

Summary of ECD Global Alliance Internet Chat 21st July 2012

9 Attendees

- Before the Chat started, a new chatter came on. The chatter's father-in-law had been diagnosed with ECD last year. He has just had his first interferon treatment. He was also told that the histiocytes were all over his lungs. Members would have been pleased to share information, but the chatter was not still "on" the Chat and did not leave an email, so it was not possible to send any information. Many chatters have had LOTS of ECD-related problems, with their chest, and would like to share their experiences.)
- As people came onto the Chat, the usual greetings and enquiries about everyone's health and well-being were made. One member is about to take a break of a few days, to see friends, and maybe go fishing on the Central Coast. Other members commented on a great golf course there, and the coastal highway. Fishing was popular for a few members, and they exchanged their opinions on favourite fish to catch.
- One of the Chatters told us about a kidney problem that needs to be sorted out. The right renal artery is completely blocked, and the left renal artery is 90% blocked. The left kidney is still functioning. If this fails, then dialysis will be needed. The blockages are too long for a stent. A surgeon will be seen soon, maybe to recommend a bypass operation. This surgeon also has experience in kidney transplantation if that becomes necessary.
- One member still needs to find a doctor who will take on the treatment of the ECD! This member has also been in contact, by phone, with another member, and had found that helpful.
- A member, who has a son with ECD, told us that he is camping out with his high school buddies. This is a regular trip, and has only been missed once, when he was on chemotherapy. Another family member has been visiting at home, and that has "been great".
- Woodturning and lathes were discussed. One of our "woodturning" members has started to produce some ornaments for Christmas. Another member needs to get his lathe "cleaned up" before any new projects are started.
- A member told us that balance was a serious problem, with unsteadiness being persistent. A number of other members were having similar difficulties. One member could only get to the bar, the washroom, and the taxi (but that was enough to get by on ☺). One member had been to see a neurologist about balance problems (there is a piece on the ECD Global Alliance web-site about balance if anyone wants to take a look. I know its there 'cos I wrote it!! Editor's note: see http://www.erdheim-chester.org/DataFiles/PresentationsAndArticles/Balance_Issues_by_Simon.pdf).

- Another member told us that his legs were weak, and that they didn't "work very well". It was suggested that he might get some benefit from using a stationary bicycle, or pedal machine. Others have found this to be helpful.
- A member, who has been having trouble with pain around the elbow, has been for therapy, and was told that there was arthritis, and a "lesion in their back". An appointment for an MRI has been made for the 30th of July. Walking has also been limited due to stiffness in the back. The temperature has been about 100, and it is very humid.
- The member who has just had a colonoscopy was able to report that the findings were of "benign polyps". We were pleased that this was all that had been found.
- A member, who is a foster parent, was asked whether he had any foster children at the moment. No was the answer. His wife is caring for her elderly father (91), and her sister, who is needing oxygen therapy.
- A member explained their heavy work "schedule". Off to work in 3 hours time. Working Saturdays and Sundays, and most Fridays (more weekdays when at school). But the member manages to fit in walking the dogs every day, and the occasional family bike-ride.
- A member is taking donezepil tablets at night, and finding that it is associated with a lot of dreaming.
- We were reminded that we have a much clearer and stronger voice when there are more of us, and that we should encourage people to register with the ECD Global Alliance whenever we can.