

## Summary of ECD Global Alliance chat held on Saturday 4<sup>th</sup> June 2011

9 Present:

- A question was posted prior to the chat asking if any other patients suffered from shaking of the hands, to the extent that it is hard to type or text. Do any other patients have speech problems, either with speech itself or volume control?
- Another message posted prior to the chat was from a patient who had been on Gleevec for five months from November 2010 to April 2011. The patient thought that the Gleevec had not helped with the illness and after one to two months on the treatment they experienced some nasty side effects including debilitating fatigue, weight gain and double vision. The patient is now receiving some 'experimental' treatments, there has been no success to date but they will keep the group informed.
- A new member was welcomed to the chat and shared what had been happening to their partner. After two years of tests the patient received a diagnosis of ECD. They have been on kineret for the last four months but as yet feel no benefit from the treatment. The patient is now primarily in a wheelchair and has lesions on the brain stem and in other areas of the brain. There is inflammation around the heart and kidneys. The patient has slurred speech and their judgment/insight is also impaired. In addition to kineret the patient also takes methotrexate (20mg/week), prednisolone (10mg daily) and other heart medications. Treatment with interferon is under consideration at present. They have been suffering from edema in the ankles over the last few weeks (this is a problem that other patients on the chat also experience). They have had problems with their teeth recently, with six teeth being removed and have had 13 cavities. The patient's eyesight has been impacted; the muscles that move the eyeball are weak so when the patient sees double it is because one eye is moving up and the other down.
- Another member mentioned that, for their partner, the eyes being affected was the first symptom of a brain lesion in December 2010.
- One patient has been on the weekly dose of methotrexate for over a year (40mg a week). The scans indicate that the treatment so far is effective and there have been no side effects. Prior to this the patient was on interferon for about 18 months. There were no side effects but no evidence (from imaging) that the treatment was effective.
- One patient who had been on Gleevec for four months commented that they had noticed an immediate improvement until the treatment caused the blood count to fall significantly. The patient had to stop the treatment.
- One patient who has been on interferon for the last five years stated that it made them feel completely exhausted; however, the patient has been stable during this time. Other patients on the chat also suffer from debilitating fatigue.

- Another patient had taken interferon for three years until the insurance company stopped paying for it. The patient didn't think the treatment had been particularly effective, but may have kept the disease stable.
- A patient who has received treatment with Cladribine commented that the treatment had seemed to help.
- A patient who suffers from edema in the legs and feet has recently been diagnosed with IVC syndrome. The ECD has infiltrated the abdomen and the IVC is flat. The ureters are also closed off and the patient has had a nephrostomy for the last eight years.
- One patient has been in hospital since Easter receiving treatment for a brain lesion. The drug being used is dexamethasone (8mg a day). High dose methotrexate had been used as the treatment prior to this.
- One patient had used kineret for 18 months, which had been effective in relieving bone pain but not much else. The patient is now receiving Actemra (once every four weeks infusion) which is just as effective as relieving the bone pain as the kineret. The patient has only received two infusions so far but is hopeful that it will have some significant effect.
- Problems with teeth were discussed, with several patients on the chat/represented on the chat having experienced this problem. Several patients have needed extractions and have developed cavities over a short space of time after the onset of ECD. The dental issues associated with ECD are not yet well understood or documented. One dentist has prescribed an ECD patient as topical cream containing calcium, phosphate and fluoride. (Following the chat session the member who discussed the tooth cream provided the following website address for the product that had been prescribed: [http://www.gcamerica.com/products/preventive/MI\\_Paste/.](http://www.gcamerica.com/products/preventive/MI_Paste/))
- Several patients are planning to commence/recommence exercise programs shortly. The advice of a physical therapist has been solicited in at least one case.
- Several members have recently organized a fund raiser for the ECD GA, whereby a local restaurant gave 10% of all its proceeds from one evening.