

Summary of ECD Global Alliance Internet Chat 28 July 2012

8 Attendees

- The local weather in member's home areas was discussed. The recent warm spell in the UK has kick started the vegetables in one member's garden. He was asked about the soil type that he had. "Brown" was the answer! In reply to a question about things to do with spinach, it was said that spinach could be steamed, folded into curries and stews to wilt down, or eaten as salad leaves.
- A UK member was not enjoying the wall-to-wall Olympic coverage, but most of the rest of the Chatterers were. Enquiries were made about traffic problems, but the UK member lives 200 miles away, so there aren't any!
- The sight of the Queen jumping out of a helicopter had amused some members. They had to be told that "her Royal Highness" had a stunt double (a man in a dress!).
- We were reminded of the contact details for the study at NIH. This is the PDF with information about the study and what they need: <http://www.erdheim-chester.org/ECDStudies.html>. You can also call or e-mail Dr. Juvianee Estrada-Veras on 301-451-7963 or email: juvianee.estradaveras@nih.gov
- The NIH now scheduling patients for later this year. One of our members is going in November. It will be an all-girls trip (just the member and her Mom). She is just about to be married, and this will be one of the first times that the newly-weds will be apart.
- A European member said that the journey to NIH would be too long to cope with, although another member from Europe has already been. And that member's records didn't arrive at the NIH until the day she left!
- Two members said that their balance was getting a bit better. One member was about the same, and one was getting worse, with stiffer legs. The subject of walking sticks came up. Some members use "Alpine walking" sticks. These are longer than normal "canes", reaching up to your chest. The members find them helpful in keeping balanced. The carbon fibre ones are light, and they have sharp bits on the end for icy conditions. These can be covered by a rubber ferrule, for when you don't want to scratch the nice floor, or tear the rugs! But the ferrule comes off very easily and quickly (useful in a life-or-death combat situation!). It was also said that they can be used to hit people over the head, and as pointers. 😊
- It was said that it would be most useful if a pair of sticks was used. One member uses them when walking outdoors, including going to the exercise centre, with a gym training bag on her back! One little problem is that people, who see you walking about with the Alpine sticks, think that you are an "athlete" and not just wobbly!
- A member, who was only diagnosed in May, has, thankfully, found a doctor in Southern California who is already treating an ECD patient. The member will be trying to make contact.
- The conversation came to an end with a discussion about people's ages. For reasons of "confidentiality" I will not discuss this part of the Chat any further. The "Old Folks" might complain!! 😊