

Summary of 10-11-08 ECD Chat

Chat Date:

10/11/08

Time:

9 am Eastern time

6 Attendees

Summary:

- We have had 7 new people register with the ECD Global Alliance via our website (www.erdheim-chester.org). Our group now represents 24 unique cases of ECD. Although we would prefer no new cases of ECD, hopefully we can become more effective in fighting the disease when we work together.
- It was stated in the chat room that Dr. Arceci had begun reviewing the website. (Since the chat session we have received word from him that he has completed his review and found the information presented accurate. He also indicated he has additional information he will be sending us to post on the website. We will be certain to share any additional information as it is received.)
- There was a short introduction among participants. Everyone shared how they had been affected by ECD
- The information we received from Dr. Haroche regarding his experiences with treating ECD were discussed. Attendees shared their experiences with interferon treatments.
 - Patient 1 began on a 5Mu 3 times per week and believes that is what has stopped the progress of the disease. They still have issues of fatigue, but the bone pain has improved. The latest CT/PET scan showed no new sites, and no progression in the existing sites. They are now experiencing more good days than bad.
 - Patient 2 was on 3Mu 3 times per week, but has stopped while on cladribine treatment. The cladribine has helped with the clinical symptoms.
 - Patient 3 has been on 3Mu 3 times per week for 6 months. This person hasn't seen any improvements, but has not worsened either.
 - Patient 4 underwent cladribine 2 years ago and has not seen any new sites since, but the existing sites are still there.

- Participants talked about how helpful it could be if we could get a symposium of ECD knowledgeable doctors and patients together for discussions.
- The timing of chat sessions was discussed. With members living in time zones from Australia to the west coast of the US, it is hard to choose a time when most everyone might be awake. It was thought 3:30 pm eastern time might be the best time to catch everyone during waking hours. It was decided to try having chats once a week, alternating between Wed and Sat. After the chat there was a request to hold the chats on Sunday, so we may try Wednesdays and Sundays instead unless we hear this won't work for someone. Reminders will still be sent out.
- Anytime someone would like to have an additional chat, we can schedule one. The chat room is always open and anyone can contact others and hold their own chat sessions. Also, the HAA has their new chat room (<http://www.histio.org/site/c.kiKTL4PQLvF/b.4448505/>) and there are sometimes people over there at various times during the day. Anyone is welcomed to check that out if interested.