

Summary of ECD Global Alliance chat held on Saturday 22nd January 2011

11 Present

- A patient who is at present in hospital receiving treatment with high dose methotrexate for a brain lesion is making good progress.
- One patient who has a pericardial window reported the good news that they have no more fluid around the heart.
- The benefits of regular exercise for patients were discussed; one patient has taken up swimming recently and plans to swim three times week.
- Various forms of alternative therapy were discussed. One patient takes a variety of supplements on the advice of a homeopathic MD. Several other patients represented on the chat also take supplements. Patients had also tried reflexology, reiki and lymphatic massage. One patient had found that seeing an osteopath helped with symptoms such as muscle spasms and muscles pulling unevenly. The same patient has also found Pilates helpful in maintaining core strength and flexibility. The importance of informing doctors of any supplements taken was mentioned due to the possibility of drug interactions. Patients may like to submit information on the supplements they take for inclusion in the case log, which is available on the ECD Global Alliance website. The case log is anonymised but does give others a view on what others are experiencing with ECD.
- Several patients represented on the chat had experienced problems with shaking. One patient said that when tired they start to shake and their balance deteriorates. This patient also described feeling a 'hum' in the nervous system. One patient said that their hands started to shake after they had commenced treatment with interferon. Two patients have experienced tingling and numbness, in the arms, legs and feet. One patient described a feeling of 'ants walking across the hand.'
- Dr. Vaglio who has recently started a study on ECD is hoping that he will start to receive medical records from patients soon. If anyone needs help in working out how to obtain records, please send an email to the usual address.
- The next chat will be held on Saturday 29th January at 3pm EST.