

Summary of ECD Global Alliance Chat 17/09/2011

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12 Attendees

- It was announced, with sorrow, that a member of the Alliance, who had been involved in the Chat Group, has recently died. This was due to the effects of ECD, and he was only 60. We all offer our deepest sympathy to his loved ones.
- Another member said that he had been in hospital for the last 3 weeks. He had had surgery for an infected elbow. He also had his gallbladder removed. He wonders whether the hospital had a special offer that week! He is feeling better but has some bowel upset.
- A member who has been having back trouble said that therapy was helping. Another asked whether any others had had similar issues. One volunteered that he had had spinal compression fractures, found on a routine scan, although there had not been much pain. Another member had only previously considered osteoporosis to be the cause of the back pain and would now think about these other possible causes. The doctors had suggested injecting a sort of cement into the broken bones to strengthen them, but this was not a very enticing prospect.
- Some members have used TENS machines, themselves, and one Chatter's relative had used one. It was generally agreed that these were good things to use and effective in helping with pain.
- A member who has just started interferon therapy had been feeling a bit tired, but otherwise was doing well.
- Two members have been in touch with the NIH team and have start dates. One, who is traveling from Europe, is bringing her mother and sister with her, and is hoping to have a "vacation" too. Scheduling the stays has not been difficult. One member is having to get her records translated into English, but plans for this are in place. It was said that the NIH most likely have their own translation service, but this is unlikely to cover every language.
- There will probably be evening passes provided, to let people leave the hospital, when they are not needed for tests.
- NIH have not specified yet whether they need participants to be present for 4 or 5 days.
- It was thought that there is not a hotel facility on campus at NIH where relatives could stay.
- We were reminded that a member completed the Iron Man competition that he was participating in. (That was his 2nd competition too!) Congratulations!
- A member has had some stomach problems and is seeing her doctors for follow up this week.
- We were given details of the current swimming activities of one of our members and her partner. She is doing very well.

- Members were pleased at the contents of the fundraising report. It is hoped that a Development Director, in a paid position, will be soon in post.
- A member joined us who has just been to see Dr Haroche, in Paris, for his 6 monthly check up. He has been taking Pegasys 2a interferon for the last 6 months, as well as other medicines. Scans have, unfortunately, showed that the disease has progressed a little, despite treatment.

Dr Haroche has increased the dose of interferon, and is confident that the disease will slow down. The member is going to be seen again in 6 months. The member is relocating from France to the UK, and was advised to contact UK(the member, not the country!) regarding this (which he has done already).

- Members discussed whether they had had skin lesions or not. A number had had skin lesions of various types.
- A member joined the chat after everyone had left. He had been trying to logon for a long time. His computer/modem were not playing ball. A recent shoulder problem has required an MRI scan, but no results have been given yet.