

Summary of ECD Global Alliance Internet Chat

30 Jan 2016

6 Attendees

- During the Chat, a member told us that there was a lot of smoke in their clear blue sky. Apparently a local stockyard was burning down!
- A member began the Chat by telling us that he had been getting ready to go out to his car and his right foot "just didn't come up off the floor!!?" He fell, but didn't hurt himself. The whole thing made him "mad" because he can usually walk OK. ..
- A European member is soon going to Florida on vacation. She is going with her sister for 2 weeks, and staying with her parents. She has had treatment with Vemurafenib, and is feeling well. She had taken a taxi that day, without her walking sticks, from her house out to a shopping center. The cabdriver said "Oh you have gotten better". He had picked her up quite a while back as well. She also achieved her highest ever heart rate (170bpm) during spinning. She used to have problems getting the rate up before, but her trainer is excellent at pushing her. Another member said that she would be pleased if she could just get her heart rate up to 100. She is on 2 different medicines to treat her high blood pressure, and these keep her heart rate down.
- A member is going to see his doctor in about two weeks. The doctor wants to finally establish his BRAF status, and he wants to find out the results of his PET scan and MRI.
- A member who has been having treatment for shoulder pain, said that her shoulder was much better now. But her hip is now causing problems. At the moment she is on a dose of 2 in the morning and 2 in the evening of vemurafenib (V), and goes back to see Dr. Diamond in April. She thinks that he may well change her treatment. She is beginning to think that Dr. D doesn't really like V, and might change her to Dabrafenib, depending on what all her scans show. He wrote to her a couple of weeks prior to this Chat, and told her not to take Bonviva (a biphosponate) any longer. This is due to its side effects and lack of efficacy. She had started it last Spring because her "bones looked so bad".
She is the only patient in KY who is registered as having ECD. She had seen an orthopedic doctor on the previous day, and he just sat down opposite her and listened! She said that it was rare to find someone in the private doctor world who is interested in anything "but seeing you and shooing you out".
- The wife of a fairly new member came on. He had just had a fall in the bathroom so she was not going to remind him about the Chat. They have had a hard week, with a lot of doctor appointments and a lot of procedures. These scans should be the last for now. These have delayed things. He has been told that he has been living with ECD since at least 2009. She also thinks that they are being prepared for the worst. She does think that the doctors are considering treatment with V, but they have to finish their investigations first. They expect to hear more about it in the next few weeks. She wonders whether the doctors will say what the V can do, or that they don't expect anything to happen. How much of an improvement will they see? People have said that they should keep their expectations low. She would like her husband to be able to move around the house safely. Wearing slippers hadn't helped him at her father's place, but stocking feet offered more support.

They were advised, by a member who has been through V treatment, that they shouldn't just accept the doctors saying "everything is going to be fine". He said that they need to make sure that blood work is done, the skin is monitored, and heart rate and other vitals are checked regularly.

- Another member who has had V said that a lot of her symptoms improved, but her balance was only a bit better. Her sisters, and doctors, said that her voice has become stronger.
- The next topic was lumps, bumps, and hard skin. One member said that she can never walk without something on her feet, because the areas around the balls of her feet are so callused. She is not removing the callosities, and was advised to do so. She was told about a tool that can be used on the feet to remove the hard skin. It costs \$5-6 at Marshall's. You should not use this tool on hands. <http://www.amazon.com/Handle-Sides-Callu...>
For the areas on the palms and soles she suggested using any OTC salicylic acid-based products. The member who asked about cysts and bumps on the hands, had meant to ask the orthopedic about them on the previous day, but forgot. They seem like hard knots underneath the skin, but with no calluses on top. As long as she can still stretch her hands and doesn't have any contractions, she is "leaving them alone".
- A member who has taken V treatment, said that if the calluses appeared after starting V, the calluses could be due to the V. It could be just thickened dead skin. V tends to accelerate skin growth.
- One member goes to a "foot lady" who fixes her feet and toes every couple of months. She had a pedicure while she was in Houston, and had been told that she "needed extra spa treatment" for her feet.
- A member told us a happy story about her medication and the pharmacy she uses. The specialty pharmacy in Michigan called her, and told her that her co-pay was \$2000, but they had a \$25 card that they could use for her! She thought about that for 10 seconds, and then said "fine, use it!"
She has BC/BS (Anthem) and it's an HSA policy. Her max "out of pocket" is about \$3500/year. They pay about \$1,200/month for the policy (which is a private policy within a group). This is a low deductible plan.
- Another member said that he always has a high deductible plan with HSA, and another said that every time he pays the co-pay for images, he gets another bill a couple of months down the road.
- A member on V said that she has an ECG and blood work every month before she sees the local oncologist. Her last PET was in August, and she will be having more in April. She will have a full body PET in NYC. And she will also have a head MRI with, and without, contrast and CTs of her abdomen, pelvis, and chest when the PET is done.
Her pituitary stalk was thickened and rotated a bit on all of the last MRIs. A neuro-radiologist friend of hers [summarizer's comment; we could all do with friends like that, couldn't we!] said that her next MRI should include a specific look at the pituitary and the base that it "sits" in.
- A member who has come off a V trial is only having PET scans now. He is in "remission" and will carry on like this unless things suddenly go downhill again, (recurrence of symptoms, like the eyes, or a PET scan reveals recurrent/new features). For him, things have been quite

steady. The spine's uptake went up once, then disappeared on the next visit. A PET picked up his colon problem once (ulcerative colitis), but it was resolved by the GI.

- Members discussed problems with peeling skin, fingernails, and toenails.
- A member asked about eye issues and what were the eye symptoms to watch for. For one member, the eyes were the first symptom. He went to an ophthalmologist in Sept. 2014, and ended up getting a diagnosis of ECD in April 2015. Once the doctors started doing scans, they had it figured it out in a month!
- The question of treatment with Kineret and V at the same time was brought up. Apparently this has been considered for the member who will be starting treatment shortly. This was not thought to be a very good idea since "Kineret can kill your immune system over time".
- Bone pain and V were mentioned. It was said that V takes away bone pain, but can cause there to be pain in the joints.
- One couple had made a "living will" 5 years ago, in which they were quite specific. They will "have to honor it now". Their 3 children are at home (aged 23, 20, and 14) and they have a dog. A website was suggested. <http://www.whatsyourgrief.com/anticipato..>
- Ages of members were compared to see who was the youngest. Chatters that were 49, 53, and 35 year olds all owned up to their age!