

Summary of ECD Global Alliance Internet Chat

July 06, 2014

8 Attendees

- A member left a message to say that she would not be with us this week. She had an 80th birthday party to go to. She told us that she was having more dizzy spells. She wished us all well.
- A normally talkative member had got a migraine so he said that he would limit his contributions!!
- The member who broke a rib in a fall recently said that he was improving, and would soon be able to shout!
- Today, the Tour de France cycle race had started in the UK. More than a million Brits turned out to watch. Roads closed everywhere! Our UK member had not been tempted to join the crowds!
- A member, who has recently gotten new glasses with prisms in them said that he was now getting used to them. Prisms are needed by another member, too. Otherwise he sees 2 of everything, even close-up stuff.
- The ECDGA conference in the autumn was mentioned. The doc that sees at least 3 of our UK members will be attending, as will a couple of his clinical team. It is fortunate that there is also another conference of interest to them nearby, and they can catch both! This doc has told one of our members that he has 15 patients now (and one of us was his very first!).
- A member is trying to have his NIH visit near the conference time, so that they can both be done on one trip. Another member said that she had just cancelled an NIH trip at the right time, so he could try to book it.
- A European member will be attending the conference with her boyfriend, and they will take some vacation days. They are thinking of arriving a few days before the conference to do D.C., and then maybe N.Y. She has been there before but her boyfriend has not. Her sister is turning 50 on Sep 21 so she is trying to meet up in N.Y.
- A member lives in Philadelphia, and offered to help show people around. He offered to show people the "bad neighborhoods". He said that no protection would be needed 'cos the bad guys are his friends!

- A member had seen a picture that had been posted on Facebook by a member, and noticed that it had attracted some comment (an old nickname had been used). The poster of the picture said that it was just a reference to a very old joke.
- A member told us that she was having a bad time with her left leg. A knot has come up beside the bone and is causing lots of pain. She has recently seen Dr. Janku and is having a PET CT this week.
- A member said that his recent visit to his oncologist went well. His docs say that they "love to see us coming", and that the member and his wife are "so thoughtful & nice". A (cynical) member, who used to be a doctor himself, said that "they can hear the cash tills ringing!! Makes `em happy". The oncologist is retiring in the next couple of years. The cynical member said that the doc would be needing time to spend all those \$\$\$\$\$\$\$\$!!
- Members talked about exercise. A member, who has had good effects from V, said that she has had 2 physical therapy sessions and 2 great workouts with her personal trainer at the gym this week.
- A member has an Elliptical training machine that he can use because there is no impact on his bad leg. Another has a recumbent exercise bike. He admitted that he doesn't use it a lot because his left knee has been painful (that's his excuse). This is also non-impact exercise but, obviously, there is a round and round movement.
- We were told that a doctor will be coming from Australia to the conference! That means that there will be doctors from 4 continents in attendance at the Medical Symposium, with many of them staying over for the Patient Gathering. There certainly seems to be a building interest in learning more about ECD. One doctor has recently indicated that he was seeing more and more patients. This may well be because more patients are being diagnosed.
- The woodturning member has been doing pretty well. He worked in the garage on Thursday with his 18 year old grandson. Mostly this was cleaning up, but he made a few things, too.