

Summary of ECD Global Alliance Internet Chat

25 Jan 2014

10 Attendees

- It is with great sadness that we must report that two members of the ECD-GA passed away the week of January 13, 2014.
 - Sandy, a blog writer (and once a Chatter), passed away peacefully on Wednesday, January 15, 2014. Efforts are underway to have her blog made into a book.
 - Michael, living in California, also passed away peacefully on January 18, 2014.

Our sincerest sympathies are sent to their family and friends.

- A member who has recently started Vemurafenib said “I am doing great!” She had not thought that things would start to change so soon. Her boyfriend said today that it is so much easier going shopping now, because she is “not glued onto his arm” and can move around on her own again. She is able to walk around a bit by herself with nothing to hold on to. She can walk further on the treadmill, and has “more energy”. She has been at the gym 13 out of 15 days, and walked 27 km on the treadmill the past two weeks! She walks at least 2 km everyday. She is going back to work at the beginning of February, although she doesn't think that it will be fulltime. Her recent PET-CT scan showed improvement.

On the day of the Chat, she had been “being a model” and had been made-up and had had taken pictures of her by a Swedish modeling business. She had done it “for fun and needed to feel pretty again”. A member said that he had “felt pretty” after having a haircut this week!

- One member is going back to the NIH in the next few days, and another is going in mid-March (this will be his third visit!).
- A member told us that he had started Vemurafenib less than a week ago. He hadn't noticed any side-effects. He feels a little brighter in himself. He was very stressed about getting the meds sorted out, so it may just be a sense of relief. He is due another PET-CT in a month.
- A member asked for us to keep him in our prayers. He is an Archdeacon and is starting a new pastoral placement in a parish.

- A member asked whether anyone had had problems after using long-term morphine/Fentanyl. He is having leg weakness, and wonders whether this could be the cause. Nobody else had had this sort of problem, and it was suggested that he should get a medical opinion. He is going to see both his oncologist and endocrinologist in the coming month.
- A member had gone for a routine ophthalmology appointment and was told by the doc that she had run into a young child (ten?) who had ECD.
- A member said that has a PET-CT this coming week, and an “ordinary” CT scan the week after. He said that he will “glow in the dark”!
- For one member the afternoon was being spoilt by a “naughty” computer, which had thrown him off the Chat 3 times.
- Members talked about head injuries that they had had in the past, ranging from concussion, to a fracture of the skull. One member wondered whether injuries like this could be related to the onset of ECD, although this has never been suggested.
- A member was asked whether he still had foster children. He said that he, and his wife, had “retired” from fostering a year ago, but missed having foster children around.
- A member from Norway is trying to help another Norwegian ECD patient. He is BRAF positive. She is also BRAF positive, and has recently started Vemurafenib with great effects, so she has emailed him, with info about vemurafenib and contact information for interested doctors and for the ECD Global Alliance. His doctors don't know anything about ECD, so she has told him to take the email with him to his next doctor's appointment.