

Summary of ECDGlobalAlliance Internet Chat on 22 Mar 2014

9 Attendees

- A member who missed the chat last week because she was out partying was at it again! She left a message to say that she was "going out again tonight to some girlfriends so won't be here for the chat". She has been on Vemurafenib and just had her 3 month check. This went VERY well. Her MRI is looking more and more normal, and the PETCT scan had improved too. She said that, now, exercise and rehabilitation are the keys. She went to a wedding yesterday, and sitting at the table for a 7 course meal and speeches was horrible for her legs, but generally she feels great!
- A member came on whose husband died while he was having chemotherapy for ECD. She told us that she had some major news. She has relocated from the UK to the US, taken a post as director of a technology centre near Philadelphia, and currently staying in a hotel in only about 15 minutes from where another chatter lives.
- Our member who likes to do woodworking has finally managed to get some done. The cold weather has been holding him back.
- All members were looking forward to Spring.
- A member, whose wife passed away a little over two years ago, dropped by to say "Hi". He follows the Chats by reading the summaries.
- Two members live in the same county of the UK (Yorkshire). They see the same specialist for their ECD. One has started on vemurafenib, and is doing well. He has been to the other's house for lunch and afternoon tea, after a clinic appointment. Another member, a woman from the Peak District (although she spends most of her time on a Greek Island) also sees the same specialist, and has also come for tea after a clinic trip. ECD patients are "Like buses, none for 7 years then 2 in a month!!"
- The member on Vemurafenib has a PETCT scan, cardiac MRI and lung function tests coming up. He has been feeling good, but in the last few days the improvement seems to have stepped up a gear, and he has been walking much faster. He said that it "feels like I've had a turbo fitted to my lungs!!" He got badly sunburned last weekend. He had been warned about Vemurafenib causing sun

sensitivity, but thought that factor 50 sunscreen and a big hat would keep him safe. They didn't!

- Members talked about music artistes from way back who were starting concert tours. The Rolling Stones, ABC, and Kate Bush were all mentioned. "Lots of walking frames on the stage, and a paramedic on standby!" One member, who was a doctor before he became ill, said that he had never been asked to help at any gigs, but that he had once been asked for help when on a plane flight to the UK, from Greece. The intercom gave out the message "Is there a doctor on the plane?" A woman had gone to Greece to have her gall bladder taken out, and the wound had opened up during the flight. The member had had to try and pack it with tissues. He had been in the airplane john with the woman, and an air hostess. He had spent the pre-flight wait in the taxi drivers' bar, and then had had some more beer when the trolley dolly came around. Luckily, he "got the tissues in the right hole"! This was not how he had hoped that he would join the "Mile High Cub"! All he got as a reward was a glass of Greek "sherry"!
- Members commiserated with each other about their "advancing" ages. One said that he looks like he is a lot younger than his age. "At least that's what all the liars say." He took the words right out of our mouths!