ECD Global Alliance Online Chat
14 January 2012

 # Attendees: 9

- A number of members mentioned that they had Skype, and that they would like to use this to get in touch with others. If you are interested in skyping with others in the organization, please contact the organization or join in a chat session and make contacts that way.

- A member came on who had not come for a while. Chemotherapy had improved things a lot.

- A member had been on the HAA website. There did not seem to be any mention of the ECD Global Alliance. In the diagnosis section for ECD, it says that MRI is a type of Xray!

- A member wanted to go to Liam's Lighthouse awareness event for NYC, but one of her parents doesn't want to go. They were encouraged to try to get to the NIH event.

- The NIH is having a RareDisease Day event on Feb. 29. Some people from the Global Alliance will be there. It would be great if others could join them. Please email support@erdheim-chester.org if you want more info.

- A member who has had a lot of trouble with his teeth has lost 3 that were crumbling and will need some root canal work. Comments were made at the NIH, but he attends the dentist every three months at home. His bone doctor was very impressed by the testing work that the NIH had done. Lesions had been seen on his heart which surprised his regular doctor.

- Another member has offered to publicize his story on a website only used by doctors, to try to get some Rare Disease day publicity. They haven't risen to the bait yet!

- Kathy has recently made a "real-life" visit to NIH, and now has some first hand experience of what a trip to NIH is like. She was impressed by the teamwork going on. The NIH team did ask that any ECD patient, being scheduled for surgery to a tumor or lesion, should let them know. Dr Estrada-Veras would like to be able to speak to the patient and doctor, to see whether he could be sent a small piece of material for his studies.

- We were told that there were plans afoot to redesign the web-site. We were reassured that so far 0$ of donated money have been used for any web-site work. A member suggested the possibility of contacting a few developers to see whether they would be willing to donate their time.

- A member, who has had trouble with back pain and swollen legs, said that she is beginning to improve. Compression hose have been very useful.

- A member who is looking to change jobs, has an interview coming up. Best of luck from us all!

- We were informed that Melissa Berger Mandisa (melissamandisa@att.net) is doing a documentary film on Histio. She needs people with different types of Histio to be interviewed. She is currently doing the ECD part of her film. A member of the GA will likely contact her by the week's end. It isn't clear yet how the film will be used. Perhaps education / PBS.

- A member who has been to the NIH already said that the NIH had been efficient in sending results onto his own doctors. The NIH did suggest a low-protein diet, but his own doctors do not think that this necessary at the moment. Such a diet is better for big people.

- Another member has been moving house, and it has all been rather chaotic. Boxes everywhere; and no money yet from the sale of the other house!

- A question was raised about the amount raised by the Grant Match offer. A formal notice will be forthcoming. $40,000 was raised, so this was turned into $80,000 to support the work of the organization thanks to all the generous donors! Thank you everyone!

- A member who often manages to come Chatting did arrive, but we had all finished by then.