

## Summary of ECD Global Alliance Internet Chat 08 Dec 2012

9 Attendees

- A member came on with a query before the chat started. The member asked whether any DNA testing had ever been done.

(Editor's note: There are a number of studies going on that are looking at the DNA of ECD patients. The NIH, Texas Children's S, MD Anderson, and other studies are doing research on this today. For this reason, all patients are encouraged to review the studies and to join those they can. Please see

<http://www.erdheim-chester.org/ECDStudies.html> for more information.

Also, remember, if an ECD patient is having a biopsy or surgery at the location of a lesion or tumour, the ECD investigators request that you consider donating a very small amount of tissue for genetic testing. Contact [support@erdheim-chester.org](mailto:support@erdheim-chester.org) BEFORE the biopsy/surgery for more information.)

- A member just arrived home, from a follow-up trip to the NIH, one year after the first visit. This visit involved blood work, MRI'S, PET SCANS, lung tests and follow ups of other appointments that the member had had the previous year. The member was found to be pretty stable, but lacking in vitamin B. A lack of this can make you more fatigued, and even cause poor balance. After the visit to the NIH, the member has had the week off from work, but has to go back to work on Monday. The time off has been spent moving into, and getting settled, in a new apartment.
- A member has just bought his first talking book, although this was not because his eyesight was being damaged.
- A member, who has been having shooting pains down his arm, has seen his doctor. He has been given a muscle relaxant (which also makes sleeping easier!), and is going to get massage therapy. He has also restarted his 25mcg fentanyl patch, which can make you feel a bit high.
- Two members are making their first visit to the NIH in April, but their visits do not coincide. They were warned that their stay at the NIH will be very busy (with all the testing that will be done) and tiring too. Although, the members who have already been, all said that the trip had been well

worth the effort, and previously unanswered questions had been dealt with. We were also told that the member stays in the hospital, whereas the spouse spends the nights at the hotel, and goes along to the tests with the member.

"Ordering lunch" while at the NIH was said to be very important, because there is little time to eat, and many of the tests require you not to have breakfast. We were told that the food at the NIH is good. One member had been fed chocolate pudding and crackers, in the rehab department, after coming over a bit dizzy. The members, about to go to the NIH, were advised, if possible, to have some "recovery" time planned for afterwards.

- A member asked, whether the doctors could "see" that the ECD had got "deeper into the bones"?

We were told that the CT and PET CT scans give 3D pictures, so that they would show the depth of ECD lesions. But, bone scans, and ordinary x-rays, would only show it, if they were taken from side-to-side, as well as back-to-front.

- Some members gave some feedback on the recent end-of-year ECD GA newsletter. It was said to have contained a lot of good information, and had even been passed on to some family members.
- Social Security (US) has just approved that ECD be put onto the Compassionate Allowance List (CAL). Kathy will be interested in getting feedback from anyone, who has been filing for the social security benefits, to hear whether having ECD on the CAL helps in getting claims approved or not.

One member is just starting a second request for SS disability, having been denied on the first shot, before ECD was put on the CAL.