

Summary of ECD Global Alliance chat held on Saturday 10th April 2010

10 Present

- The question for this week's chat was 'When you are feeling especially down, in more pain, depressed etc, what are some things people do for you that helps you manage? How did the things they did help you?'
There was only a brief discussion on this question, with one caregiver commenting that they always felt better when people took the time to recognize what was going on and to offer support. Often it was just knowing that someone cared that made the biggest difference.
- It was mentioned that it may be helpful to include the question for discussion in the notification e mail that is sent out a few days before the chat and the possibility of this will be considered. The question for discussion in the next chat is always included in the summary.
- One patient has finally come off prednisolone and has found the tapering off the drug difficult, with days 7-9 after a reduction in dose being the worst. The patient has recently been disappointed to hear that treatment with Kineret has not gained approval; doctors are considering the drug Tarceva although the patient does not yet understand the reasoning why. The patient is hoping that the decision will be re-considered and has read promising reports that Kineret may help in the treatment of pericarditis. They are exploring ways of challenging the drug review process in their area.
- Several patients in the group, have, or have had, cataracts and one patient is awaiting surgery at present. It was thought that past steroid treatment was a factor in the development of cataracts.
- One patient who has granulomas on their lungs/ribs described how they lose their voice when they lie on their side. The patient has been on Imuran for a year now, with no improvement and the development of some new granulomas. Doctors are considering cladribine as the next treatment; several patients in the group have experience with this treatment.
- The group has been encouraged that there are a handful of researchers interested in learning more about ECD and who are looking to the group to collaborate with them in their studies.
- One patient who suffered from bone pain since the 1990s has found treatment with Kineret to be very effective, with the bone pain almost gone. Previous treatments had been unsuccessful and had only managed to take the edge off the pain.
- One patient who has just gone back onto interferon is finding that they are ill for 24 hours after the shot. They are hopeful that things will get easier the

longer they are on the drug. They had previously been on interferon for three years until the insurance company withdrew approval and it was stopped for three months.

- The next chat will be held on Saturday 17th April at 3pm Eastern time.

Question for discussion in next week's chat

I am at my worst when.....

and I am at my best when.....

Please share with the group the whys and whens of your answer.