

Summary of 12-20-08 ECD Chat

Chat Date:
12/20/08

Time:
3 pm Eastern time

9 Attendees

Summary:

- Chat participants caught up with how things were going in each other's lives. Those who haven't attended in a while were asked about to see if anyone had any news from them.
- One member mentioned he had met a man whose wife has had fever and chills for about 2 years with no diagnosis. It is a reminder that many people suffer without a diagnosis. The man and his wife were invited to join our chats. There was mention of a software product called Isabel (<http://www.isabel.org.uk/home/default>) that given a set of clinical findings will produce a list of possible diagnoses.
- One patient has been in communication with Dr. Julien Haroche in Paris and is thinking about a trip to see him in the early spring.
- One patient has had their dosage of interferon lowered to 1mil 3Xweek and seems to be tolerating that dosage much better. With the lower dose the nausea has subsided and some weight has returned.
- It was discussed that when a treatment is found to stabilize the disease with no or few side effects it is a very good thing.
- Problems with eyesight and focusing for those with eye orbit involvement were discussed. At least two patients have multiple pairs of glasses as they find their eyes do not adjust to different distances as well as normal.
- Weather changes were mentioned and how they impact some patient's pain levels.
- One patient recently discussed our website (www.erdheim-chester.org) with their doctor. He thought the website was valuable. He also suggested that as a patient group we might want to document some of the symptoms patients have relative to ECD that have never been documented before. Once we have something documented perhaps we could talk to one or more of the leading knowledgeable doctors about what it would take to get the undocumented symptoms written up in a medical journal article. The participants talked briefly about this perhaps becoming a project we could do.

- Our webmaster, dropped into the chat to meet folks. Everyone gave him thanks for his great work in developing our website (just because he cares, with NO compensation). He asked that everyone send in their ideas on how to improve the website even further and stated he is glad the website helping others.
- A mention was made that one patient's doctor was thinking about stopping his interferon treatment. Based on the information we have heard from Dr. Kurzrock and others, this patient and his family have some additional information by which to base their decision and contact information if the treating doctor would like to confer with Dr. Kurzrock.
- Some ideas for projects in 2009 were brainstormed:
 - Document symptoms associated with ECD using a questionnaire that would be completed by patients and their carers/caregivers. We can start with questionnaires from other areas (neuro centers for example) and perhaps using the Isabel software program in some fashion.
 - Update the 'Patient Log' that is posted on the website under 'Patient-to-Patient | Case Log'.
 - Do what we can to support Rare Disease Day on February 28. It was suggested that we could do things locally by partnering with others in our communities who might be affected by other rare diseases.
 - Help make it easier for treating doctors to learn more about ECD and its treatments.
 - Do what we can to move toward the idea of a physician conference devoted to ECD knowledge sharing.
 - Concentrate on a few ideas to raise awareness of ECD in the physician and general public populations.
 - Seek out and support any and all research being done relative to ECD.
 - Search for a celebrity spokesperson to 'carry the ECD message'.
 - Publish a human interest type story in a highly-read general public magazine.
 - Contact as many doctors as we can to gain their wisdom and make them aware of our efforts and the need to learn more about ECD.
 - Added after the chat: Inform patients and carers/caregivers of things that might help their lives be safer, easier, and more fulfilled.

- An email was received this week from a patient who has registered with the ECD Global Alliance but has not yet been able to attend any chat sessions. He asked to share with everyone his thanks for the work we are doing and sharing the content of the chats. He said, “Your discussion points have been very helpful and enlightening. ... Several of the topics discussed (knowledgeable physicians, medical protocols, etc.) are some of my current challenges.” I hope our efforts can reach more and more people who find it helpful and that others will be able to join us in future chats.