

Summary of ECD Global Alliance chat held on Saturday 21st August 2010

9 Present

- A journal article has recently been published describing two ECD patients who took anakinra to good effect. The patients had previously been treated with interferon. Anakinra is marketed in the US as kineret. The abstract of the paper may be found on the link ‘
”<http://bloodjournal.hematologylibrary.org/cgi/content/short/blood-2010-04-279240v1>”.
- Members were reminded to submit information for the case log update if possible.
- A question had been raised regarding how many patients were still working. Of the patients represented on the chat, one stopped working in 2004, one in 2005, one in 2007 and one in 2009. One patient is self employed but has had to cut back on working significantly and there are periods when they do not work at all due to surgery. One patient still works a 40 hour week but due to eyesight problems, no longer works after 5pm nor does on call work. Amongst the members who no longer work, some undertake voluntary work as their condition allows.
- One patient’s doctor has suggested treatment with Gleevec and asked if there was any experience with this drug in the group. One patient has recently started taking Gleevec to very positive effect; they now have much more energy and are pain free. They experienced stomach problems initially but these resolved after the first week. (Another patient, not at the chat session, also suffered from stomach issues whilst taking gleevec and stopped the treatment.)
- One patient is taking a low dose of methotrexate weekly and the last PET CT scan showed an improvement. They have had no side effects with this treatment.
- One patient had to stop a clinical trial with Enbrel after only two weeks as it was too hard on the heart.
- Several members described how they had experienced problems getting into the chatroom.
- The topic of fundraising for the group was discussed. One suggestion was to try to get ideas for fundraising from other local groups. One member has written to businesses asking if they would consider asking for a \$1 donation on their charge machines. One member has contacted a restaurant chain to see if they would donate a proportion of each bill. Consideration is being given approaching an art college to see if students would donate pictures for sale.
- One patient sees a homeopathic MD and has found the supplements they take helpful.
- Several members take St Johns Wort for depression and have found this to be effective.
- The next chat will be held on Saturday 28th August 2010.