Summary of ECD Global Alliance Internet Chat
02 Aug 2014

8 Attendees

- A new Chatter came on, but did not make any comments.

- A member told us that she was soon to have a 3 week rehabilitation stay, which she is looking forward to. She spoke with another member about their upcoming trips to Bethesda. They have both been making the necessary arrangements.

- A member came on who has not been with us for a few weeks. He was in Minnesota, where it was hot and humid. He is in the clinical trial at Sloan-Kettering. He has been on Vemurfenib ("V") since late May, and is taking three tablets in the morning and 3 tables in the evening (or 3-3) a day. This type of weather does not help. His skin is very sensitive to the sun and heat, and he also has some "hand and foot syndrome". This is a side-effect of the V. The capillaries of the hand and/or feet are damaged by the drug. This often happens to patients on chemo. They have skin peeling off, swelling, pain, and rashes over the body. This makes it hard for him to walk and to use his hands, at times.

- A European member told us that she had started on "V" in December. The Norwegian government is paying for the "V", and her doc is in contact with Dr. Haroche in Paris, France. There is at least one UK patient on "V". The "V" is provided by the National Health Service. The doc involved has managed to get it all financed. We were told that in the US, your insurance must agree to pay for the "V", or you must pay for it yourself unless you're on a clinical trial.

- A member has been having shoulder problems with some serious right shoulder pain, that shoots into her neck, and also to elbow and down through her wrist into her middle finger.

- The member, who recently fell and broke a rib, is feeling better, but still can't help much with the chores!! Not that he ever helped much, anyway!! He hopes that he can keep this up for a long time.

- A member said that it was "a pain" not being able to help. He is having to learn how to chew on the right side, having lost a tooth. He is having to think of having a bridge fitted. He wonders whether this was ECD related. Other members have quite often told us about their dental problems. He has been on interferon injections since 2008, and been stable since 2009. He takes 3cc 3 times a week. Another member had also taken interferon, but it had not helped very much. Her walking was getting worse. She started V in December 2013. She takes 1+2 daily. She was asked about possible V-related side-effects. She said that she had joint pain, sun sensitivity, and thinning of her hair.

- A member has had to have a rod put in the bone of her left lower leg because "the stuff" was coming through the bone, making a large knot on her leg and causing pain. She is taking methotrexate & Kineret.

- One member has recently been sent a urine testing kit. This is a new test for the BRAF mutation using urine and is currently under investigation to prove its effectiveness. The member who had been started on "V" at

Sloan Kettering, told us that he had to provide urine samples 3 times a day the first week of the “V” treatment.