Summary of 10-26-08 ECD Chat

Chat Date: 10/26/08
Time: 3 pm Eastern time

3 Attendees

Summary:

- A discussion was held about participation in Dr. Haroche’s HLA study. One patient’s doctor has ordered the test, another is awaiting word back from their doctor and the third is having a difficult time getting their doctor interested.

  (If anyone has any suggestions on how we can help improve the participation rate regarding this test, please send your ideas to support@erdheim-chester.org. We are still attempting to locate funding to help off set any costs that may be incurred with this testing. We have not yet found a funding source, but we continue to search.)

- Suggestions were discussed about how to help raise awareness of ECD. They included:
  - Passing out the ECD brochure
  - Talking to friends and family about ECD
  - Sending friends and family the website address and encouraging them to review it
  - Speaking about ECD and/or Orphan Diseases at professional gatherings, civic clubs, etc.
  - Writing your personal story about living with ECD and working to get it published in magazines or newspapers or even book form

  All of these activities are currently underway by various members of our group. Everyone is encouraged to do what they can to help raise awareness.

- It was brought up that The ECD Global Alliance now represents 27 unique ECD cases. By banding together, and being as active as possible in fighting this disease, we hope to make a positive difference.