

Summary of ECD Global Alliance Internet Chat

14 Nov 2015

7 Attendees

- A chatter left us a message to say that she wouldn't be able to attend because of a business meeting for school. She hoped that everyone was doing well and that they have a great week. She is well, apart from being dizzy, and having some back pain, but other than that she "can't complain".
- A member, who has just had a kidney stone removed, told his story. He had a percutaneous nephrolithotomy. After the op you have a nephrostomy (a tube going from the outside world, through a hole in your back, and on into your kidney). This is to drain away any bleeding, and to make sure that the urine produced by your kidney can get out of the body. This is left for a few days. Then they PULL it OUT!! His advice is "DON'T GROW KIDNEY STONES!!!" At least he was home after just 4 days!! He had made the operation day exciting for the doctors, by stopping breathing AFTER they had "woken him up" and taken the breathing tube out! They had to stick another one down, leave it in for 8 hours or so, and then take that one out!! Sore throat time!! Maybe the drugs that they paralyzed him with, when he was on the ventilator, hadn't fully worn off. It had been a 4 and a half hour operation! The surgeon got out a stone, crunched some others up and sent them on their way, and shot the rest with his laser gun. When the member goes back to see the surgeon, he is going to give him a coconut, like they do at the fairground!
- The member's kidney function was fine, but he was getting lots of urine infections that were resistant to most antibiotics. He had kidney stones that were growing quite quickly on a scan, so the doctors thought that they should come out. He didn't have any pain though!! Another member said that her twin sister had kidney cancer 8 years ago and had one kidney removed. The member had wanted to stay healthy, in case her twin needed a kidney.
- A member changing her doctor team, now has an appointment for Dr. Diamond in NYC. She has seen 2 orthopedics in Lexington and she has asked Dr. Diamond to get her to see an ortho at MSKCC, because her right shoulder and arm are so painful. She has been on vemurafenib(V) for 6 months, and hopes that Dr. D will tell her that the dose needs to be decreased. She has been on a dose of 3 in the morning and 3 in the evening since June. Apart from the shoulder/arm pain, she also feels dizzy. She thinks that she needs a "team", which won't happen where she is located. She has been trying to exercise more. She had cleaned out the garage that day, and was now feeling sore.
- A member has been going to a physical therapist 3 times a week. She had climbed 1,100 stairs that day and was now walking zigzag! She has finally got her flu shot. A UK member got his a month ago as did a US member.
- The question of using acupuncture was raised specifically for numbness. A member told us that she has seen acupuncture help patients with numbness, when they are on chemotherapy, "so why not for ECD too".
- The question was asked whether the use of new treatments like V would prevent ECD patients from suffering some of the symptoms that a lot of us have. Symptoms particularly mentioned were joint pains (especially around knees), difficulty swallowing and eating, balance issues

(needing to hold onto walls when walking), loss of sensation around fingers, excessive sleeping (14 hours a day for some), mobility problems and a feeling of stiffness.

- A member said that he thought that most of those symptoms will still occur, because it will still take ages for folks to get a definite diagnosis of ECD. Only then can V be considered, and if you are one of the lucky ones you will get better. People diagnosed and treated early sometimes never get the "full house" of symptoms. For those who already have symptoms, these may never go away. The member said that he will be wobbly and slurry, and have double vision "till the end of time".
- A member, whose sister was diagnosed with ECD at the age of 44, said that they had been helped greatly by Dr. Diamond. She was seeking information about treatments for a wound that her sister has had for 9 months. It isn't healing. The wound occurred because she was too sick to get up, and wasn't cared for in the hospital. She mentioned hyperbaric treatments specifically. She asked whether any of us had used such a treatment, or knew of any articles in support of it.
- A member on V, who sees Dr Diamond, has been told that he is going to have his dose reduced. Dr. Diamond says that the disease is so minimal that there is no need to be on 4 + 4.
- Chatters discussed where they lived, and what areas they had connections with. Quite a few of us have these "connections" although we didn't know it.
- A member said that he was "on the wagon" that night because he had taken his weekly methotrexate chemotherapy that morning. This was why he was staying up so late! The Chat time is in the evening in the UK. He takes 40 milligrams once a week, and it has been the same dose for a few years. He said that he doesn't get any real side effects, except "a thirst for a stiff drink"! He will probably stick with this treatment forever, if he stays in remission. It gives you at least one booze free day a week, and this sure helps to keep the doctors off your case!!