

Summary of 11-15-08 ECD Chat

Chat Date:
11/15/08

Time:
3 pm Eastern time

8 Attendees

Summary:

- There was a good discussion about various treatments, side effects and how both those relate to sites of ECD activity. Summary of the discussion among the patients participating in this treatment conversation is:
 - Patient 1 – Currently having 3 weeks off from CD2a chemo treatment and then goes through one more 5 day treatment cycle. The hope is this will help the retro orbits and neurological symptoms being experienced. Tried azathioprine before but it caused problems with the liver.
 - Patient 2 – Tried chemo but it didn't work. Did radiology treatment on the eyes and it helped for about a year. Currently on tamoxifen and azathioprine which is holding everything steady with blood work at almost normal levels.
 - Patient 3 – Is taking interferon B (5 MIU 3x week) along with 5 mg of prednisone and anti-depressants which help to alleviate interferon caused symptoms. Although the interferon causes fatigue and flu-like symptoms intermittently, it has slowed the progression of the disease considerably. Provigil is taken as necessary to help provide energy. The pain level has been reduced since being on interferon.
 - Patient 4 – Started last week on interferon again at a dosage of 1miu 3Xweek. This patient tried a higher dosage in 2006 for 8-1/2 months but had to stop due to side effects (headaches, chills, nausea, fever, etc.). After stopping interferon the first time, vinblastine and prednisone were tried. After that methotrexate and remicade were tried. With all treatments there were too many side effects. Had radiation on the eyes in 2001 and 2002 but did not see any results, however localized steroid injections did help the swelling in the eye orbits.
- There was a brief discussion about the possible use of pegylated (long-lasting) interferon as opposed to regular interferon. The reported side effects of pegylated interferon are less than that of regular interferon for those taking it as treatment for other diseases.
- Interferon A vs. interferon B was discussed. Although at least some doctors say there should be no real difference in the use of these, at least

one patient is wondering if they see a difference in the level of fatigue-related side effects.

- One patient asked if others experienced pain in the neck and legs. Many expressed that aches and pains, especially in the legs is something they deal with. Another has pains in the arms. Still another has intermittent pains throughout the skeleton, often coming with no warning. A couple of patients have pains in the lower back/spine area. For some the bone pain results in muscle pain/spasming.
- Patients deal with their pain through the following methods
 - Aleve every 12 Hrs
 - Panadol (Tylenol) at night and sometimes during the day if it gets too bad
 - relief from headaches and neck pain by visiting a chiropractor
 - Ibuprofen
 - fentanyl patch
- There was discussion about how some patient's show bone abnormalities in X-ray and/or scans. Others have normal looking X-rays and/or scans yet still experience the bone pains.
- The participants were all reminded that it is possible to get copies of xrays and scans. They must be requested and can usually be provided on a CD and it will usually be done quickly and for free if told it is for another doctor (which it normally is).
- A short discussion took place about what a blessing it was that people had a place to share their experiences with others who understand.
- The ECD Global Alliance now includes 27 patients, 30 members. We've had 12 members join us via the website.
- There was talk about the rarity of ECD.
- Exercise options for those with balance issues were discussed. At least one patient uses a 3-wheeled bicycle for exercise. The possibility of water exercises and/or physical therapy as forms of exercise and/or help with balance issues were also talked about.
- There was a brief discussion on how to draw more patients/loved ones to the chat sessions.