

August 2018

**Northside Multiple Myeloma Support Group Meeting  
August 4, 2018**

The August meeting was our annual luncheon, sponsored by Takeda. Nearly 70 people attended.

Before the program, Nancy noted that the group would need to re-print our brochure since we have changed location. While we are re-printing the brochure, this would be a good time to change our name. Nancy was talking to a patient on the phone about the group. The patient said that she was not ready for a “support group”. After talking about the group and the shared experiences for this cancer that is different from the others, the patient said that she did not realize how valuable the sharing would be. She had a predefined vision of a “support group” that was not what we actually do. So, think about this opportunity to change our group name. What would better describe what the group does for patients and caregivers? We will send out a survey in the next week or so asking for your input and thoughts. In addition, Nancy will be having a fundraiser for the support group to raise funds for printing the brochure and other outreach efforts.

Elizabeth Carter, RN, BSN, OCN, Nurse Educator for Takeda, spoke about Ninlaro at the August luncheon. Only a couple of people in the group are on Ninlaro. Elizabeth was explaining about Ninlaro, which is a proteasome inhibitor. It is similar to Velcade but is an oral treatment. With Revlimid and Dex, that all-oral protocol can reduce trips to the clinic.

Proteins build up faster in myeloma cells compared to normal cells. The proteasome acts like a garbage disposer that gets rid of these proteins in the myeloma cell. The drug class of proteasome inhibitor interferes with the garbage disposer and causes the proteins to build up in excess and the myeloma cell dies. The FDA approval for Ninlaro is conditional and can only be prescribed if the patient has received prior treatment. Some doctors believe that a patient must relapse on a prior treatment before they can get Ninlaro. Relapse is not required. Elizabeth is working to educate the doctors and nurses about this difference. Ninlaro has similar side effects to Velcade and those must be discussed with your doctor. Elizabeth stressed that the schedule for taking Ninlaro is important and should be followed closely.

After the program, Elizabeth read a poem. Several in attendance wanted it re-

printed in the newsletter.

## LOVE AFTER LOVE

By Derek Walcott

The time will come  
When, with elation,  
You will greet yourself arriving  
At your own door, in your own mirror,  
And each will smile at the other's welcome,

And say, sit here Eat.  
You will love again the stranger who was yourself.  
Give wine. Give bread. Give back your heart  
To itself, to the stranger who has loved you

All your life, whom you ignored  
For another who knows you by heart.  
Take down the love letters from the bookshelf,

The photographs, the desperate notes,  
Peel your image from the mirror.  
Sit. Feast on your life.

### **Southside Multiple Myeloma Support Group Meeting August 25, 2018**

**September Meeting Speaker: Kendelle Miller, LCSW, ACM, Clinical Social Worker, Emory Winship Cancer Institute and Tricia Hernandez, Senior Manager – Patient Access, Leukemia and Lymphoma Society, Georgia Chapter.**

Our August meeting was a special breakfast meeting hosted by TGI Friday's at Camp Creek Marketplace. We truly appreciate their service to the community, and that they often provide breakfast meetings for our Support Group. Gail asked the group if they would complete a health survey from Morehouse School of Medicine's CA CTSA (Georgia Clinical and Translational Award) Program. The purpose of this 5-10 minute survey is to collect opinions from Georgians on what health issues they feel are important. All completed the survey – and we promised to send copies via email for others to distribute to their own networks. The surveys can be completed online.

We were fortunate to have two speakers, psychiatrists on the faculty and in practice at the Morehouse School of Medicine. This husband and wife duo have been friends and supporters of the group for many years, brought to us initially by member Rev. Arthur Lewis, about 10 years ago. Our group has had a number of deaths this year among our Support Group Family – patients, caregivers, and friends. We felt we needed to improve our skills in coping with grief – whether for ourselves or others – whether the grieving is for a death, illness,

finances, or some other loss. Drs. Gail Mattox and James McCoy led the group in an interactive session on “**Building and Sustaining Resilience: Coping with Grief.**”

**Dr. James McCoy** talked about the importance of maintaining balance in our lives. He assured us that loss of a loved one is one of the most stressful events in our lives and can cause a major emotional crisis. Grieving, feeling sad, and spending time in mourning is perfectly normal and expected. Everyone does grieve differently, and we must allow for our differences. Before Dr. McCoy became credentialed in psychiatry, his specialty was cardiovascular surgery. With those combined specialties, he has come to appreciate fully the connection of the health of our mental and physical selves – our heart, blood vessels, and cardiovascular system are intimately interwoven with our mental and emotional well-being and our overall health. He has witnessed the pathology/effects of unbalanced lives – distress, lack of exercise/poor nutrition, etc. on the cardiovascular system. Many people report physical symptoms that accompany grief. Stomach pain, loss of appetite, intestinal upsets, sleep disturbances and loss of energy are all common symptoms of acute grief. Of all life's stresses, mourning can seriously test your natural defense systems. Existing illnesses may worsen, or new conditions may develop. Profound emotional reactions may occur. These reactions include anxiety attacks, chronic fatigue, depression and thoughts of suicide. An obsession with the deceased is also a common reaction to death. However, the body is marvelously made – and is resilient.

Dr. McCoy stressed the importance of self-care in all aspects of our lives. He shared a handout with us that showed the six dimensions of wellness in a circle (Bill Hettley, Co-founder of the National Wellness Institute). Those six dimensions are: **Physical** -Exercise/nutrition; **Intellectual** - regular reading and learning something new; **Spiritual** - some relationship to a power higher than ourselves; **Emotional** - as humans, we must nurture Love – deliberate and intentional; **Occupational** – always have some work, whether paid or volunteer; and, **Social** – at the time we are grieving, we often pull back from social connections. We might get angry with God. It's a time to keep those connections -- friends, family, church members, Support Groups. Maintain connections with people who care and can help to put your problems into perspective. When we maintain balance in our lives, we are less likely to suffer the ill-effects of grief. He spoke of the importance of this balance for all of us – caregivers, patients, and supporters alike. In each part of the circle, take care to stimulate intentionally. Set wellness goals in each area.

**Dr. Gail A. Mattox** (Professor and Chair of the Department of Psychiatry, Morehouse School of Medicine) took us back to basics. **Resilience** is the “occurrence of rebounding or bouncing back.” Resiliency is like a rubber band that can be stretched almost to the breaking point. Instead of snapping, it springs back into shape. She talked about the five stages of grief. The stages do not occur in any order – and you might repeat stages at any time. You do not have to go through each stage in order to heal. Give yourself permission to grieve – and know that it is okay. There is no time limit on your grief – it may be days, months, or years. Do go back to the well-being/coping and balance in your life. **Remember:** It takes time to fully absorb the impact of a major loss. You never stop missing your loved one, but the pain eases after time and allows you to go on with your life.

#### **Five Stages of Grief**

**Denial:** “This can't be happening to me.”

**Anger:** “*Why* is this happening? Who is to blame?”

**Bargaining:** “Make this not happen, and in return I will \_\_\_\_\_.”

**Depression:** “I'm too sad to do anything.”

**Acceptance:** “I'm at peace with what happened.”

**Do not ask** those who are grieving, “*How are you feeling?*” Instead ask, “*What can I do to help?*” The person in need must also be open to receiving love. You must know that “*I am not*

alone in this process.”

**Some tools you can use include a daily practice of:** singing a song that uplifts you; find a favorite quote to recite; engage in meditation; watch something humorous; or Hug somebody. You can even hug yourself. Hugs help to release hormones that can help lift your spirits. Others in the Group shared their strategies: only be around positive people – no negative people or situations (Vena), stay busy – exercise, volunteer (Carole and Jameca), or play some music (Carole). Do not hesitate to make a call for help – conversely, you can offer -- “*I’m coming over*”; “*I’m here for you*”; or “*I am happy to just listen, if you would like.*” If someone you care about has lost a loved one, you can help them through the grieving process.

**Share the sorrow.** Allow them — even encourage them — to talk about their feelings of loss and share memories of the deceased.

**Don’t offer false comfort.** It doesn't help the grieving person when you say, "it was for the best" or "you'll get over it in time." Instead, offer a simple expression of sorrow and take time to listen.

**Offer practical help.** Baby-sitting, cooking and running errands are all ways to help someone who is in the midst of grieving.

Dr. McCoy gave the group homework. He asked each member of the Support Group to complete a **Resilience Plan** to be submitted to him by **September 15**, submit them to Gail McCray, who will get them to Dr. McCoy. The forms to use will be sent again by e-mail. Let Gail know if you need one.

### Announcements/Upcoming Events

- **Light the Night**, the annual event and fundraiser of the Leukemia and Lymphoma Society is fast-approaching. The culmination event will be on October 6 in Piedmont Park. Doris has made things easy for the Support Group. You can contribute through the special website or contact Doris, if you would like to arrange another form of payment.
- There are two upcoming **Health Fairs** for which we need volunteers: (1) **Saturday, September 29, 2018 at Camp Creek Church of Christ** from 9 am until 2:00. (Location: **2400 Merk Road, SW Atlanta, GA** ); and (2) **Our Lady of Lourdes' Health Fair, Sunday, November 4th from 9:30 am – 2:30 pm.** 25 Boulevard, NE, Atlanta, GA 30312.
- **Town Hall Meeting: The Proactive Myeloma Patient: Putting key Myeloma Research and Treatment News into Perspective.** Sunday, September 23, 2018. Hyatt Midtown. 10 AM. You may attend in-person or online. Register at: [www.patientpower.info/mmsept23](http://www.patientpower.info/mmsept23) or telephone **1.888.739.3127**. Will feature a **live Q & A Session** for patients and caregivers. Produced by Patient Power with Winship Cancer Institute of Emory University. 125 10<sup>th</sup> Street, Atlanta, GA. 30309. Free parking is provided.
- **MMRF - Fall Webinar Series: 1. Evaluating treatment options for relapsed/refractory patients. September 5 @1:00 ET.; 2-Caregivers: An essential part of the myeloma care team; 3 - Multiple Myeloma in African Americans: Staying informed about risks and care.** Register online or call 866.872.5840
- **IMF - Stand up to Cancer (SU2C).** New project to model population study in Iceland. For Myeloma patients over age 45 and African-Americans -- with first degree relatives (Mother, Father, Sister, Brother) who have MM. We learned a bit more about this project – it is a \$10 million-dollar effort to be led by a “Dream Team” of Myeloma specialists. We (Atlanta Southside Support Group Leaders) have expressed our interest in being very involved.
- **African Americans and Myeloma.** The IMF has established a **Diversity Communications/Planning group** to raise awareness among African Americans and others about Myeloma. A new brochure was introduced in July, and it featured our own Jameca Barrett, among others of African descent across the country. Please lend your talents and your voice to this effort. Email and request to be added to the Group: [diversity@myeloma.org](mailto:diversity@myeloma.org)

- **LLS. Funding Updates.** There are two travel assistant programs for patients. Susan Lang Pay-It-Forward Patient Travel Assistance Program for Myeloma and the General Fund. Neither is accepting applications at this time. **Check back to see if more funds have become available.** LLS has changed from a 12 month to a 6-month award period, allowing patients to potentially receive assistance twice in a 12 month period, if funding is available.
- **Free rides for cancer patients. Lyft partnering with American Cancer Society through its Road to Recovery Program.** Call 1.877.277.2345. Must call at least three days before appointment.
- **LLS.** Patients and Caregivers may get one FREE Nutrition Consult. (800) 955-4572 or provide your name for email.

Respectfully submitted, Gail

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Southside Multiple Myeloma Support Group – Southside group meets at 10:00 on the fourth Saturday of each month in second floor Meeting Room at the Macy’s on Greenbriar Pkwy. Doris Morgan 404-346-1372; dorismorgana@aol.com , Gail McCray 770-996-4964; mccray@aol.com web site: [ssatlanta.support.myeloma.org](http://ssatlanta.support.myeloma.org)

**Southside Meetings: 9/22/2018; 10/27/2018**

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**Northside Meetings: 10/6; 11/3/2018**

Meets 11:00 AM on the 1st Saturday of each month

**New location starting in July ----**

**Shallowford Presbyterian Church**

**2375 Shallowford Rd.**

**Atlanta, GA 30345**

**[mmsg.org](http://mmsg.org), email: [aammsg-2@comcast.net](mailto:aammsg-2@comcast.net)**

*For additional information, contact:*

Nancy Bruno 404-374-9020;

Sandy Brown 470-514-5330

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.