

Summary of ECD Global Alliance Internet Chat

15 February 2014

12 Attendees

- A new chatter said that he has had ECD for 4 years, but only just got connected to the Web. He has had problems with his cortisol levels, due to the disease affecting his adrenal glands. Bone scans, done at the Mayo clinic, have shown disease to be present in his lower left leg.
- Weather was discussed, as usual. Heat in Australia, wind and rain in Europe, ice and snow in the US! One member said that he had been "stuck in" for the last few days. He has been coughing, so his trumpet practice has been put on hold for a bit! It has even been too wet and windy for his wife to "visit" the nearby shopping mall! Another Chatter said that that "sounds like the weather must be horrible to keep a lady from shopping! :-)".

A member who has woodturning as a hobby has not been able to get out to his workshop due to the cold. He hopes that things will improve in the coming week

- A member who has been on vemurafenib for only 4 weeks, told us that he had not had any MRI's yet to see if there is discernible improvement, but he feels that it is working. He has "felt just fine" since he changed treatment from interferon to Kineret some 3 years ago. But he believes that the vemurafenib is reducing the retroperitoneal fibrosis that is obstructing his ureter.
- Another recent vemurafenib starter has not noticed too much improvement, over the last week, but has made good progress already. After being on vemurafenib for a number of weeks, she has returned to work, doing 30% of what she used to, for a couple of weeks. This is making her tired, not surprisingly! She feels that something is happening in her feet. They seem to hurt, and have a tingling feeling.
- A member, who is a Deacon, has recently started work in a new parish. This is working out well with "lots to do, lots of wonderful people welcoming me - great boss."
- A member, whose son is currently being treated for Hodgkins, was asked how his treatment was going. He has already had his 2nd dose of chemo. He is tired, and has a little nausea. A member, whose wife had chemo, said that it had always made her very tired.
- A member, who is on week 10 of peg interferon, said that it is too early to tell what exactly is going on. He thinks that the frequency of the pain episodes has been reduced, but with other complications, it is hard to say what is causing what. The opiate medications make him quite ill, and give him insomnia. He finds that he still needs to take Aleve. He is hoping to get to NIH in March/April for a full workup. His Docs watch his inflammation markers, closely. So far the interferon has only impacted his CRP. He asked whether anyone else was watching their CRP, LDH or ESR, and if anyone was finding that their phospholipids antibodies were "off the scale". His BRAF status is negative. It was tested at Northwestern and MSK. He wondered whether anyone, who was BRAF negative, was taking anything other than interferon. Many treatments are being used, but if interferon is working, the docs like this as the starting treatment.

- A member told us that she was seeing Dr Janku on the following day. They are working on getting her to the NIH. She had a biopsy done, but there wasn't enough tissue to be sure about her BRAF status. She was already taking methotrexate for her rheumatoid arthritis. Adding anakinra has been a big help. She has been taking anakinra since October. She began to feel better after just a few weeks. Her fever went away, her night sweats got better, as did her sleeping. She was less fatigued and the pain in her legs was better. A very close friend is amazed at how much more she can do.

Her husband recently had an operation for bowel cancer. He has been through chemotherapy, and needs a second operation. Recently he was on the way to preop, when he was found to have a low blood pressure, and he ended up in ER. Hopefully, he will be going back for the surgery this week.

- Kathy hopes the ECD-GA will have a sign up for the Patient and Family Gathering soon to be held in Bethesda, Maryland on September 19-20, 2014. Once a contract at the hotel is signed, registration will begin. She is hoping people will register early!
- A member has recently worn a heart monitor to try to get to the bottom of her dizzy spells. She is yet to receive the results. The dizziness has been very worrying because she needs to drive to school, and to doctors. She has been feeling very depressed lately, because of her medications. She is taking the maximum dose of an antidepressant. She is seeing a counselor in the next week. Her insurance changed this year, and it has been difficult getting in to see anyone. She went to the NIH in 2012, and plans to go again, near to the time of the conference so that she can get it all done in one trip.
- Another member is thinking of asking Dr Estrada whether she can make a return visit to NIH, in the week after the conference in Sept. So that she doesn't "have to fly over the ocean an extra time!" She is a European!