

Summary of ECD Global Alliance chat held on Saturday 3rd October 2009

9 Present:

- One patient who has been having a battle with their insurance company to fund treatment with cladribine reported that approval had finally been granted for six cycles of cladribine. The patient has just finished the first week of treatment (which consists of attending for 5 days for 2 hours each time) and said that they had not suffered from any real side effects. The next cycle of treatment will commence next month. In approving the treatment the insurance company acknowledged that all treatment options for ECD were experimental and off label and therefore they approved the treatment recommended by the doctors.
- One patient reported suffering from cold and flu this week, which disrupted their blood sugar levels.
- A patient has just started their routine rounds of seeing doctors again. The doctors include an ophthalmologist, an endocrinologist, a nephrologist, a hematologist, a local GP and a cardiologist.
- A patient being treated with Gleevec has recently seen their specialist who was pleased with the progress. However, the patient's blood counts had fallen, necessitating a blood transfusion. The patient had been advised to continue with the Gleevec, to continue to have regular blood tests and to attend for another appointment in two months time.
- A patient reported a significant amount of pain related to the kidneys, for which they were taking pain killers. Nausea, fever and aches, related to kidney problems, were also mentioned. This patient has taken prednisone for ten years and interferon for almost two years.
- Several members on the chat discussed bone pain, and felt that an increase in bone pain was linked to a change in atmospheric pressure.
- One member mentioned cramps, linked to a drop in magnesium or the legs becoming cold. Another patient had tried B12 injections to help relieve cramps, but so far with no effect.
- A patient described itching on the inside of the legs 'as if little bugs were crawling around'. Another patient mentioned that they had experienced the same sensation on their face.