

Summary of ECD Global Alliance chat held on Saturday 26th September 2009

13 Present:

- One patient is due to start cladribine on Monday, although the insurance company is still refusing approval to provide funding for treatment with this drug. A letter of appeal had been sent to the company and the patient is having to fund the first round of treatment themselves.
- One patient reported that their treatment with cladribine had gone well, with increased tiredness being the only side effect (no nausea nor weight loss). They are waiting for the results from tests to see if the progress of the disease has slowed. Another member described how cladribine had caused a metallic taste resulting in loss of appetite and weight loss; the patient had lost approximately 50 lbs.
- A member described how one patient has a new burning pain in their neck, with, unfortunately, no relief at present.
- A question was raised about the possible benefits of massage. One patient's doctors had recommended this. Another patient, who had previously been diagnosed with MS, said that they had been advised not to have massage to avoid over stimulating the immune system. They were intending to ask the doctor whether this was still the current thinking on massage and autoimmune disease.
- A patient described how reduced abdominal pain meant that they were now able to lie on their stomach (for the first time in 15 years!).
- A patient described how their doctor had suggested surgery to alleviate bone pain and/or to avoid possible fractures. The surgeon is proposing taking out a bone lesion and replacing it with a cadaver bone. There was no experience/knowledge of this amongst the people on the chat. The patient plans to discuss the alternative of radiation therapy at the next medical appointment.
- A question was asked about receiving a shot of neulasta at the end of each chemo cycle to ward off infection/ increase white blood cell count. One comment was that most people who have chemotherapy treatment do not receive this drug unless the immune system is compromised.
- There was a brief discussion about non-symmetrical lesions. The literature indicates that bone lesions in ECD are almost always symmetrical, but amongst the members on the chat there was knowledge of at least two patients who had non-symmetrical lesions.
- One patient on treatment with Gleevec had needed a iron infusion this week, due to low iron levels. Is this a side effect of Gleevec?
- Dr Vaglio has assured the group that he is still working on a study and we will be hearing something soon. He will be requesting as many medical records as it is possible to obtain.
- One patient has just been diagnosed with sleep apnea. It has been suggested that the patient may need to wear a mask at night. Some members commented that they knew of patients for whom a mask had been a great help.
- One patient is due to start Imuran to treat a growth behind an eye. They also have problems with their teeth caused by ECD and are only able to eat soft food. They will commence laser surgery in the next few months.