Summary of ECD Global Alliance Internet Chat
24 Nov 2012

10 Attendees

- Before the Chat started, a new member came on telling us her situation and difficulties. Her husband has ECD, and they have just returned from a visit to Bethesda. The overall findings were that things were generally OK. But, she did find out that most patients on interferon, take it 3 times a week, whereas her husband is only prescribed it as once a week injections.

  Her husband has long bone, skin, and brain lesions. He gets very tired, and his walking ability has diminished. He also has diabetes insipidus. She is finding that being the “caregiver” is becoming difficult. She is trying to find out more about this disease. She has come across some doctors, who seem to be afraid to even want to learn about the disease.

- Also, before the Chat we were “visited” by Alex. She is the daughter of a deceased patient. Her grandparents are founding members of the organization. Alex would like to join our Chat Room. Her mother was diagnosed with ECD in 2008, and died, in 2010. She would like to know of anything that she could do to help with raising money for our organisation.

- A member has been able to go out for a meal, with his wife, this week, and to attend the monthly meeting of his local Ataxia Self Help Group. This member has also booked to go out for lunch on Christmas Day. He was congratulated on having no cooking, or clearing up to do! And also congratulated on the news that his wife is well ahead with Christmas shopping!

- A member said that they had missed the Chats for approx 1 ½ months because they hadn’t had an internet connection.

- Two members had met recently, and enjoyed each other’s company. Hopefully, more of us will be able to meet at the San Diego convention, being scheduled for November 1-2, 2013. All members are invited to attend. Please put the date on your calendar. You will be hearing more about this in the months to come.

- Our member, who has recently been ordained a deacon was asked how things had gone. He said that it had been “a marvellous ceremony and reception after, and I had a good weekend with family, and assisted at Mass on Sunday, and since have been finding out what it all means. It is definitely 'me'.”

- A member, who has been having balance problems, is still having difficulty. He has been trying to vac his yard and can hardly stay on his feet. An ENT appointment is awaited. He was asked whether he had a brain scan, and this has been done. No new brain lesions were seen (just a lot of empty space!). He has also been having problems with a painful shoulder, which he thinks is due to bursitis. And, to put a cap on things, his breathing is not too good. On his trip to Bethesda, ECD was found to be in his lungs.

On a lighter note, there has been some “interest” in a song that he has written, and he is excited about this.

- One member told us that they live in the Houston, Texas area, and then a member, from Australia, told us that he had lived in Houston from ’89 to ’95.

  The member, from Houston, sees a Dr at MD Anderson. She also has rheumatoid arthritis (RA), and her Drs, for ECD and for RA, are trying to work out a suitable treatment. She is still on treatment for the RA, for which she takes methotrexate, and has Remicade infusions. She will have more tests at MDA on Dec 10. The ECD has only been diagnosed 4 months ago. Methotrexate for RA is used at a low dose, usually 15-17.5 milligrams, in a once weekly dose.

  Another member has been taking methotrexate, as the main treatment for his ECD, for a couple of years. He also takes it just once a week, but the dose is 40milligrams. This treatment has coincided with much better scan results. There had, previously, been brain and other organ involvement. The methotrexate is going to be continued “until it stops working”.

- A member was asked whether he had been able to do any woodturning recently (this is one of his hobbies). He has made over 40 ornaments, 15 bird houses, a large walnut bowl, 10 maple vases, and 3 hamburger presses, for the Artistry in Wood show (Nov 10 & 11). Unfortunately, he is still having problems with his balance.

- A member is having difficulty sleeping, especially if he is disturbed during the night. He thinks that the sleep problems make his balance difficulties worse.

- A member told us that they had been “missing” for a while, because she has downsized to a condo, and then “crunched” a couple of vertebrae, which had laid her low. These are getting better now, but there is a way to go yet. She is glad that she made the move - the house was too big for her to live in, and care for, and had it lots of stairs!

- Another member told us that they live in an area which is hilly, and lots of people are finding that getting up and down their stairs is becoming impossible, so they move to a single level house or apartment and down size in the process. He, himself, is hoping to stay in his home of 30 years. The house has had a lot spent on it, kitting it out and modifying it for single level living, and disabled access, but NONE of this helps to deal with housework.

- The member, who had just moved, was asked whether she had had fun going through all the stored stuff, and had memories brought back as she chose what to keep. She said that she had kept more stuff than she would have room for, but some things were too important to lose. So she has not finished unpacking yet! Her kids all live close, so they got a bunch of memorabilia too.

As regards her ECD, she is hoping to be well enough, to get back to Houston in Jan. for an ECD check-up. The disease seemed to stabilize a couple of years ago, but, now, she is having more trouble breathing. Her ECD mainly affects her lungs, although she does sometimes have abdominal problems too.