

ECD Global Alliance Chat Summary

Date 29 Oct 11

10 Attendees

- Kathy couldn't attend but had left some questions for the Chatters to discuss. She asked a question asked by a patient's wife, "If those of us who knew our blood cholesterol results (HDL and LDL) would mind sharing them?" Another question had been asked about calcium levels. Finally someone else had enquired, "How do other ECD patients fight fatigue?"
- One patient reports an overall cholesterol of 140, but almost no "good" cholesterol (presumably they mean HDL).
- Somebody has a low calcium level despite taking 1200 milligrams of supplements twice a day.
- Another patient finds that fatigue is his greatest challenge. He has been trying to eat a higher protein diet. He wishes to know whether anyone has found anything that is helpful.
- Cholesterol levels seemed to vary amongst those who knew their results. One member had good levels of HDL and borderline levels of LDL. The levels of another member are normal, but had been abnormal, in the past, due to some of the drugs used to "help" fight against ECD.
- A member gave the results of the blood tests which have come from her child who has ECD. HDL is 31 and LDL is 70. Calcium is 2.35 and Calcium tablets are taken daily. She thinks that Gleevec treatment has helped with fatigue.
- Another member contacted us to say that, despite taking 6 citracal a day, the blood calcium is still below normal.
- Fatigue had also been a problem for some. Pushing yourself, and then taking naps was suggested. Taking B12 complex was also suggested, and having your other medications reduced was generally thought to help.
- One member has needed to re-start DDAVP but only takes the lowest dose, and only needs it once a day.
- A number of Chatters (all in the US) have started to have this year's snow already! The effects are various. Everybody, please take care!

- The NIH team have sent out packets of blood sample bottles to family members of one of the first patients to go to NIH.
- The dental team at the NIH commented on the bad state of one patient's dental health. This was likely due to the ECD.
- A member is using an exerciser Gyro to help with hand problems, and also rides regularly on a stationary bike.
- Another member reported, that the NIH team have examined the records that had been sent, and may be scheduling a visit for January.
- Nobody on the Chat had ever seen a doctor who was already aware of, and up to speed with ECD, apart from one Chatterer who once met an eye doctor who had heard of it.
- It was reported that, so far, Dr Vaglio in Italy has received 16 sets of records. Members, who are lucky enough to be doing well at the moment, were encouraged to get involved, and to send their records.
- A member said that he would be with us next week, but then he would not be able to get back to us until after his trip to NIH.