

Summary of ECD Global Alliance Internet Chat

09 Jul 2016

6 Attendees

- We were told that one member is having a better week, ironically this started to happen after he had had a fall earlier in the week. He is still tired, but today was able to get around the house. Two appointments were coming up that week.
- A member, who had to stop vemurafenib (V) due to liver problems, has been taking Dabrafenib to good effect. He has been feeling good since starting this treatment last year. He is on full dose D. His doctor is extremely happy with the way things look. The doctor had a quick look at his scans and said he noticed bone lesions are gone. Essentially all disease is gone, and the doctor wants to discuss lowering the dose of Dabrafenib soon. Every 8 months or so this member goes for a scan, and has blood work once a month at a local hospital.
- A recent FaceBook posting was mentioned. One member said that it looked like a doctor is refusing to authorize PET scan for an ECD patient. CT scan and MRI have been done. A member said that "doctors don't refuse scans, the insurance companies do".
- A member said that if you have ECD and are on the newer drugs, it's important to get scanned at least once a year, because some drugs cause secondary cancers.
- Our "galivanting" member logged on from the Grand Tetons and Bridger-Teton National Forest. She was leaving Wyoming in the morning and flying to Atlanta. Then she will drive with one sister to the Atlantic coast in NC for 10 days. Her husband and other family will stay at the beach. Reality and ECD will resume on July 15 when she will be back in Kentucky and see doctors and have brain scans.
In Wyoming she has been at 8,000 feet, so she lathers herself with sunblock, and wears clothes and hat with UV protection. The vemurafenib is terrible for sunburn as we know, and her lips are particularly vulnerable, especially because of the wind. She has gloves and a neck "turtle", made by a company called Buff, to protect her hands and face. The gloves are really made for fishermen so the tops of the fingers are exposed. She also drinks a lot of water at this elevation.
- We were reminded that we must constantly moisturize our skin. One member said that he has a naturally very dark skin, so he thinks that he has less problems than some, but even he has to find clothes to protect him. Fortunately there is the internet, which allows him to "surf" for companies selling "the right stuff".