

Summary of ECD Global Alliance Chat on 15 October 2011
www.erdheim-chester.org

7 Attendees

- People asked whether there was any report back from the first person to go to NIH, but no-one had heard anything yet.
- A member had recently been to see an endocrinologist and received a good report.
- A member had been contacted by the co-ordinator of the work at NIH and had been told that there would be help with travel expenses related to their participation in the ECD study. Reimbursement of expenses is unique to each person and will be dealt with on a case-by-case basis. At this time, no one should decide not to participate due to monetary issues. If you are interested in participating in this study, but are concerned about the costs, please contact Dr. Estrada-Veras (Juvianee.EstradaVeras@nih.gov) or Kathy (support@erdheim-chester.org).
- A member had had to go for a blood test during the week, and their spouse suggested to travel on the parkway to see the leaves. It was a lovely trip.
- We were told that Liam's Lighthouse Foundation is seeking adults with ECD and Histio to participate in their awareness campaign for "The Today Show" centred around Rare Disease Day. They NEED more adults to participate by submitting a photo and short DX story for a poster to be held up that day. A check for \$40(US) covers the poster. For more information go to www.liamslighthousefoundation.org.
- A number of members had either had massage treatment, or had had it recommended to them. It was agreed that this was a good form of treatment. One member encouraged the use of a TENS electrical stimulation machine.
- A member has just been approved for Orientation and Mobility (travel skills) for Blind people. This has already started with training in the better use of the white cane.