

Summary of ECD Global Alliance Internet Chat

11 June 16

7 Attendees

- Before the Chat started a member came on to apologize for his absence. He was going to the Belmont Stakes, (a horse race presumably). His usual excuse for missing Chats has been "going to a communion". He seems to be going DOWN in the world!
- A member told us about his new mattress. He had overslept his alarm by 3 hours, but that gave him more energy for his volunteer work and his exercise class.
- Another member said that when he gets pain he sleeps on a mattress with "pimples". He said that it is like acupuncture. He was asked whether it was "a bed of nails", but he said it was a "flower carpet of rose-shaped flowers whose ends are sharp".
- A member has found that massage is very good for loosening body stiffness. This month he will start weekly massages lasting 1 - 2 hours. Another goes twice a week to the physio and also has a massage with jets of water.
He wants to get his condition stable without drug treatment. He is trying to use "natural methods" as much as he can. But he is afraid that he will "have to take those damn drugs". He is especially afraid of side effects. He said that he was lucky, in that he was retired now and didn't have to work!
- The wife of a member, who has had very good results from vemurafenib (V), told us that he had gone shopping his carer. It is for their daughter's birthday party. He still has balance issues, but wants to move. He will be seeing the physio soon. He had been ill for many years with no treatment. He got worse, and then started V 4 months ago, and now his quality of life is much better. It is not just the V, it is also the additional help - community home care -OT, having the right wheelchair, and finally having the right doctors that know what to look for. He is now being properly monitored. Exercise and a good diet are encouraged. He is just waiting to see the physio. He saw the first "ECD doctor" 6 months ago. He has been lucky that side-effects have been minimal and he is now able to work. He will be having another set of MRI and PET scans at the end of August.
- A French member is still awaiting confirmation of the diagnosis after his biopsy, but he has a lot of the conditions that are associated with ECD (leg pains, hairy kidneys, eye problems, and pain in the lungs). He thinks that he can contact a rheumatologist. He has not seen Professor Haroche yet, but the team that follows his case is associated with him.
- Another member has been referred to an Endocrinologist for further opinions about bone metabolism. One of the radiologists that had seen his scans had had one previous case with a similar bone scan, and was confident enough to point out ECD as the primary diagnosis. His tests reveal increasing bone size; his femurs are growing thicker in the bottom half, which, while it is in the process can be painful, comes to an end after months of bone remodelling.