

Summary of ECD Global Alliance chat held on Saturday 29th May 2010

9 Present

- One patient is currently awaiting approval from an insurance company for the drug Enbrel. They have had 10 months of prednisolone, which has brought no improvement in their pericarditis, so their doctor has decided to try something else. They have been suffering from a fever since coming off the prednisolone.
- A patient recently received the results of their PET CT scan which showed an improvement. The patient is currently taking 5mg prednisolone a day and 40mg methotrexate a week. Another patient mentioned that they had been unable to tolerate 15mg methotrexate a week, as it has caused stomach problems.
- One patient takes Advil and prednisolone for pain relief.
- One patient described the strain of being a caregiver to their partner as well as suffering from ECD. This patient has had an especially difficult few weeks, with their partner only recently being discharged from hospital and requiring a significant level of care.
- A patient who started pilates a few years ago and has found it very helpful has recently ordered a pilates reformer bed, to help with stretches/core exercises. It is hoped this will alleviate the extra muscle damage caused when doing pilates but not taking enough care. Another patient said that did gentle Tai Chi which helped their balance.
- One patient has recently been diagnosed with rheumatoid arthritis; it is not clear whether this is linked to ECD.
- There was a brief discussion in the subject of fundraising; several members have been working hard on various ideas for fundraisers. The point was made that we need to market our need so that it stands out from the other 7000 rare disease organisations that also want help. It might be better to try to produce something that people want rather than ask for others to give to us?
- The next chat will be held on Saturday 5th June 2010 at 3pm EST.