

## February 2011 Meeting News

### **Business & Other Information**

**Joe** led the meeting. Approximately 40 people attended the meeting, and there were no new members present. **Donnesha**, a student from GA State University attended the meeting as part of her research for a project about support groups.

### **Guests**

A big thank you to **Andy**, one of the founders of our group, who attended the meeting to provide information about the International Myeloma Foundation (IMF) (<http://myeloma.org>) Andy is currently employed by the IMF, and travels around the country setting up support groups nationally; and visits over 30 groups a year. The IMF was started in 1988 by Brian Novis who was diagnosed with myeloma at the age of 36. It was officially founded in 1990, and its mission is to improve the quality of life for myeloma patients while working toward prevention and a cure. The four main areas of focus are education, support, research, and advocacy. Its global reach is 113 countries and there are over 195,000 members. A toll-free hotline exists and you are encouraged to use it when you have questions or need assistance: 1-800-452-2873. The IMF also conducts seminars and produces publications regularly – examples follow.

### Annual Seminars Include

- ✓ 8 International
- ✓ 4 Domestic – comprehensive two day seminar, with average attendance of over 200. Each year one of the seminars is filmed and becomes available on DVD.

### Publications Include

- ✓ Myeloma Today (quarterly)
- ✓ Myeloma Minute (weekly email)
- ✓ Information packages
- ✓ Annual CD – contains all IMF publications in PDF format (can be downloaded from IMF website)
- ✓ Clinical Trial Information
- ✓ Other publications for doctors, nurses, etc.

Andy also explained what to expect at the Regional Community Workshops, which were initially started for smaller cities, where patient/family seminars are not held. The workshops are held in classroom type settings, and some of the best myeloma doctors in the area and in the country are present. They have been successful, and as an example, a recent workshop in the Raleigh-Durham area resulted in over 100 attendees and spawned three new support groups.

### **Member Updates & Collaboration**

**Sandy** provided an update on **Milton** who had a stem cell transplant in September. Milton has learned that the stem cell transplant did not work, so he is now deciding on next steps. **Bill** reported that he plans to begin a clinical trial for oral Velcade, for which less neuropathy is expected. **Debra and Lou** reported that Lou had a stem cell transplant about a month ago. He is feeling good and eating well. **Chuck “Chaz”** is planning for a stem cell transplant in March. **Andrew** reported that he

is in remission and is currently not on any maintenance drugs. **David** had an allogeneic (donor) transplant in August 2009. David's brother was the donor for the transplant. David has experienced graft-versus-host disease since the transplant. He is in remission from myeloma and he is working on getting off Prednisone (a steroid) by tapering the dose. Much of the general discussion surrounded the importance of having a good rapport with a doctor that you like and trust and who is willing to negotiate with you to determine your best care as an individual. Various members discussed the importance of second opinions and/or changing doctors. **Andy** mentioned that it is important to have your records transferred and that you also have copies, and to get the copies while they are recent. When a medical record is no longer recent it can become costly to obtain copies and you may be charged by the page – as much as \$10/per page was mentioned. Also, we talked about clinical trials. Although these trials are highly regulated, some of the trials have some leeway in adjusting dosages if there are adverse reactions, especially in those trials that are comprised of multiple agents – dosages of the already approved agents may be adjusted, as an example. Also – if you are on a trial and experience adverse effects, you have the option of getting off of the trial

Submitted by Wendy