

Summary of ECD Global Alliance Internet Chat

02 Apr 2016

9 Attendees

- The Chat started off with a discussion about being "dry needled" by a physical therapist, as part of treatment. A member is going to have this done on her hip. A "dry needle" has no medicine. It is just used to "stir up" the tendon or muscle, with the goal of loosening muscles or tendons around her hip joint to relieve pain. See:
<http://www.neurosportphysicaltherapy.com/services/dry-needling>)

- Tiredness was discussed, particularly for those taking vemurafenib (V). The answers varied from no tiredness at all, some improvement, to one member, who was not overly tired, but said that anyone who gets up at 0430 for work should be tired! One member said that his wife does this on her days off! Although she had slept in that morning until 0700. She has to be up and ready to let her husband's caregiver (or PSW) come in. The PSW comes every morning to look after him.

At his next doctors visit she is going to ask whether vitamin and hormone levels are measured in his fortnightly tests. He goes for an EKG, has the blood test and sees the doctor every 2nd week. On the last test the doctors were concerned about his heart beat, which was occasionally a little long (in "Doctor-Speak", the doctors have probably noticed that the QT interval is sometimes extended). They want the other medicines to be adjusted to stop it, presumably.

He was asked about his progress on vemurafenib (V). The V has made him feel better than he can remember in the last 7 or 8 years! He is walking better with improved balance. He does feel tired, but also feels stronger. He also thinks that his speech is better. He still gets shaking hands, and this has gotten a little worse on the V, but he "can cope!" He recently met someone who had seen him earlier in the week and during the previous 4 years. She was amazed at the difference. He was even able to walk around and give a "guided tour".

- A member said that she also has shaking hands, which started after going on the V.
- A member who has been on V said that he gets short of breath a lot (this must be quite a problem for a trumpet player!).
- Members discussed their plans for going to Paris. The recent events (the attacks by ISIS) has given some concern. Some are planning to be there just for the conference, while others are going to stay longer.
- The member whose son has been working at a golf course in New Zealand, told us that he has just come back to the US and is at The Masters to work the golf tourney there.

- A member has had a week where her head "swooshed" everyday, for an hour or two. It was so loud that she couldn't hear very well. One day she was "such a mess" that she took Advil and went to bed. Her blood pressure was 116/54. An hour later she felt better and it had gone up to 130/90! She is still a bit dizzy but doesn't fall anymore.