

## **Summary of ECD Global Alliance Internet Chat** **March 24, 2017**

4 Attendees

- A UK member came on for the first time in seven months! He was in the hospital from August until the end of November after breaking his neck, and has been home for nearly four months now!! He can't remember how it happened. He said that he must have been "Drunk as Cooter Brown"!! He spent lots of time in various intensive care units and didn't wake up for a month!! He didn't have a halo splint, although it was considered. He had a week in a standard neck collar before he was operated on, and he has got "a cool scar" all the way down the back of his neck!! He has two "numbish" fingers on his right hand, but is otherwise "neurologically intact."

He is beginning to move about a bit, and used his "Harley" disability scooter yesterday. He got around the block (with a physiotherapist walking beside him!). He had only been outside twice in the previous 7 months!! He is sleeping downstairs on a "hospital bed." He has only managed one shower since August (and no baths). The shower was on the hospital ward and the nurse, who was waving the shower head around, had her uniform on, got herself wet too, and screamed! And NO ONE came!!

He has been on methotrexate for some years, and was able to restart it after a few months. His other medicines have been reduced, but he has an area on the inside of his right knee that has become hard and calcified. It is like he has "grown another kneecap" where the medial collateral ligament is located. This very limiting of his mobility.

At home, he can get onto his stair lift and go up, but he can't turn around to get off at the top! He wouldn't be able to get into (or out of) the shower or bath anyway. Good job he had a "spare" dining room downstairs. That has become his "temporary" bedroom.

He had a fracture of the C1 vertebra (the hangman's fracture!) and is now "Mr Titanium", after they "plated" it. He wasn't paralyzed, but for the first few months, he had to be hoisted in and out of bed with a "sort of" crane. Now he can get out and transfer to a wheelchair with his wife's help. He has been told that they can't operate on his knee, so he has a leg that won't bend! He said that he needed it chopping off so that he "can be a pirate and have a wooden one, and a crutch!"

He and his spouse get a professional carer in twice a week so that his wife gets a few hours "respite", when she can go out. The member and carer spend the time listening to music on YouTube (and to his ginormous music collection). They made bread last week!! The carer has a degree in "music technology" and she wants the member to start playing his trumpet again! They wonder why, since she has a degree, she is working as a carer wiping bottoms and changing diapers!

- The other member on the chat is having to sleep with a splint on her right hand. Her middle finger is triggering, too. She has to get sunshine for Vitamin D, and had to rely on vit D tablets when she was on Zelboraf (vemurafenib). The other chatter has to get all his vit D from supplements, having not been in the sun for seven months!