

Summary of 12-6-08 ECD Chat

Chat Date:

12/6/08

Time:

3 pm Eastern time

6 Attendees

Summary:

- Our webmaster joined the chat room today. He has done all the website work as a volunteer. He does this because he is a friend and a good guy. Everyone in the chat room expressed their gratitude for all he has done to help those who have been affected by ECD. A HUGE thank you to our great webmaster!
- One person mentioned she is handing out ECD brochures to nurses and doctors in her area to help raise awareness of the disease.
- A question was raised about whether there was an ECD registry where patients could register and find other ECD patients. As far as anyone in the chat room knew, the only two places for ECD patients to register are our website and the HAA website. Both of these websites encourage someone to register at the other site as well.
- A suggestion was made that we write our 'stories' related to how ECD has affected us. If we didn't include names or other identifying information, the stories could then be posted on our website. If you are interested in doing this, please write your story and send it to support@erdheim-chester.org.
- NORD (National Organization of Rare Disorders – www.raredisease.org) has announced that Feb. 28, 2009 will be Rare Diseases Day. On that day, and the weeks leading up to it, NORD will join with others around the world to conduct a variety of activities to raise awareness of rare diseases and the need for safe, effective treatments. We'll keep you posted on what this will entail, but maybe some of us will want to get involved.
- There was discussion about contacting more ECD knowledgeable doctors to see if we could get permission to include their name and contact information on the website. If you know of a doctor who might be appropriate to list on the website, please ask them if we could post their information. If you do not feel comfortable asking them yourself, please contact support@erdheim-chester.org and we can contact them directly.
- A suggestion was made that we include something on the website to explain that statistics are just that. The suggestion was to include a section on the website along the idea of, "Living beyond the statistics with ECD".

- Brain wave entrainment technology was discussed and one patient told how it helped him deal with his pain.