

Summary of Global Alliance Internet Chat on 01 March 2014

8 Attendees

- During the week before the Chat a new member came on, whose father has recently been diagnosed with ECD. He has started interferon, and the new member asked whether anyone had experience with this. Kathy left a message asking for the new member to e-mail support@erdheim-chester.org. Then the ECD Global Alliance will send some information.
- As the Chat started we had some more fun with the Dragon- Dictate program. It is getting better with time. The "Autocorrect" feature, that some members use, was also producing some odd results.
- As usual, we started with the weather. Heavy snow was forecast for New York. A member in Ohio was expecting some too. The UK is clear at the moment.
- A member told us that she was "dog-watching" at her home. She does go to the owner's place if she is "watching cats". She is still having some dizzy spells, and her back has been painful. She got the results of her recent heart monitor test this week. It showed that she had a very wide range of heart rates, but no abnormal rhythms, and nothing that seems to be dangerous. She is going to see a cardiologist, and then, maybe, have a tilt table test, to see if this gives useful information about her dizzy spells. She turns 21 next month. Happy Birthday from all of us!
- A member came on whose husband has been on chemotherapy for bowel cancer, and has been waiting to have an operation to see whether things are better. The operation has been done, and he is at home, recovering, although he is still waiting for the results.
- A member asked whether others had a problem with facial flushing. The member who asked is young. She wonders whether this could be due to her medicines. Neither she, nor her doctors, is sure. No others said that they were having similar difficulties, but members did discuss the problem of low testosterone.
- A member had been to the NIH and been told that his testosterone levels were low. Apparently, this has been the case in most of the male ECD patients that they have seen. Testing has to be done between 7 and 8 am to get an accurate reading. Dr. Estrada seemed to think that there may be testicular involvement for those who have ECD in their abdomen/pelvis. The NIH noticed some "pooling" on his nuclear medicine pelvic scan in the testes. Then they did a testicular ultrasound, and tested for testosterone levels which were 153. This is apparently very low. He is now being tested to see if those low levels are normal for him. He finds that "the worst part of all" is that he has to follow up about all these tests. He says that he "needs a medical advisor" to do this for him!