

Erdheim Chester Disease Global Alliance Internet Chat Summary **22 October 2011**

8 Attendees

- A member who has already visited the NIH, has reported back. He says that it was a good experience. Another member is flying from Europe, later this week. It is not yet clear, how much of the traveling expenses will be met by the NIH.
- One of us has been indulging in his hobby of woodturning. He has just made a wooden hickory bell. Some e-mail pictures will be circulated.
- A member who has sent records to Dr Estrada-Veras has not yet heard anything back.
- Another member had her flu-shot today. It is important to have this every year, when you have chest problems. Some other members have just had their shots too.
- The NIH team has been working on an idea that ECD may have a genetic component, and are doing blood workups on the families of those who have ECD.
- No one on the Chat could think of a familial link in their cases. One member thought that it was just too random a disease, for a genetic link. The only thing that we could choose to do, if it was inherited, is not to have any kids!
- Our leader was reported to be in BatIB Rouge, not a place that I had ever heard of before. But having examined my keyboard carefully, I see that this is just 2 keys away from BatON Rouge, so that is where I think she really went!!
- We have one member who has been spending his time unclogging drains. He also has had to go to the hospital, to sign release forms for his imaging studies. These are being sent to Maryland, and he is expecting for Dr Estrada-Veras to start organizing the schedule for his forthcoming visit to NIH.
- Finally, our member from Oz, whose wife has been so poorly, joined the chat after the rest of us had finished. He reported that things seem stable at the minute, and we send them both all our love and best wishes.