

Summary of ECD Global Alliance Internet Chat 10 November 2012

7 Attendees

- A member told us that she was moving to a new, and bigger, apartment. She has a boyfriend who will carry all the boxes! It's a chance to buy new furniture. The best choice of sofa was discussed (one that is suitable for napping on, was the recommendation). A repeat trip to NIH in Bethesda is rapidly approaching.
- A member, who has recently started taking morphine for his pain, thinks that it is helping. At a recent visit to the doctor he was told, that from the CT scan and leg X-rays, the disease looks to be stable, but the legs are badly affected. This oncologist seems to think that this is where the member's leg pain is coming from. A PET scan has not been done. He was asked whether he would feel comfortable asking if a PET scan was warranted? The member, and his doctor, is concerned that the health insurance may not cover this. The member was advised that, if the ECD-GA can help, then please let Kathy know, and he should let his doctor know, that we are willing to do whatever we can.
- Our newly wed member told us that she is settling well into married life.
- A member asked whether anyone knew of a case of ECD "coming back" after 8 years. Nobody knows the answer to this question, but the good thing is that the number, and types, of treatments that are available are growing. So, if one treatment doesn't stop the ECD, or it comes back after a treatment, there are others that can be tried.
- The meeting with the ECD interested doctors is this Tuesday. There is hope that we might see some good collaboration come from the meeting and that it be the beginning of more sharing among the experts. More sharing will hopefully lead to greater strides in learning more about ECD.
- A member has visited his ophthalmologist this week, and was given the good news that his optic nerves have "improved". Also, his wife has got the week off work, at Christmas, so family visits will take place. His video is now linked to our website, and has been seen by some of our members.
- The healthcare plans of the recently re-elected US President were discussed. Members were concerned about the effect that age restrictions might have on their healthcare provision.
- A member, and his wife, have booked for lunch on Christmas Day, at one of their favourite local restaurants. This will mean that the folks CAN'T "drop round"!!, because they WON'T be there!) There will be a traditional Christmas dinner, but there will be lots of other stuff as alternatives. They should be able to stay at

their table for a good long time, so they might try "a bit more" after awhile. They have already planned the day with the owner of the local taxi firm, so that transport should be no problem. And there will be NO washing up to do, either!!!!!!!!!!!!!!

- A member made a general enquiry about people's balance. The answers were "Bad" and "Poor to average". The member, himself, has been having balance problems, and has been advised to see an ENT specialist. This is probably because the parts of the brain that deal with balance, are mainly in the inner ear. He has been told that test needed may make him sick. There is an article about balance on the ECD-GA website. It can be found at - http://www.erdheim-chester.org/DataFiles/PresentationsAndArticles/Balance_Issues_by_Simon.pdf.
- One patient has some sensitive issues that they wish to discuss with Dr Estrada.
- A member has some more tests due at the beginning of December. Her doctor is collaborating with Dr Janku.
- Two of our members will shortly be at the NIH at the same time. They haven't yet arranged details, but intend to meet up.
- A member asked for the name of a pain-killing patch that another member is using. This member was not available to respond, but we are fairly sure that it is a fentanyl patch. Fentanyl is a morphine-like drug, that is used to kill pain. As it is a patch, it delivers drug through the skin and this prevents any sudden bursts of the medicine.
- We were reminded that, our organization is founded on the thought that, if patients share information, then they can take what they learn, back to their doctors. That way the doctors can know what other doctors are doing.
- A group of doctors, with an interest in ECD, will be gathering in Houston on Tuesday to talk about it. This will be the first time that this many doctors will have come together to talk about just ECD! This meeting has been arranged by the ECD Global Alliance. As patients join together, their collective voice becomes stronger, and the medical community suddenly has access to more patients.
- There is also a proposed meeting in San Diego for the end of October 2013. This will meeting will include patients and their families. Please "Hold the Date" for the last couple days in October and first couple days in November. Exact dates and more information will be coming soon.