

August 2013 Meeting News

Business & Announcements

Joe and **Tom** co-hosted the meeting. Over 40 people attended. Local support group leaders **Doris**, **Joe & Sandy**, and **Nancy** recently attended an IMF Summit where **Dr. Durie** announced that there will be a cure for myeloma within the next 5 years! Technology has drastically improved communication between doctors and the ability to share research results.

Jim is part of the advocacy support group in Atlanta that supports the **drug parity bill for GA**. If you wish to join **Jim** and others at a district meeting please contact **Jim** and/or sign up at a meeting. Currently 26 states (not GA) have passed the parity bill, which specifies that certain cancer drugs are no longer more expensive than other cancer drugs simply because they are administered orally. The goal is to have GA become one of the states that has passed the bill in 2014. In support of cancer drug parity, IMF-sponsored postcards are available at meetings. If you have signed this form in prior years, it must be done again, and please take additional forms to get signatures from other registered voters in your community. The signed forms can be returned at meetings.

New Members

The group welcomed **Rolf** and his wife, **Phyllis**. After his primary care physician noticed abnormalities from his blood test, **Rolf** was sent to another doctor and was diagnosed with MGUS in 2009, with 10% plasma cells discovered in bone marrow. He was monitored every six months but did not begin any treatment. Then, in March 2013 an increased IGG level was found, and an increase to 15% plasma cells was noted, and a diagnosis of smoldering myeloma was made. Rolf explained that he feels fine and has no pain or bone involvement. He is in the process of gathering opinions and options from multiple facilities relative to potential treatment and has found the results to be astonishingly different, which is one of the reasons he and Phyllis wanted to join the group – to learn from others who are experiencing the same thing and how they are positively coping. **Vinnie** explained that he has had smoldering myeloma for 10 years, and has only taken Curcumin with good results. Others mentioned that they have, or know someone who has had smoldering myeloma for many years (18) before progressing, or not progressing. Also joining our group this month was **Beth** who was diagnosed in 2007. Beth is a runner and had been experiencing pain in her hip. She was also losing her appetite and weight but felt fine otherwise. A sports medicine doctor noticed that her MRI looked unusual and was sent to an oncologist who found her to be extremely anemic with 3 broken ribs and 95% plasma cells in her bone marrow. Beth began Revlimid, Dex, and Velcade immediately and obtained remission and felt better. She considered a stem cell transplant and got very different opinions on a transplant from various doctors ranging in tandem, combination autologous and allogeneic, single, and none at the time. She opted to postpone transplant then and did well, remaining in remission for 3 years. She became very anemic again and 1-1/2 years ago opted for a single autologous stem cell transplant, resulting in a full remission and feels great. For maintenance she is taking Revlimid daily and a Velcade shot weekly with no side effects or neuropathy.

Meet Your Members

Thank you to group member **John** who shared a deeply moving story of his family's journey before and after his wife, **Kimberly's** myeloma diagnosis; and how they've gained new strength and perspective along the way. In 2004, John and Kimberly, who have 5 children, relocated from CA to GA. In 2005, their daughter was shot and killed in an accident, and Kimberly went into a deep mourning period. John mentioned that while Kimberly mourned deeply to the point of having self-

destructive thoughts, John felt numb and tried to focus on taking care of his family. Kimberly eventually took a job caring for babies who were developmentally delayed. Along the way, Kimberly was diagnosed with plasmacytoma which was not eradicated with either radiation or chemotherapy, and so she had a stem cell transplant in 2009. Prior to the stem cell transplant they were worried about their son who is autistic and who was in 8th grade at the time. Their son stepped up to the challenge and did a great job with his new responsibilities taking care of not only himself, but also his parents; providing his parents with a new understanding of his capabilities and level of independence that was achievable, which they've now learned to encourage. Kimberly is in remission now and doing well. John said that his wife's diagnosis drove him to get more involved in social justice issues, believing that if you can do something that will make things better, then you will ultimately also become better. John has become involved in the presidential gun control campaign along with his wife and son. He shared a picture of Kimberly who was honored by a fellow member who admired Kimberly's progress.

Updates & Discussion

Sandy shared news of members to keep in your thoughts and prayers. **Tim**, who has had myeloma for 18 years, and has been on Velcade for 8 years is not doing as well as before and is considering other options. **Mary** was on a clinical trial at MD Anderson that didn't work for her and is now in hospice care. **Pat** was diagnosed in 2004, had tandem stem cell transplants at Northside in 2005 (not a bad experience), and has been in remission since. She gets Zometa quarterly but is not on other drugs. She suggests getting a lot of advice and understanding all options before making decisions in order to make the best decisions for you. (A different) **Pat** shared that she was diagnosed 4 years ago and was very sick in the beginning. She was considering a stem cell transplant, but ironically had just attended a group meeting where 3 people told of their experiences with stem cell transplants without good results and it turned her off from the idea. After enduring 3 years of medications with some serious side effects she revisited the idea and decided to have a stem cell transplant. She chose Northside because she had worked there for 14 years. After one transplant, a 75% overall improvement was achieved, and a second transplant was suggested. Pat opted for that and had a second, and has now achieved a full remission. She is currently on maintenance using POMALYST (pomalidomide), with no side effects. **Joe** is doing well and celebrating post-transplant success. Joe has opted for maintenance with Revlimid and Dex due to genetic issues. **Virgil** is doing well and walking well again since having to relearn to walk from an illness earlier this year. **Dana** has been on a clinical trial at Emory since March using Dex and ARRY. A few members had questions: **Loretta** asked if anyone else has experienced discomfort from a bone marrow biopsy years later? No one had. **Bernie** asked if anyone in the group with myeloma also had a sibling with myeloma. A few had, or knew of siblings both having myeloma. Others responded that not a lot is known yet about the genetic components of myeloma, but a lot more research is being conducted on this topic. **Jim** offered a tip for those who choose not to be sedated during bone marrow biopsies. Ask for the drill mechanism rather than the crank. Also, when the device is being removed, ask them not to pull the plunger fast, all at once. Instead, request that it be pulled slower, more gently, a little at a time with is much easier to tolerate, far less painful. Or, if you chose to be sedated, and can still feel anything ask the provider to "hit the meds again" and they will do so to make you more comfortable. **Bob** recommended a [myeloma survival website](http://myelomasurvival.com/) (<http://myelomasurvival.com/>) with an interesting blog and mentioned a study done that explained how where you lived could affect your survival outcome, with those having access to major myeloma centers generally doing better than average.

Submitted by Wendy