## <u>Summary of ECD Global Alliance Internet Chat</u> 08 Feb 2014

7 Attendees, 7 people checking in and leaving messages after the chat

- A member told us that she appreciated the help, that had been given by the other members on the Chat, to her and her husband. They had had a very difficult time at first, but he is now on weekly interferon, less tired, and less ill.
- There was the usual discussion of the weather in the different locations where members live. The hottest night temperature ever recorded in Australia, rain in Belgium and the UK. Snow in the US.
- A UK member said that "ECD patients are like buses. None for 8 years, then 2 on your doorstep in 2 weeks!" He has been visited by 2 other UK members recently. Both of them have come for tea and cake, after their clinic visit to the Prof in Leeds. All three attend the same clinic. One of them has just started Vemurafenib. The other spends most of her time on a Greek island, flying back to the UK for her clinic appointments and scans! She brought some olives and Greek cakes, which were much appreciated.
- A member, who has just started work as a deacon in a new parish, is settling in. He is not
  enjoying the 20 min. commute, which tells him that he has been spoilt, over the past 10 years,
  having mostly a 3-minute commute.
- A member has been given the good news that he is stable. His treatment has been Intron for 6+ yrs, and his doctors have him on a "if it ain't broke, don't fix it" plan. He does have to go back on testosterone injections for a while but he can "deal with that".
- A member is using "Dragon Dictate", a speech recognition program. This program has to "learn" the way that you speak, and it then converts your speech into typewritten words on your screen. At first it makes quite a lot of mistakes in it's attempts to check the sounds you make with it's library of your spoken words. And so, at first, it types things that you have not said. When such a program has been "taught" how you speak, it should cope with any slurring, or odd pronunciations. For the computer to learn your speech pattern you must speak to it! One member had to read, out loud, a whole chapter of a philosophy book to his PC! But he now can't find the speech recognition program to switch it on! But at least he has learnt some philosophy!
- A member, who has wood-turning as his hobby, has recently been to Tennessee, to a wood-turner's show. "It was a great, we got to meet a lot of nice people and see some beautiful work. I even won a prize."
- A member, who has been troubled with falls, told us that he had only had a few recently. A Doc has recommended physiotherapy for his shoulder, but he has to clear it with his family doctor first so that it will be covered by his health insurance. He has just switched to Humana, as that was the only company that his family could afford. He has been on a Medicare supplemental.
- One of the UK members is hoping to meet another one again. He has recently started vemurafenib, and his wife is making a list of jobs for him to do when, or if, he gets better. Since starting vemurafenib he went from gasping for air, to being able to breathe, in just the first 2 weeks. He has now started to get some side-effects, and told us that he looks like he has been out in the sun all day!

- Then members reminisced about the things that they used to do before getting ill, and how the ECD had stopped many activities. They agreed that they all had to do what was still possible.
- A member told us that when he was weighed, at a recent clinic visit, he had lost 12lb. He had been over 190lbs, and had been worried that he might need to start wearing a bra!
- A member left a message after the chat saying, "I just wanted to let everyone know that with having all my dizzy spells and passing out my dr had me take and EEG and wear a 48hr heart monitor this week. the EEG results were normal. I have not yet returned the heart monitor but hopefully that will have an answer."
- Another member came on after the chat was concluded, stating, "Missed the first chat session since a "most consistent to ECD" diagnosis for my husband. I look forward to the community."