

Summary of ECD Global Alliance Internet Chat

11 Mar 2017

7 Attendees

- A member whose diagnosis of ECD was confirmed in July 2016, and has been on Kineret for six months, has been in the hospital in Paris for check-ups. He had a heart and a brain scan, a PET scan, and blood tests to see if he is BRAF positive. He said that he won't get the results for three months. (A Norwegian member said that her doctor looks at her scans right away, and can tell her the news. This is what happens for one of the US members.)
After six months of treatment he does not see much improvement. By contrast, his Diabetes Insipidus has improved a lot on the treatment. He hopes that he will not have to take vemurafenib (V) because of the risk of depression and the skin problems (that seem to be common). A member said that he has been on V since it came out. The side effects like skin problems, etc. are very debilitating, but it keeps his ECD at bay. There has been no progression. He thinks that if you have this disease, that alone is enough to cause depression. It was said that to avoid depression, it is very important not to isolate yourself in the disease. Keep in touch with your friends.
- The member who has been having shoulder problems has had a cervical spine MRI and is being sent to a neurosurgeon. Her doctor thinks the origin of her shoulder pain is in her neck. Also, her blood pressure (BP) has been about 170/90, and she now has a doctor addressing this. She has also been having a "bounding" heart rate of 100. She is one of the members who has swapped V for dabrafenib (D). She asked another member, who has swapped too, whether he had had any increase in his heart rate or BP since going on D. They didn't make an issue of his heart rate being increased when he last visited the clinic.
- Another member spoke of his problems with shoulder pain. He believes that it was totally chemo induced. It was shoulder pain for a long time, then back, arms, etc. After about two years, it disappeared completely! But he now has extensive neuropathy. He has had Diabetes Mellitus (that is the sugar diabetes, and not the Diabetes Insipidus) for a long time (this is commonly associated with neuropathy). He thinks that this neuropathy is chemo induced, too. He was treated for the pain with a special, very expensive cream that helped. He now uses capsacian and it helps tremendously. This is made from the "hot" bits in red chilli peppers!
He has been on Kineret since 2013, as well as V. He also told us that in the US you have the right to your medical notes and scans the next day. The physicians want to be the ones that give us the results, but they don't always know which ones are significant to us.
- A US member said that she gets all her scan results within a week. She also keeps a copy of the disc with all of her scans. But, she doesn't read them! She goes back to NYC and Dr. Diamond in late March. She will be having the usual checks and a PET/CT scan. Her daughter from DC always meets her in NYC, but as she is 15 weeks pregnant, she won't go, so that she won't be around when the member is a bit radioactive.
- It was mentioned that many of the people in hospital waiting rooms are very ill. One said that when he goes to MD Anderson (he now goes about every three months), he is acutely aware that he may be the healthiest patient in the hospital.
- The wife of a member with ECD said that he is still on his temporary stay at a nursing home, but comes home this week. There is a different pace of life in the nursing home, and he seems to be

enjoying the experience so far - moving around more on his own, having delicious meals, and having easier transportation from A to B.

- The French member told us that he gets a massage as part of his treatment! He finds this very helpful. A number of other members would like a massage to be added to their "treatment package".