

Summary of 11-30-08 ECD Chat

Chat Date:

11/30/08

Time:

3 pm Eastern time

9 Attendees

Summary:

- The chat room participants spent time getting acquainted and sharing their backgrounds. The following is a summary of information shared.
 - Patient 1 – Female. From Virginia. Newly diagnosed. Initially treated with interferon. Is back on interferon after a short 'rest'. Taking injections 3 times a week. Finding she has less pain now that she is back on interferon. Is having difficulty finding comfortable position for sleeping because of the bone pain and is investigating the use of a pressure relief mattress to help.
 - Patient 2 – Male. From Long Island, NY. Diagnosed in Vancouver in 1998 via biopsy of the orbits ("where it started"). Had a craniotomy to remove a tumor initially. Was initially treated with interferon and has been treated again for about 2 years, injection given 3 times a week. Has good days and bad days, mostly tired. Last CT scan showed no disease progression.
 - Patient 3 – Male. From Idaho.
 - Patient 4 - Male. From north UK. Diagnosed in 2005. Initial presentation was in the orbits, but there was no biopsy as a diagnosis was made in another way. Was on interferon but now finishing up his last round with chemo (2CDa). He never experienced many symptoms while on interferon.
 - Patient 5 – Male. From Florida. Took three years for a diagnosis.
 - Patient 6 – Female. From Melbourne, Australia. ECD first presented in the orbits although a correct diagnosis took some years after the initial biopsy.
 - Patient 7 – Male. From rural Georgia. Diagnosed 2 years ago. Has good days and bad days, mostly tired. He has been on interferon for about 2 years and has had a reduction in pain during that time. Last CT scan showed no disease progression.
- There was some talk of crankiness being a symptom of ECD and/or treatments. At least one patient finds anti-depressants help with this symptom.

- The HLA tests that Dr. Haroche in Paris is requesting were discussed. At least one patient has had the test performed and is awaiting the results to send to Dr. Haroche. Any patients wishing to participate in this study should have an HLA I & II blood test performed locally and the results sent to Dr. Haroche in Paris, France. To do this you will most likely need to have your doctor order the test. Some have discovered their insurance will not pay and the price is about \$1500. We are hoping there will be a solution at some point to this particular problem. To learn more about Dr. Haroche's study, see http://www.erdheim-chester.org/Dr_Haroche_HLA_Study_7-Oct-08.pdf. (Our UK patient is considering a trip to Paris!) (For information about the HLA blood test itself, see <http://www.nlm.nih.gov/medlineplus/ency/article/003550.htm>).
- Travel tips were discussed and the following suggestions given.
 - Take lots of breaks. If you can, get up, stretch and walk around every so often. It helps avoid cramps and such.
 - If you wear glasses (specs), take an extra pair in case they get lost or broken.
 - Plan, do what is necessary to help reduce stress.
- The Histiocytosis Association of America (HAA) National Conference on Histiocytic Disorders was mentioned. This conference will be held August 1-2, 2009 in Milwaukee, Wisconsin. It was thought if enough ECD interest was shown it might be possible to get some focus on the disease during the conference. To learn more about this conference, see <http://www.histio.org/site/c.kiKTL4PQLvF/b.4764623/>.
- There was a discussion about how to raise awareness of ECD. Because ECD is such a rare disease it is hard to raise awareness and get focus on the disease. However, because so few know about it there may be some who go undiagnosed. Some brainstormed ideas included:
 - Getting the media and/or politicians involved
 - Work to raise awareness of ALL rare diseases so doctors might learn to 'think rare' when diagnosing
 - Hold 'awareness' events at various locations
 - Set up an ECD conference via computer
- A question was asked if anyone knows the number of ECD cases diagnosed. Although the literature tells us there are about 250 documented cases, that does not mean this is the total number of diagnosed cases. If our group is any indication, most cases are not documented in the scientific journals. The HAA tells us they have had 59 ECD patients register with them since 2006 when they began tracking. The ECD Global Alliance has had 28 total patients register since April, 2008.
- The episode of the TV program, "House" that was about ECD was discussed.