

Summary of 12-27-08 ECD Chat

Chat Date:
12/27/08

Time:
3 pm Eastern time

8 Attendees

Summary:

- One patient mentioned he will have been on interferon for a year in January and was thinking about getting off of it. He said all the testing during that time has shown the disease has remained stable.

The discussion that followed included a reminder that Dr. Kurzrock spoke of getting off interferon in our teleconference this past July when she said, "...if you stop the Interferon the disease tends to comeback. So we have not recommended stopping the Interferon if the patients are responding." (see 'Technical Papers | Emerging Information from Dr. Razelle Kurzrock' on the website for more information) One patient represented in the chat did stop interferon and saw rapid spread of bone lesions while off the treatment and thus has resumed it.

Some patients have stopped interferon because they were unable to tolerate the side effects, but at least one has started back on it, but at a lower dosage.

There was a mention that for some patients it can take a year or so before improvements can be seen when taking interferon.

- Fatigue issues associated with ECD and interferon were discussed along with the psychological difficulties of maintaining a positive attitude. It was mentioned there is a book entitled, "Sick and Tired of Being Sick and Tired". No one has read it, but some were interested. Most patients admitted they struggle with keeping a positive attitude but having a good support structure helps. Also, trying to reduce stress and finding things that can be enjoyed are methods people use to better cope.
- One patient mentioned he has lowered his fatigue by eating more whole (uncooked) foods. He is currently getting about 85% of his diet from products he has found at www.ama-ama-products.com and has seen an improvement with less 'down' time. Another patient is planning to improve his diet by cutting out as many preservatives as he can.
- Two patients on interferon seem to need to sleep or rest for 14 hours/day and are still unable to do much strenuous activity the other 10 hours/day. Another patient who is not on any treatment says he also requires a lot of sleep. There was a question posed as to why ECD patients need so much sleep.

Although no one had any ready answers, it does seem to be universal among patients.

- There was a discussion that exercise seems to help with the physical and mental issues. It is important to do exercises that can be done safely.
- It was mentioned that one patient and their family were going to do some local community work to help raise awareness of ECD on Rare Disease Day on February 28, 2009. They hope to get the media involved to maximize the exposure.
- One patient will be seeing Dr. Arceci at Johns Hopkins for the first time this coming week. We all wish them well.
- This past month three new ECD related technical journal articles have appeared in Pubmed. Subjects covered include:
 - (1) Orbital infiltration (in Spanish, no abstract or article available, only title and authors);
 - (2) Bone scans (abstract only available, authors are in Greece);
 - (3) Case study about patient with brain involvement (abstract only available, authors from Argentina)
- Our group is continuing to contact more ECD knowledgeable doctors asking for their permission to place their contact information on our website. These are doctors who have either written technical journal articles or are treating ECD patients. For those who have written articles we are also asking for a copy of the article.

To date we have written 80 letters to physicians around the world and we have had 22 physicians grant us permission to post their contact information. We have had 8 decline our request because they don't feel they have the experience to be considered ECD knowledgeable. We've had 10 of the 80 letters returned to us due to bad addresses. There are still 40 letters that remain unanswered. It is impossible to know if the letters actually reach those doctors who do not respond.

We are also receiving copies of journal articles that do not appear on the internet without paying a fee. We are working to see if we can gain permission from the publishers to post these papers on the website. If you have a particular interest in reading an article that you have been unable to find, please let Kathy know and if we have it she will get the information to you.