

Summary of 12-13-08 ECD Chat

Chat Date:
12/13/08

Time:
3 pm Eastern time

5 Attendees

Summary:

- Some folks discussed getting their treating doctors involved with our efforts by asking them if we could post their information on the website. One of the participant's treating doctor has agreed. Another participant will contact his doctor for his permission.
- One patient has contacted Dr. Haroche in Paris and is considering a trip to visit him there. Dr. Haroche has indicated he will be contacting him about the possible visit.
- Another patient has sent the results of the HLA I and II tests to Dr. Haroche who quickly responded with a thank you.
- The ease with which patients can get infections was discussed. Chemo and immunosuppressant medications can both result in the immune system being unable to fight off infections. The use of the Airborne product was discussed and at least one patient believes it helps him.
- Information about our group has been successfully added to the Wikipedia article on ECD, complete with a link to our website. This is very helpful in that the Wikipedia article is one of the first entries to appear when using the search engines to find information about Erdheim-Chester Disease. Since we do not have the funds to pay to have our information appear at the top of the list, this is the next best thing. It should help those searching for information to find us a little easier.
- One patient mentioned he will begin with cytoxan at the beginning of the year. His doctor at Mayo and Dr. Arceci conferred and decided this treatment would be as good as another, with the same or less side effects for this patient.