

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Northside Meeting

March 7, 2020

Northside Meeting

The Northside meeting opened with discussion about the virus news. Remember that this was the first week of March, before any impact on our way of life. We shared the information that was available at that time. We also talked about Myeloma Action Month. Several people submitted photos and stories of what Resilience means to them. Nancy collected the pictures and stories to make a poster of Resilience with the group photo at the top. It was posted in the library and will be there when we get back to our meetings in person. Nancy noted that there are several great action items for members to do to raise awareness of myeloma and maybe help someone be diagnosed sooner. One way to raise awareness is the Patient Action Letter to doctors. Click here: <https://mam.myeloma.org/patient-action-letter/> and scroll down to get the letter. Think about which doctors you can send it to – primary, chiropractor, orthopedist, physical therapist, or anyone else who might see someone with bone pain. Also, check out the Resilience photos at <https://mam.myeloma.org/>

We welcomed three new members as they shared their stories. Ulysses was recently diagnosed and scheduled for transplant in April. We all remember the overwhelming information and confusion when first diagnosed! Betsy was diagnosed last May and transplant last October. She is still within first year of diagnosis. Catherine was just diagnosed the first of this year and is trying to learn the terminology. We gave her some of the booklets to get started.

The group then separated into patient and caregiver sessions for more direct discussion.

Caregiver Session –

The caregivers let the new members drive the discussion based on their questions. Since one member was heading to a transplant within two months, that caregiver had lots of questions. The group shared experiences with transplants and warned that the paperwork to sign is very scary. They talked honestly about the days when the white count crashes and diet changes to keep calories going in. They talked about preparation of the home and the care after transplant. The group shared phone numbers with this caregiver to offer connection and support. Another caregiver said that they wished they had been to the group before their recent transplant. The patient had a very tough transplant but came through with a great attitude. Caregivers talked about the continuous stress and offered suggestions to each other about how to get help and find time for a break. Stress is unhealthy for both patients and caregivers. Take time to breathe and find an outlet. Meditation was suggested as well as “Moving Meditation” which is a focus on nature as you walk. Walk and be aware of your breathing; listen to the birds and other sounds; see the trees and flowers; and feel the air on your face. Be at peace and count your blessings, especially in these stressful times.

Patient Session -

The beginning topic for discussion was “When people look at you what don’t they see inside of you?” Or as some said what don’t people see when they look at you?

The first person said that people do not know you have cancer but see that you are tired, but not why you are tired. They might say it looks like you have lost weight, but do not know why. So, people see you, but do not try to find out why and pass judgement.

Another person discussed meeting someone for the first time and mentioning that they have cancer and trying to not make it out to be a problem or a stigma. People do not know what MM is and how it affects you.

Another mentioned having to try hard and to be resilient. People look at you like you should be able to do anything because of your appearance. But this also gives them hope because others look at them in a good light and makes them feel good.

Others liked it when people talk with them and do not make cancer the center of conversation because they look good. It makes them feel normal!

People look at them and think they should be able to do more. However, they are not stable and are in pain. But others feel that they are not as bad off as they are feeling even though their capabilities have diminished

Several said that when people say they look good they simply say, Thank You!

Some said do not change all your habits. Keep some old habits and work to keep some of your old normal while adapting to your “New Normal”.

Live well with the abilities we have.

Several agreed with the statement “I am glad I don’t look like what I have been through!” Stay positive and embrace your situation!

A newly diagnosed person asked how to deal with people who ask how they are doing or ask about their condition. They were not comfortable talking about where they were. Most people said it takes a while to become comfortable with your situation and to embrace yourself and your situation. It is a journey and some people are able to become more comfortable with their situation while others may take a while to embrace their diagnosis.

Another newly diagnosed patient asked how many others were aware and knew what it was before being diagnosed? No one said they had heard of MM before diagnosis. Everyone said it was a shock and some recounted the shock and depression after the initial diagnosis. It took time to understand and digest the diagnosis.

Everyone agreed that it is Very Important for everyone to be their own Advocate! Also, be very aware of Stress in your life. Many said that stress could have negative effects on their cancer

Submitted by Nancy Bruno

Southside Myeloma Support Group

Virtual Meeting Minutes
Southside MM Support Group
Saturday, March 28, 2020

Due to the state and national COVID-19 orders everyone to remain socially distanced, the Southside Atlanta MM Group held its first meeting in March 2020 via the “GotoMeeting” virtual meeting platform. The IMF (International Myeloma Foundation) supported the meeting with their

90-day subscription and training for Group leaders to ensure a smooth meeting. We scheduled the meeting for 90 minutes versus the usual 2 hours, from 10:00 AM – 11:30 AM. Leaders were on the line 30 minutes early to work through potential problems prior to the start time. We had about 25% who used the telephone-only for connection. Others used the computer. Some may need to use telephone for sound with computer screen for any visuals to reduce background noise.

Next Meeting: April 25, 2020, The Role of Imaging in Myeloma Diagnosis and Treatment, Vermell Samford, N.P. (retired)

There were a total of 23 people on the call. We were excited to hear from **Patt**, who moved to the San Francisco area over 4 years ago but remains in touch through our monthly newsletters and Paulette's email communications. We were delighted to be joined by **Sally**, who cannot attend our meetings in person due to illness.

Our agenda for this meeting was to find out from our members how they were coping with this unprecedented, very contagious virus, and its impact on their daily lives as individuals, families, myeloma patients, and caregivers. We also wanted to provide some important information and resources for practical use.

First, **Gail** welcomed everyone and took roll call. She gave a quick overview of the numbers of COVID-19 as it relates to Georgia, the nation, and reports from the IMF about the mortality of myeloma patients from the Asian Myeloma Clinical Trials Network, (AMN), the Japanese Myeloma Network, Shanghai, Beijing, Singapore, and South Korea. The International Myeloma Working Group (IMWG) have reported no myeloma deaths, likely because myeloma patients stayed home. She encouraged everyone to remain **physically distanced** but enhance social connectedness.

Doris led a moment of silence for us to acknowledge the sadness of this time. People are suffering physically, emotionally, mentally, and financially. There are some in assisted living facilities, and some who have passed away during this time. Families and friends cannot grieve and support each other in their usual ways. We will express gratitude for all that we are and all that we have.

Vermell, N.P., gave an overview of COVID-19 and Myeloma. What should you

Consider? You first shared the number of cases and deaths as reported the same morning. New York City has taken over as the epicenter of the pandemic from Wujan, China. Georgia has the 5th highest incidence (new cases) in the nation. Saturday, March 28, 2,188 cases, and 61 deaths (~3.0%) — growing everyday (those numbers for April 18, 2020 are 18,301 cases, 687 deaths or 3.5% - from GA DPH). In about 24 days, the numbers grew by almost 120% even with the shelter-in-place edict.

Vermell gave us a brief background on coronaviruses. This is a class of viruses called “corona” because under the microscope, it looks like there is a ‘crown’ on the viruses. There are hundreds of these viruses, but primarily 7 of them that affect humans. Viruses affect our Upper Respiratory Systems. Most of us remember **SARS – CoV**. SARS (Severe Acute Respiratory Syndrome) started in China in 2002. **MERS** (Middle East Respiratory Syndrome) started in Saudi Arabia in 2012 and is thought to come from camels. These diseases are called **zoonotic**. These are viruses that can commonly affect animals, like birds, bats, camels, and pigs. The virus can “jump” species, transmitting disease from animals to humans, through direct or indirect contact.

SARS-CoV-2 causes COVID-19. We are still learning a lot about this virus, as we try to prevent transmission. Is the transmission mostly through droplets? Is it airborne? Symptoms of COVID-19 include, cough, fever, shortness of breath, and fatigue. Other symptoms can include nasal congestion, sore throat, and headaches. We have to stay current on new information and abide by the science to avoid transmission.

Vermell went through some of the questions from Dr. Durie – top 10 Questions related to COVID-2. Below is a Summary of Action Items from IMF based on those Questions. She also told us the good news that a 102-year old in Italy has survived the virus.

Action Items for Myeloma Patients Now – (See link in resources below)

- Make all **routine contacts by phone, email, or telemedicine**. (With [the FDA's recent approval](#), even your pet's veterinarian visits can be done via telemedicine.)
- **Avoid grocery shopping** by ordering groceries delivered (if possible). The link for a suggested YouTube video is below for unpacking delivered groceries safely at home.
- Make sure you have a **clear treatment plan** in place with your doctor for the next few months.

Topics to discuss with doctor:

- NO visits to the clinic unless essential for ongoing infusions or urgent care.
- Can you skip Aredia or Zometa infusions for now?
- Can any medicines be switched from IV/shot to oral? For example, maybe Ninlaro can be used instead of Velcade or Kyprolis?
- Can the dexamethasone dosage be reduced right now to reduce risks of infection?
- Any planned ASCT (autologous stem-cell transplant) should be delayed.
- Can you continue in a clinical trial? Can some parts be delayed or given locally? A new trial will probably not be started now. It may be necessary to use a bridging therapy (using combination of approved drugs) for relapse therapy for now.
- There may be special questions depending upon your own situation. Please make sure your concerns and/or questions are answered! Remember that each patient's situation is different.

Paulette provided us with a list of easy, common sense ways to increase our protection from this virus.

1. Stay home whenever possible.
2. When you have to shop, take advantage of the early morning designated hours at supermarkets, Walmart, and pharmacies for those at higher risk for contracting the virus – over age 60, immune compromised, etc. Cleaning takes place overnight, so fewer people have touched items and other surfaces. The downside: If you like fresh baked goods or ready-made items like rotisserie-chickens, they will not be available.
3. Wear an outer layer of clothing that can be removed carefully and washed before it comes into the main areas of the house.

4. For grocery items – pantry items, etc., leave them outside the house for a few hours or the next day, so any possible droplets can lose their power.
5. Do self-check at the counter. Have as little personal contact as possible. Paper money is extremely dirty. Clean your debit/credit card after using. Virus can remain airborne for up to 3 hours; stay on plastic, like grocery cart handles or food wrap for 72 hours; on cardboard for 24 hours; and on stainless steel for 72 hours; and on glass for up to 96 hours. (JAMA)
6. Clean your surfaces frequently with soap and water, wearing gloves.
7. Try out the delivery services. This is a good time.
8. Get the 90-day supply of whichever medications you can. We have been warned to keep a 30-day supply of medications on-hand in case of emergencies. We thought maybe hurricanes, like Katrina, floods, fires. Now we have a pandemic to teach us how to create that supply.

Others in the group shared how they were negotiating live with COVID-19.

Darcel said that she has been in remission for 7 years. She was only on acyclovir – no other medications. She discontinued it in January and is concerned about shingles. *She should consider the new shingles vaccine, Shingrix – and be sure to get the two dosages; Pat C.* reminded those of us who have a port to get it assessed on a regular basis to avoid infection; if we have regular lab tests scheduled, should we get them? *Discuss this with your doctor, but any routine lab work might be cancelled. You might also ask for a review of your dosages of medications. Please also see the list of action items from Dr. Durie;* Darcel also talked about allergies and COVID-19. She has a supply of masks to protect from pollen. The recommendation at the time was not to wear masks (that has since changed and masks or face-coverings are now strongly recommended). Also, there is a need to clean fabric surfaces. One has to be careful about bleach on car fabrics and others. Some cleaning products to substitute when stores are out include white vinegar and baking soda; new members **Sheila and Ulysses** – are scheduled for Stem cell transplant (SCT) during this period and wanted to hear from others who had experienced it. We reminded them of the IMF's recommendation to delay, still noting that every patient has different needs. Any visitors – and so support -- would be limited. **Sally** reminded us about the different experiences of patients going through SCTs, and that for some it was a very challenging time; **Gloria** shared that she was now working her part-time job remotely, learning Spanish, and strengthening her relationship with God; **Carole** encouraged us all to move more – take advantage of this time to improve health. Reading, singing, cleaning and reducing clutter are also high on the list of pastimes. While COVID-19 was not on the radar when the theme of Resilience was chosen for Myeloma Awareness/Action Month (MAM), we are all showing and learning more about resilience daily. Gail did write an article about myeloma – with emphasis on Myeloma and African Americans for the Georgia CTSA/Morehouse School of Medicine newsletter, March 27, 2020. Gail led a relaxation, deep breathing, mindfulness exercise to end the session. Deep breathing has many health benefits. It increases calm, decreases stress. It increases the immune response and helps to decrease pain. It lowers the blood pressure, increases energy, and helps to improve posture.

The COVID-19 pandemic is a very serious and unprecedented challenge to the global health of the planet. It is affecting each of us and our families' and community locally with frightening symptoms and economic challenges. Many of us are feeling great anxiety and uncertainty. The **good news** is that there are always unforeseen gifts and the opportunity for beneficial

transformations that take place after a crisis. Look for those “silver linings” and gifts.

Resources/Announcements/Upcoming Events

- **Number of COVID-19 Cases/Deaths.** Daily Report. Georgia Department of Public Health. <https://dph.gia.gov/covid-19-daily-status-report>
- **Safety Ideas for bringing Groceries into House.** Revised. Jeffery vanWingen, MD. https://www.youtube.com/watch?v=zmoBl5m2_uw&feature=youtu.be
- **Action Items for Myeloma Patients – COVID-19.** Dr. Durie’s blog. March 26, 2020. <https://www.myeloma.org/drdurie-blog/covid-19-collaboration-resilience-are-paying-march-26-2020-update>
- **How Long does Coronavirus stay on surfaces?** USA Today, NEJM, JAMA. March 25, 2020. <https://www.usatoday.com/in-depth/news/2020/03/25/coronavirus-survives-on-metal-plastic-cardboard-common-objects/2866340001/>
- **Chair Yoga with Adrienne** - <https://www.youtube.com/watch?v=-Ts01MC2mlo>
- **Mental Health** – CDC - <https://www.cdc.gov/mentalhealth/index.htm>
- **LLS** – all myeloma patients are eligible for \$250 COVID-19 grant. There is no income requirement. www.lls.org or 1-800-955-4572
- **Census 2020.** Complete your Census form and remind others to be counted.

Respectfully submitted, Gail