

September 2009 Meeting News –

New Members

The group welcomed **David and Gloria**. David was diagnosed with myeloma in April 2009 after experiencing back pain. He went to his doctor a few times prior to being diagnosed. He eventually went to the emergency room one day when he couldn't get out of bed and it was discovered then that he had kidney failure and three broken vertebrae. David has since had kyphoplasty to repair the broken vertebrae and is currently taking Velcade, Doxil, and Dex. He is on his third cycle of Velcade and has not experienced any neuropathy to date. He has also tried Revlimid, but was unable to tolerate it.

Business & Other Information

Nancy led the meeting. Approximately 27 members were present. Nancy mentioned that some upcoming program plans are in process, including a nutritional guest speaker as well as guests from Proteolix, inventors of the drug, Carfilzomib. Also mentioned was the MMRF Race for Research in Atlanta on November 1, 2009, starting at Manuel's Tavern.

Member Updates & Collaboration

With sadness the group acknowledged that one of our members, **Drew**, has passed away. Condolences are expressed to Drew's wife, **Charlene**. **Nancy** heard from **Juanita**, who is doing well and mentioned that she appreciates receiving the monthly newsletter. **Carole** reported that her husband, **Raphael** began a therapy called VTD-PACE (Velcade / Thalidomide / Dexamethasone) (Cisplatin, Adriamycin, Cyclophosphamide, Etoposide) at the end of May. Raphael has used this treatment before with good results. Current results are pending as the treatment is still in process. **Virgil** mentioned that while going from his third to fourth round of Velcade, he experienced severe neuropathy pain and he has used an over-the-counter lanacane cream combined with support hose, which have helped a lot to control the neuropathy. **Bill** is doing well. Bill had been taking 25 MG of Revlimid with Dex, which was working, but then stopped taking the Dex and the myeloma became less controlled. He has since re-added the Dex with better results. Currently the myeloma is being held, but not reduced. Since the myeloma numbers are still very low he plans to continue with this regimen for now. **J'mee** mentioned that she has recently changed doctors. She had been going to the Mayo Clinic in Jacksonville, but it is no longer an option with her insurance company to continue going there. J'mee will now see Dr. Hefner at Emory, where she has an appointment scheduled for the very near future. **Kimberly** is preparing to begin Neupogen injections in mid-September in preparation for a stem cell transplant at Northside. **Sharon** reported that she had been on Carfilzomib for seven months with a 60% reduction in myeloma after three months, but it eventually stopped working. Sharon mentioned that Carfilzomib is a drug that is very hard on the body and on the kidneys. While she was on it, her red blood cell count was very affected and she experienced anemia. She took Procreit and had to have blood transfusions, and she was extremely exhausted constantly. Sharon also mentioned that a second phase Palinomide trial is expected to begin at Emory soon. Palinomide is considered a second generation of Revlimid and third generation of Thalidomide. Also, fewer problems are expected with the Palinomide than what was experienced with Revlimid. **Al** reported that his father, who is 88 years old and diabetic experienced a very serious reaction when on Velcade while also taking the oral drug, Glucotrol, used for diabetes control. Al's father became unresponsive and was taken to an emergency room where he was given glucose and fluids to normalize his blood

sugar levels. Al noted that the Velcade has actually been working very well for his father's myeloma and has been otherwise well tolerated. The good news is that he has been able to continue on a lowered and less frequent dose of Velcade while also continuing to take the Glucotrol, but not at the same time as the Velcade. Al expressed that he especially wanted anyone else who is diabetic and taking Glucotrol to be aware of this ***potential drug interaction!***

There was a lot of discussion surrounding the group's understanding and experiences with Medicare, Medicaid, supplemental Health insurance, disability, social security; and eligibility with the various plans. Many in the group provided valuable information about their personal experiences, and it became very apparent that the many personal variables makes it difficult to conclude and interpret rules and regulations in order to determine the right mix of options and eligibility for individuals. It was discussed that this would be a good topic for guest speakers at future meetings. In the mean time, there are web sites and social workers that may be able to assist with specific questions and needs.

Various members had other questions that were posed to the group for their assistance as follows:

Q: Is there anyone else in the group who has had an unsuccessful stem cell transplant?

A: The group noted that there are some members who have had unsuccessful stem cell transplants and also some others with short-lived beneficial results.

Q: Does anyone understand the myeloma staging process and how it is used?

A: The general consensus seemed to be that currently not much emphasis is placed on the staging process from a treatment perspective, with the exception of smoldering versus active myeloma (since smoldering myeloma generally is not treated). Some members mentioned that their doctors had told them not to be overly concerned with the current staging system.

Q: Does anyone know if unused medications can be donated for use by others?

A: Some in the group mentioned that unused medication can be collected to send to other countries. Others noted that some pharmacies will collect drugs but it is for the purpose of disposal, rather than reuse.

Q: Has anyone experienced vision problems with some of the chemotherapy drugs, and specifically with Velcade?

A: Some in the group have experienced vision problems that they know were associated with Dex. Others have experienced changes in vision but it is difficult to determine which drugs may be the culprits. Since often Dex is taken in conjunction with other drugs it is difficult to isolate the side effects to any single agent.

Submitted by Wendy