

Summary of ECD Global Alliance Internet Chat **05April2014**

8 Attendees

- Members spoke about the signs of Spring. Some of the US seems to be still stuck in winter. A member in the UK said that there were lambs about. Another asked where they had come from. The reply was that they had probably come from mummy sheep or maybe from the North Pole in a big wagon driven by Santa! It should be said that, at this time, all the Chatters were men! They continued to be silly. One asked "How many feet have forty sheep, a shepherd, and his dog?" The answer is 2. Sheep have hooves, the dog has paws, and only the shepherd has feet!
- A member has stopped driving because his double vision has made it unsafe, both for him, and for other road users. This has meant that his wife has to drive him everywhere. He is concerned that she has to come home and deal with "all my stuff" after working a long day. He was asked whether there was someone in the church, that he attends, who could help him to run errands while she was at work. He said that they offer to help, but he doesn't like to bother them. He was encouraged to take people up on their offers of help. People enjoy the chance to help others who they care about.
- We were told that one member is going to be going to see Chris Botti (he is a world famous trumpet player). Another trumpet superstar, Wynton Marsalis, will soon be playing in the North of the UK, and one of the Chatters may well go and see him.
- A member told us how she and her husband were doing. He has just finished a year of chemotherapy for bowel cancer, and his recent surgery has shown good results, but recovering from the surgery and the chemotherapy will take time. She, herself, will be finding out more about her treatments in a couple of weeks. She has 3+ days of tests coming up in the week of 14th of April, if Medicare will cover this. She has just got an email from the NIH, and she is planning to go there in the Summer or in the Fall. She had tried to get there earlier, but with her husband's problems, this was the best she could do.
- We got more details of the potential difficulties in using a speech recognition program. The program has to learn your way of speaking, and this takes time and practice. The member having the difficulties was told that he was welcome to come into the chat room and leave a "message of the day" to get in his practice! Tongue twisters were suggested. "She sells seashells by the seashore", "Peter Piper picked a peck ...". And for the more confident (and daring) among you; "I'm not the pheasant plucker, I'm the pheasant plucker's son, and I'm sitting plucking pheasants in the pheasant plucking sun." Or to change things around a bit; "I'm not the pheasant plucker, I'm the pheasant plucker's mate, and I'm sitting plucking pheasants 'cos the pheasant plucker's late!" [No mistakes on either of these when there are elderly ladies, or children, in earshot!]
- A member has started doing some physiotherapy exercises to ease his arm pains. Another member has a book of exercises that can be done sitting in a chair. This came from the VA in Asheville.

- Kathy asked those thinking about going to the Patient Gathering in September - are there any topics that they would especially like discussed? It would be helpful if people could let her know if there are things that they are expecting to hear about, then she can make sure that these are on the agenda!
- A member said that a recent renal CT scan, requested by a urologist, had shown some "funny stuff" around the kidneys (?hairy ones). His medical team is going to look at the scans, and the urologist has ordered a mag3 nephrogram. This is a nuclear medicine scan which looks at how the kidneys are producing the urine, and how the bladder deals with getting rid of it. It is being used to see if any of the urine in the bladder is going "the wrong way" back up to the kidney. This can be the cause of repeated urine infections.
- One member told us that a company called Trovogene is marketing a urine test for BRAF. It is still being investigated, but early results look promising.
- A member asked about the procedures that would be needed for him to be able to donate his body to science. If a person wants to donate his body to science, he needs to let his local doctors know. Then they need to contact the NIH to make all the necessary plans.
- A member, who has been having difficulty moving about, told us that he has been doing better lately. Stairs have been less of a problem.
- A new member came on after most of the other Chatters had left. She is from France, and has been told that it is very, very likely that she has ECD. It is affecting her maxillary and leg bones. She had surgery for a tumor in her nose 7 months ago, and the results of the biopsies show probable ECD. She is 39 years old and lives in Burgundy, 2 hours drive from Paris. She spent a year as an au-pair near Chicago, some 20 years ago! Then she worked as a flight attendant, but she quit in order to take care of her children. She also studied English at university but that was a very long time ago! She said that she could have been a teacher but she felt "too much like traveling!" She has already seen Dr Haroche and will see him again before the end of the month.