

Summary of ECD Global Alliance Online Chat 18 August 2012

Attendees: 9

- A member who is on interferon is finding that it is still sapping her energy. She has also been trying botox injections for spasm in the leg muscles. This seems to have made things worse, so may be stopped. There is a doctor's appointment at the end of August, when the option of stopping the botox will be discussed. It was suggested that it would be interesting to get the opinion of Dr. Estrada-Vera. This member has already been to the NIH and is keen to return after a year from the first visit.
- Another member, who has been using interferon since 2005 (except for a one month trial without it), said that he had felt exhausted EVERY day! Also, he was having bad cramps in the lower legs, and his balance was worse. It was pointed out that there had been a couple of papers, that had come out this month, that talked about other possible treatment options. But then, it was pointed out, that if the interferon is working, most doctors would be hesitant to suggest changing to a different treatment.
- A member had managed to go with his wife, and some "hired help", that morning, to get some old wood from a house that is being torn down.
- It would be a help to the organization if members could let Kathy know (support@erdheim-chester.org), if you are scheduled to go to the NIH. The Alliance has got a little something, that it would like to send to your room, so that you will know how much your efforts to participate in the NIH study are appreciated. One member, straightaway, told us that an NIH stay was all booked up for 30th September 2012 (somebody WANTS their "little something"!).
- We were told that someone, who does not attend the chats, had e-mailed Kathy to say that they read them EVERY week and appreciate learning about other member's experiences. They wanted Kathy to tell everyone, "Thank You."
- A member asked the other Chatters about their experience with interferon, and whether anyone was experiencing low white blood cell and ANC levels (these are the baby cells that grow into either red or white blood cells). Interferon treatment ended 2 months ago, but the levels had not rebounded yet. They have rebounded in the past, but this time it is taking a lot longer. Some members had had the same experience after chemotherapy. It was suggested that the member might want to encourage the treating doctor to contact one of the other doctors, who has treated a large number of patients. Drs Kurzrock, Haroche, and Estrada-Veras were mentioned as being suitable to contact, with others list on the website under the "Physicians" menu selection.
- A member joined, who has a busy period coming up! There will be visits to the neurologist, oncologist, and dentist.

- A Chatter raised the issue of carers. Her son's main carer is his wife. Another Chatter, who is a carer, said that she was unable to leave her husband alone overnight. This problem had been dealt with, a few years ago, by getting the in-laws to come and stay. This had allowed the carer to go on holiday with friends. Very helpful, and the break was refreshing.
- We were told that Dr. Kurzrock's assistant believes that she will be seeing patients in her new position in San Diego. This is not a confirmation, but it sounds hopeful. It would mean that she would be on the West Coast, and Dr. Janku would be in the south. That will make it easier for people to get to them.
- A member told us about plans to move from her large house to a smaller condo. Between getting older, and the ECD, she is finding that she is just not up to all the work of a large place. Other members did say that "moving is not a piece of cake". It will be exhausting, and hard to give up the family home, but there comes a time, when it is best to make this kind of change.
- Kathy told us that her recent absences have been due to increased work commitments. Saturday is often the only time for getting errands done (and Simon believes the charge cards do make SUCH a noise, when they start shouting to be let out into the light!).