

Summary of ECD Global Alliance Internet Chat

24 Jan 2015

6 Attendees

- A new member left a message during the previous week. The member asked whether there are any foundations to assist with the co-pay for interferon therapy.
- When the Chat started the first topic of conversation was the good ole weather! Snow in the Philly area, and snow in the UK.
- A member told us that he had managed to have his PET CT scan this week. It had been cancelled at the last minute the week before, because the positrons "wouldn't come out to play". The contrast injection was not up to standard = not radioactive enough! This time the positrons were "bright as buttons!"
- A member told us that his daughter, who has ECD, has been going to physical therapy, and doing a lot of walking around with her rollator (a walker). Her husband has bought a very fancy bike. There's a seat for her in the front of it, with a sprocket and gear and chain setup, so that she can pedal. He can do the steering. When spring comes, they will "get it on the road". The family hopes that this will increase her strength. Her oncologist thinks that part of her balance problem is due to lack of strength. She is strong enough to pedal. The trick will be balancing!
She is going pretty well, and "in remission" with no active disease. Because of her near-total blindness and trouble walking, she didn't appear to be particularly well at last year's Bethesda meeting. She wants to go to Houston for the conference later this year, but this is going to be quite an undertaking. Her mother doesn't like flying, and it will be an expensive trip. Last year was ideal. Bethesda is not even a day's drive from where they live!
- One member on the Chat said they are still able to drive while another is not.
- A member came on and told us that she would be going to NY next week to see her doctor, and get a PET and MRI. She is not looking forward to the cold weather! She is hoping that the scan will show that her disease is not active, although she told us that she has many symptoms. Her eyes are affected badly, so she will be very surprised if the orbital lesions are gone. "I can still hope."
Her doctors had stopped her Anakinra and her fevers have returned, along with chills. She is about to be started on something new; and hopefully, this new drug will take care of these issues. The drug is a "cousin" to the vemurafenib (V). The doctors have found an ARAF mutation (like the BRAF mutation, but earlier in the alphabet!), and the new drug better targets that mutation.
- The member who lives in Norway has a checkup due in the middle of February. She sees a doctor in Norway, but he is not an ECD specialist (only a neurologist!!). She has been on V for 14 months, with very good results. Her dose is now 1 in the morning and 2 in the evening, and she has no

active disease. She is planning to get to Houston this year. Registrations can now be made for the 2015 Patient and Family Gathering.

- A member came on to tell us that she was doing OK and back on Anakinra. This had been helping a lot, but had to be stopped while she had a course of chemotherapy for lymphoma.
- Lastly a message was left by a member who had forgotten that it was Saturday! She has been doing pretty well, other than having some pain from the shoulder that she recently had surgery on.