

Summary of ECD Global Alliance chat held on Saturday 7th November 2009

Number Present: 12

- One patient taking Gleevec reported that the treatment continues to keep energy levels and breathing at a good level.
- One member asked a question regarding bones and ECD. The patient has severe knee pain, thought to be caused by the tendons rubbing on the bony growths of the patella and surrounding bones. Does anyone else have this problem and do we know if the bony growths are related to ECD? Two people on the chat had heard they were related to ECD, with three people reporting joint pains. Several patients reported that the weather, particularly a rapid change in barometric pressure, caused an increase in bone pain. Increased humidity also caused problems for some patients.
- One patient is experiencing increasing problems with angina. Another patient suffered from this some years ago and required a coronary artery stent.
- A patient who had previously had pain scores of 7/8 had found that commencing treatment with fentanyl patches had helped with pain control such that the score was now usually around 3.
- The drug sirolimus had been suggested by one doctor as a possible treatment, but there were difficulties in gaining approval from the medical insurer for this particular treatment. Several patients said that their doctors had engaged in discussions with insurance companies to try to obtain treatments, with varying degrees of success.
- There was a discussion on the strains and difficulties of being a caregiver and support was offered to all those who undertake this role.
- A question was asked about the type of doctors that patients who have ECD see. Amongst the members on the chat, there was a wide range of specialists that were consulted, including oncologists, ophthalmologists, nephrologists, endocrinologists, rheumatologists, neurologists etc. One member advised trying to see a consultant who had seen multiple cases, or, if this is not possible, to see someone who is prepared to discuss your case with a consultant who has seen other cases.