma after a physical in early 2010. Later that year, his mother was diagnosed with pancreatic cancer and passed away. Then he got word that his MM had progressed and had a transplant in 2011. He is currently in remission and on Revlimid maintenance. **Kathryn** was diagnosed in 2014 and had a transplant later that year. She achieved remission for one year and has tried several treatment combinations since relapse. She is currently between hospital stays and will be going back in a couple days for an intense treatment, DCEP, to get the Myeloma under control. **Janusz** was diagnosed in 2014 with fatigue and kidney problems. He had a transplant that year. He is currently in remission, but had pneumonia and sinus infections earlier this year. He ended up with Legionella (Legionnaire's disease) and has had many rounds of antibiotic and anti-viral medications.

Program
Speaker was **Victoria Collier,** eldercare and disability attorney, from Decatur. She is also a veteran and helps with VA benefits. She said that there are many options to protect your assets, but the most important thing is to get the processes in place before you need them. She brought three books that she wrote or co-wrote. One was on veteran's benefits for seniors, but is out of print: only available digitally. The other books were: Don't Go Broke in a Nursing Home, and Blooper Episodes in Estate Planning and Elder Law. She did not have a presentation and answered questions from the group.
Q – I am an MM patient and getting displaced (laid off). I am ready to stop working but not eligible for retirement or Medicare. I will be getting severance pay until the end of the year. Working was getting more painful from sitting all day and wonder if I could go on disability. **A** – If you were working, then you are employable and may not qualify for disability. Talk to your employer to see if you can get on short term disability and then long term disability (LTD) and apply for SSI. The benefit of SSI is that you are eligible for Medicare after you are on SSI for two years. Healthcare coverage is the biggest benefit of SSI. The company that is paying your LTD may help you get on SSI to reduce their LYD payments. Some attorneys may not take your case until you have applied for SSI and been rejected. Their fee is capped and comes only from the back-payment on benefits.
Q – My FMLA and short term disability ran out and I am now on long term disability (LTD). How long can I stay on LTD? **A** – Check if there is a cap on the amount of payment. If not, then it is age 65.
Q – I just had a transplant and can no longer do the job that I was doing before. Do I qualify for disability? **A** – Short term disability is determined if you can no longer do the job you had before at the same level. SSI is given if you can't do any job. We all have good days and bad days, but when applying for SSI, explain the bad days. You can't retain a job if you are easily fatigued, need to rest regularly, or are mentally confused.
Q – What is the difference between SSDI and SSI? **A** – For SSDI, you must have worked for ten years with an income above a certain level. It has income and asset requirements. SSI is more like Medicaid with low income and no savings. With SSI, you can go on Medicaid and then change to Medicare after two years. There are different waivers with each benefit, depending on your income. Waivers can provide additional money for transportation, caregivers, etc.
There are attorneys with Medicaid and Social Security expertise. Special needs people below the age of 65 need a lawyer to help get assistance and save the family's assets. Use Georgia Advocacy for adults with disabilities. Although Victoria does not handle SSI cases, she can refer to several experienced attorneys that can help.
Q – How can we prepare for Long Term Care (LTC)? **A** – This is Victoria's specialty. Most common for covering LTC costs is to use your own money. Medicare does not pay for long term care, only short term care and rehab after a hospital stay. You can use a reverse mortgage on your home to pay for care. LTC insurance is too expensive and the rates can increase annually. If you have sufficient resources, leverage funds to cover LTC. The Pension Protection Act of 2006 was revised in 2010 to allow retirement funds to cover LTC without taxes. Annuities are covered under the Pension Protection Act and certain annuities can cover LTC and provide money for your heirs. There are also life insurance policies that have a LTC rider so you can use the insurance money for LTC, up to the amount of the insurance. There is also VA benefits and Medicaid coverage available. Many people want to avoid a nursing home that takes Medicaid patients. They feel that the quality of care is less. In Atlanta, only one nursing home does not accept Medicaid patients. When Victoria was 19, she was a nurse aid at a nursing home in TX. She noted that the main issue was that there were too many patients per worker. The primary attention of workers went to those patients who had visitors. They got the first care! If you have the funds, you can get private duty nurses to give you extra care. In Atlanta, nursing home care costs $6500 to $8500 per month. You need a plan to protect your assets. You don't qualify for Medicaid until you have spent most of your money on care. If you are married, up to $121,000 is protected from Medicaid. If you are single, only $2,000 is protected. Your home is protected from Medicaid, but when it is sold, Medicaid can come back to claim some of the proceeds. Your IRA is protected if you are getting Required Minimum

Distribution (RMD). You can take distributions early to protect your IRA. Take the time before the need arises to evaluate your plan for LTC. Consult an expert and discussion your wishes with your family.
Q – How do we design our wills? **A –** If you are married, everything goes to your spouse. If you married later in life and there are children from previous marriage, check state laws if they can get assets when you die and be sure that all assets don't go directly to your spouse and bypass what is stated in your will. You can set up your will to have a special needs trust within the will to take care of a special needs child. Do not leave your money to one person to assume that they will do the right thing and distribute as you wish. For example, one person left the money to a sister to give to the kids. The sister went bankrupt and all the inheritance was lost in the bankruptcy.
Q – If you are single with kids, does the IRA require distribution when you die and is it protected? **A –** An inherited IRA is not protected from bankruptcy. The beneficiary must take distribution within five years of death. Those distributions are taxable income, as they would be for the owner. If you don't name the kids as beneficiaries, then establish a trust to minimize taxes, control distribution, and protect from creditors.
Q – What is the overhead on a trust? **A –** A trust becomes irrevocable upon death and cannot be changed. A trustee takes a fee, usually 2.5% per year on funds coming into the trust and 2.5% on funds paid out of the trust. The trustee will have to apply for a tax ID and file a return on income earned. A bank or professional trustee charges more fees. The executor on a will is allowed to take similar fees based on the value of an estate.
Q – How is quality of life and quality of care handled in documents? **A –** The Power of Attorney (POA) for finances and healthcare name a person to make decisions for you. Living Will specifies the level of care you want. You can get these documents online, but they don't talk to you about your background and family relations that might impact your decisions. The POA can be given to some as guardian of a child, step-child, or spouse. Get documents in place before they are needed! When the need arises, it may be too late. Look at your resources and how to protect them. Carolyn said that she had an 88-year-old aunt who refused to prepare the documents. She always said "I'll know when I need it". She fell and needed to protect the value of her home from Medicaid. But it was too late and there was nothing left for her family.

Southside Multiple Myeloma Support Group
August 27, 2016

Doris led the group in a moment of silence. There were 21 present with no new members. Next month's meeting on September 24th we will be an opportunity for members to share.
Speaker- **R. Donald Harvey, PharmD, BCOP, FCCP, FHOPA**, Associate Professor, Hematology/Medical Oncology and Pharmacology, Emory University School of Medicine, Winship Cancer Institute. His topic: "Optimizing Drug Use in People Living with Myeloma". Gail introduced and welcomed Dr. Harvey. Dr. Harvey studies the mechanisms of drug therapy and is involved in conducting clinical trials.
Members introduced themselves providing insight of their MM status. **Kimberly**-diagnosed in 2008, after MRI of fibroids found a plasma cytoma on sacrum. She went through novel chemotherapy treatment (Revlimid/Velcade/Dex) and a Stem Cell Transplant (SCT); she is in remission and has some neuropathy; Kimberly is not currently on medications. **Larry** was diagnosed in 2013 after a car accident; tests showed MM—he had novel treatment with R/V/D then a SCT. He is now in a stringent complete remission (SCR). He is not on medication for MM but is taking Duloxetine 2x/day for neuropathy, 1 baby aspirin and medication for high blood pressure and high cholesterol. **Karen** is Larry's wife and caregiver. **Gloria** was diagnosed in 2014; went through novel treatment; then SCT; she is now on 5 mg Revlimid for maintenance and Alendronate, a bisphosphate like Zometa and Aredia**. Doris** was diagnosed in 2006, never had a stem cell transplant; she is currently on 25mg Revlimid. (Doris' sisters **Mary, Frances and Marie** were present to support her.) **Toanna** was diagnosed in April of this year after a visit to the emergency room; she is now treated at Emory Winship with Kyprolis, Pomalyst, and Dex. (**Ilksen** is her husband and caregiver); **Toanna** says she is considering using Tylenol as well for pain relief; Ibuprofen caused GI bleeding. **Pat** was diagnosed in 2004, had tandem Stem Cell Transplants and has been in remission ever since. She was scheduled for a PET scan last week; but, she did not have it because the medicine needed for PET was not at the Newnan clinic. **Yvonne** is a MM supporter, and a breast cancer survivor. **Gail** was diagnosed in 2008 went through 4 cycles of R/V/D, then a SCT; she had 7 years remission and is now on 3mg Ninlaro, 4mg Pomalyst, and 8 mg Dex. **Paulette** is her sister and supporter.
Dr. Harvey says anyone who treats cancer must have a passion for it. He noted that myeloma is more prevalent in black populations; though, not necessarily more aggressive. He says the role of the pharmacist is to support patients and make sure what the doctors and/or practitioners prescribe is provided. He says we must keep in mind, if we give

everyone the room the same treatment, i.e., 3 milligrams of Ninlaro, every person may respond differently. **Dr. Harvey** provided a wealth of information. He says there are a lot of options now for MM patients using monoclonal antibodies combined with standard drugs. Treatments that use 3-5 drug combination drug therapies are very popular due to the enhanced results achieved when combining drugs. Amazing differences have been realized with next generation drugs. Just small changes to drugs in the same realm have resulted in remarkable changes that benefit the patient. The FDA approved four new MM drugs in 2015; they include **Ninlaro** (ixazomib), **Daratumumab** (Darzalex), **Elotuzumab** (Empliciti), and **Pomalyst** (Pomalidomide). **Dr. Harvey** made the following points, some in response to discussions and questions from the audience.

- Make sure you take medications as prescribed; know if it should be taken with or without food. Also, some medications are best taken at certain times; for example: **Dexamethasone** (Dex) is best taken in the morning; if taken in the evening, it may cause sleepless nights. Revlimid and Pomalyst may cause you to fell sluggish and may be best taken in the evening.
- Hydration is extremely important during cancer treatment, particularly if on blood pressure medication (diuretics). Water is the preferred beverage to take medications. Try to avoid high sugar drinks and those with caffeine. Water is important to protect and keep kidneys flushed as well as keep calcium levels down. If you have kidney concerns, speak with your doctor—the amount of water may need to be moderated. Always track your kidney function (creatinine) each time on lab reports along with other important values determined by your health provider.
- Dr. Harvey says he considers MM is the diabetes of Cancer. MM affects so many parts of the body. Also, Dex or Prednisone can cause blood sugar to rise; so, carefully monitor blood sugar levels if you are diabetic.
- If you are on a bisphosphonate, be sure to advise your oncologist of dental procedures that may be planned. You may need to stop Aredia, Zometa or other bisphosphonates in advance of a root canal or other procedures. Osteonecrosis of the jaw could become a major concern.
- Bisphosphonates should be taken for at least two years after diagnosis or until bones are stronger. Scans can monitor the strength of bones.
- MM patients can maintain normal sexual activity when on chemotherapy; however, male patients should use a condom and female patients can use oral contraception. Be aware that some treatments, i.e., Thalidomide, Revlimid and Pomalyst have been documented to cause birth defects.
- **Tylenol** (Acetaminophen) is a very effective, overlooked pain reliever. It does not affect the stomach and kidneys as much, but in large dosages can affect the liver. He shared, at the recommended dosage, there are very few side effects compared to other pain relievers. Always follow the labeling on any over-the-counter (OTC) medication since they are proven to be safe and effective for use without physician consent when used according to the product labeling. It is always a good idea to double check with a doctor or pharmacist before starting any new medications to determine if the new medication is right for you based on your personal health and to make sure that no interactions will take place.
- One member shared her endocrinologist monitors her adrenal gland's production of cortisol as Dex may impact the natural production of this hormone. (Cortisol is a hormone that is released under stress.) Dex acts like the cortisol hormone and caution should be taken when used long term. Also, discuss gradual reduction in dosage rather that drastic reduction. If you have thyroid problems, you may also want to include an endocrinologist on your health team.
- **Know your numbers**-including Para-protein, IgG/IgA, free light chain-as well as other lab values. Be the best informed patient/partner in your care term as possible.
- **Dr**. Harvey stressed the importance of continuing appointments with your primary care doctor so any concerns can be identified early.
- **Cramps**-(Charley-horse). To reduce cramp frequency, stay hydrated. Include more foods in your diet rich in magnesium and potassium. Asparagus, bananas, leafy greens such as spinach, Swiss chard and kale, cantaloupe, white and sweet potatoes with skin on, citrus fruits, tomatoes, kiwi, papaya and squash are all sources of both potassium and magnesium. Aim to eat 5 servings of fruits and vegetables each day. Also, nuts and beans are good sources of magnesium and potassium. Gail asked about using a regular calcium tablet underneath the tongue for immediate release of cramps. Dr. Harvey said this was okay.

Dr. Harvey said approximately 30-40% of his time is spent working with MM clinical trial patients and the rest with other hematologic cancer patients. He says it is important for us to know that the development and approval of new drugs is not possible unless patients participate in clinical trials. Fifteen years ago there were no drugs specifically targeted for MM. During these 15 years there are 9 drugs approved for treatment of MM. Since we all may respond differently to treatment regimens it is important for African Americans to be included in clinical trials. Clinical trials are often available when patients are not responding to approved treatments. We have to continue to address concerns of

African Americans and the distrust of participation in medical research and clinical trials. Myeloma trials at Emory are proud of African American participation – 25-30% participation.

Mechanism of action for MM treatment regimens

Proteasome Inhibitors: These agents, including Kyprolis (Carfilzomib), Velcade, (bortezomib) and Ninlaro (ixazomib), interfere with the protein destruction required for myeloma cells to grow. Like a plug in a garbage disposal, proteasome inhibitors prevent the destruction of myeloma cells' unwanted proteins. Without that garbage disposal, the myeloma cells become saturated with unwanted proteins, go into metabolic paralysis and die. **Immune System Modulators**: IMiDs include Thalomid (Thalidomide), Revlimid (lenolidomide) and Pomalyst (pomalidomide), starve myeloma cells by cutting off their blood supply while at the same time rousing the body's disease -fighting T cells. **Monoclonal Antibodies**. Stimulate the immune system and increase its ability to attack cancers. Includes Empliciti (Elotuzumab) and Darzalex (Daratumumab). **Histone Deacetylase Inhibitor**. Targets enzymes involved in the regulation of gene expression. Includes Farydak (Panobinostat). **Steroids**: Dexamethasone and the other steroids are useful in myeloma treatment because they can stop white blood cells from traveling to areas where cancerous myeloma cells are causing damage. This decreases the amount of swelling or inflammation in those areas and relieves associated pain and pressure. More importantly, in high doses, dexamethasone can actually kill myeloma cells. When combined with other myeloma drugs, it can also make those drugs work even better. Dexamethasone and other steroids are sometimes used by themselves to treat the disease. Dr. Harvey says **"think of Dexamethasone like bacon—it makes everything better, but you don't want to get too much".**

Announcements

Shop for a Cause- We got $810 from Macy passes this year. Thank You.

Gail and Paulette are now Ambassadors for Ninlaro (Takeda). Ninlaro is an oral MM therapy approved in 2015 to be used in combination with Revlimid and Dexamethasone. They participated in training for this role in August and they will speak to groups as a patient and as a caregiver.

LLS – Light the Night –. RSVP – 404.720.7826 Join us for the 2016 Atlanta Light the Night Walk - Saturday October 8, 2016 04:30 PM EST Centennial Olympic Park at 265 Park Avenue West NW, Atlanta, GA 30313

LLS. Oral Therapies in Myeloma. Medication Adherence. http://www.lls.org/patient-education-videos/oral-therapies-in-myeloma-medication-adherence .

Telephone Support Groups. Cancer Care's telephone and online support groups are free and professionally facilitated. contact at 1-800-813-HOPE(4673). For online support group, register through the website at www.cancercare.org

IMF - Smart Patients is an online peer-to-peer program – to share MM experiences: www.smartpatients.com

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.