

Summary of ECD Global Alliance Internet Chat

06 Sep 2014

6 Attendees

- Members discussed whether they would be in Bethesda shortly. Putting faces to names was eagerly anticipated.
- A member has recently been to see his oncologist who is going to retire in November. When asked what he was going to do, he said that he was going to play in a rock band!
- The recent report from the doctors at last year's conference was mentioned.
- One member is on vemurafenib (V). When he first started it, a slight improvement was seen. He has been basically stable since. One of his nurses said "Hey, around here, nobody dies from stable." He feels good, but some of the time he doesn't have much energy. He has had some side effects, mainly the skin lesions that are a recognized problem, but these have tapered off considerably. At the last visit to the dermatologist, he had none. Also, the skin on his feet has grown thicker, and sometimes causes some pain.
- It was said that "ECD is a TAKER". It takes your strength, and most everything else, and leaves you a shell. Your strength and balance go, and you have to make yourself do the things you love.
- Most of the medications that are used against ECD are strong, and have some side effect. These, in turn, lead to more medication...
- Members discussed where they have ECD involvement. For one, the ECD is in his chest, making it hard to breathe. He has ECD on his right lung, aorta, esophagus, and in his lower abdomen. He had pneumonia in 2006 or 2007. "All this leaves is sitting, sleeping, and playing on the computer."

For another, he has a small mass growing on his heart.

- A member told us that she will be attending the upcoming symposium, and then going to the NIH afterwards.
- A member came on and told us that her scheduled visit to the NIH had not occurred because she had to have some leg surgery. She is now taking chemotherapy for large B cell lymphoma. Dr. Janku, who is supervising her treatment, does not know yet what he is going to do with ECD during this time.
- Finally a "dirty stop-out" member came on who had missed the Chat. She said that she had been "with a friend at a fair in a different town". She is still having bad back pain as well as right shoulder pain, but, other than that, "can't complain too much".