Summary of ECD Global Alliance Internet Chat June 8, 2019

4 Attendees:

- The first topic of discussion was sports. On that very evening the Finland Women's team were playing a game. A UK male member said that he used to referee English Rugby Football League (fighting with rules and no helmets or padding!). He was once asked to referee Birkenshaw Dragons against Hull Dockers Ladies! He forgot his way back to the clubhouse, so he missed the chance of a shower with 34 wild women!
- A US member has had a two-week vacation from chemotherapy, which she extended into three weeks.
- The UK member is stable regarding the ECD. His chemo is methotrexate 40mg once a week and has been for a good few years. It was started before all the fancy drugs were invented!
- The member from New York whose haematocrit has been a bit high said that it was 44.3% on the previous day. This is the lowest that it has been since he started dabrafenib.
- A US member has been travelling. Her most recent MRI in May had shown something on her thoracic spine, so more tests are being set up.
- The Norwegian member managed to tear her attention away from the women's football and joined the chat! At which point Norway scored!

The member herself is not feeling too well with many UTIs and she is walking poorly. She also feels exhausted.

• The UK member said that he, sometimes, just stays in bed all day! Some days he feels good, others bad.

Their car has been adapted a bit so that he can get into the front passenger seat. He does manage to get out on his scooter to get to the local shop, but not further.

He said that "there aren't many of us left who were ill before all the new drugs". "My methotrexate was started a few years before vemurafenib arrived. So, I may well be stable but I'm not going to get any better! I have to find ways to cope as I am."