

Summary Of ECD Global Alliance Internet Chat

3 Dec 2016

13 Attendees

- A new member introduced himself. He has been "with the ECDGA" since his diagnosis at the end of 2012. He was started on Kineret before vemurafenib (V) came out as a treatment. He found the ECDGA and "it's works" to be "a huge source of support and information". He has been on V since it started to be used in ECD. It "keeps me breathing". He has had Type 2 diabetes for 25 years. He has never had problems with neuropathy, but wonders about it now, in connection with ECD or its treatment. He wonders if neuropathy comes and goes like some of the other ECD symptoms and treatment side effects.
- A member filled us in on the current state of play for him. He is taking a dose of two in the morning and two in the evening of V, and has been on it for about two years. He goes to Houston periodically to see Dr. Janku and is still on the V trial. The protocol has changed, and now he only goes about every three months. Some of his tests now happen in Michigan. It's hard to keep going to a hospital that is a long way away, "the travel gets tiring". He gets a three month supply of V each visit. He keeps hearing that he is "stable", but he still gets skin rashes, and thick skin on his feet. He said that this was a "Great excuse to get a pedicure"!
- Another member who has been through V treatment said that he was "pretty normal now" and doesn't have much in the way of side effects, except for dry skin and skin rashes. He feels that, for BRAF positive patients, V is the solution, and probably dabrafenib as well. Patients will probably need to stay on a low dose, maybe just 1+1, after finishing the trial.
- The member who has been on the V trial said that he was started on 4+4 and he had many side effects. Then his dose was lowered to 2+2 and he felt much better. He thinks that 1+1 would work just fine, and so does Dr Janku!

When he goes to Houston he has a selection from the following list: PET, CT, MRI, EKG, and Echocardiogram. He said that his cardiologist mentioned that MRIs done too frequently can hurt the kidneys. This was new information to other members on the Chat. It was said that you really need 1-2 PETs a year; although, PET involves exposure to radioactivity. MRI is just REALLY strong magnets, and CT is radiation. [Summarizer's note: Ultrasound uses very strong sound waves like Ozzy Osbourne and the rest of Black Sabbath having a party inside you!"]

- A new rare histiocytosis registry is being formed in Toronto, Canada. A member, who is going to take part, says that it will involve nothing much more than allowing your doctor to share information with the database.
- A member who missed the Chat said that she was doing well apart from having an upset stomach.
- Another absentee said that he had been at his annual Thanksgiving party with friends. The person hosting the party this year could only do it after Thanksgiving, and so the member had been "busy".