

Summary of ECD Global Alliance chat held on Saturday 18th December 2010

11 Present

- A new patient was welcomed to the chat. The patient has recently had MRI and CAT scans which have shown ECD in the bone marrow only. Information on 'ECD knowledgeable' doctors was shared. Some of these contacts are available on the ECD Global Alliance website and it was agreed that this was a useful source of contact information for both doctors and patients. If any patients are seeing a doctor who is not listed on the website, it might be worth asking them if they would be prepared to be included.
- One patient has a new ECD growth in the brain, by the brain stem, near to the pituitary gland. The growth is progressing rapidly, causing bilateral loss of feeling in the face, loss of control of the eyes and loss of feeling in the fingers of the right hand. Members were asked if they had any experience of treatments for this particular situation. The drugs cladribine, prednisolone and interferon were mentioned. A patient commented that they had a tumor in the pituitary gland which had been there for at least twenty two years and did not receive any treatment for it, apart from desmopressin to replace what is not being made naturally.
- One patient was diagnosed two years ago. It took ten years for them to receive a diagnosis. They are affected in their lower legs, back and kidneys. They are taking Gleevec and doing well on this treatment.
- A question was asked about stopping treatment with interferon; had anyone experienced any deterioration in condition when stopping this drug? One member commented that their family member had stopped interferon a year ago with no noticeable deterioration.
- One patient is taking Low Dose Naltrexone for ECD.
- One patient has been taking 40mg of methotrexate for the last ten months and is doing well.
- There should shortly be an announcement about Dr. Vaglio's study in Italy. He will be looking for the medical records of patients who have been diagnosed longer than six months in the hope of being able to suggest a classification of the disease. It is hoped that as many patients will participate as possible; this is an opportunity for us to increase understanding about ECD.
- Two members have recently organized a very successful fundraising /awareness raising event and appreciation was expressed for all their efforts.
- Members wished each other a very Happy Holiday and Merry Christmas.
- The next chat will be held on Saturday 1 January 2011.