

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

8 Present:

- One member kindly posted an update on their relative's progress. Recent repeat scans have shown no changes, however, the patient still has significant problems with balance. A doctor has suggested vinblastine instead of interferon; the member would be interested in hearing from others who have experience of vinblastine. With regard to interferon, the patient had been told that the multi dose injection pens were no longer available and larger needles had been supplied instead which were difficult to use. Another patient represented on the chat had experienced similar problems with their interferon supply.
- A patient asked whether anyone had taken methotrexate before. If so, was there any improvement and how long did this take? No-one on the chat this time had experience of this drug.
- One patient who has been taking Gleevec has discontinued it due to health problems. Although the drug seemed to effect an improvement for the first three months, it then seemed to start causing problems without any change in the underlying symptoms. Splitting the dose between morning and evening did not help.
- One patient had been suffering from back problems, where a mass is located.
- The newsletter editor recently requested pictures of ECD patients for the next newsletter. Please send these to stanceforlance@hotmail.com.
- Members were looking forward to the group receiving a tax exempt status in 2010.
- Members all wished everyone a very Happy New Year!