

Summary of 11-22-08 ECD Chat

Chat Date:
11/22/08

Time:
3 pm Eastern time

6 Attendees

Summary:

- A new patient was represented in the chat room. The patient's first symptom was hip pain and she was found to have a medistinal mass with lesions into her long bones.
- A question was asked of each patient represented about where their first primary source of lesions was found. The answers included:
 - Brain, causing lack of coordination, slurred speech,
 - Kidneys
 - Bones
- Some patients seem to find stress makes their symptoms worse. As a result some of these patients take anti-depressants to help them remain calm and better cope with the stresses they experience. At least one patient wonders if there could be a chemical change that might occur in the brain as a result of the disease.
- Some patients find weather conditions increase their pain and/or balance symptoms which leaves them feeling more tired and needing more sleep.
- It was mentioned that the website contains some good information regarding the interferon treatments that have been done at MD Anderson by Dr. Kurzrock. (See www.erdheim-chester.org 'Published Papers | Emerging Information...') Don't forget to look at the good information from Dr. Haroche as well.)
- A discussion was held about the rarity of ECD. So few people are diagnosed that it is considered incredibly rare. However, it may also be under diagnosed. The symptoms are so non-specific it is hard to diagnose, and because so few doctors have ever heard of it, diagnoses is difficult even with specific symptoms and signs.