

## Summary of ECD Global Alliance chat held on Saturday 23rd May 2009

8 Present

- The difficulty in obtaining a diagnosis, in finding a doctor with some knowledge of ECD and experience of treating other patients was discussed. One of the aims of the group is to increase awareness among doctors and hopefully therefore increase the number of cases diagnosed. The difficulty in dealing with the unknown in trying to cope with ECD was described and everyone on the chat agreed.
- People discussed different therapies they have used in trying to cope with the effects of the disease. One member has used reiki, another member goes to an osteopath regularly to relieve muscle pain/spasming that seems to arise from ECD bone pain. Another member is planning to have some reflexology sessions soon to help with the problem of cold feet! The benefits of exercise were discussed, one member described how they find pool walking helpful; this can be useful exercise for those with balance problems as the water aids support. The importance of having periods of rest, of pacing yourself and not 'overdoing things' was also mentioned.
- Several members reported that ECD had started in their long bones. There was a discussion about where the deposits form and the cause of the bone pain. There were some differences in what members had been told about where deposits form.
- One member is due to have a first appointment with Dr Kurzrock (in Houston) in June. Another member reported a very positive experience in consulting Dr. Kurzrock.
- One member who has started taking interferon in February reported that it was going well. One member who has recently started cladribine therapy reported that it was going well with no serious side effects.
- One member who has recently seen Dr. Haroche (in Paris) reported that the tests in France had revealed one new piece of information (ECD in the atrioventricular groove in the heart). Dr Haroche had recommended a transfusion of antibodies, due to a lower level of antibodies in the blood, but, as the patient is currently well, this was not planned at present.