

Summary of ECD Global Alliance Internet Chat 27 Feb 2016

6 Attendees

- A member is looking forward to flying to New Zealand this week for a 2 week stay (although the flight takes 15 hours!). They are going to visit their son, who is working on a golf course in Napier (half way down the north island on the Pacific side). Then all three of them will fly to Christchurch, then down to Queenstown on the south island. They plan to go sightseeing, including penguins and hobbits!! After making the Lord Of The Ring movies, the Shire was left in place at the south end of the north island, so they hope to see that.
- Another member who is travelling is about to fly from Norway to Florida.
- The member who received a Genentech card isn't able to find it now. This card showed how much of her vemurafenib (V) cost would be covered. Diplomat Pharmacy in Flint, Michigan called her and told her about the \$25 co-pay, then Genentech sent her the card. The letter from Genentech said that they would cover up to \$25,000 of the V cost. She has a BC/BS HSA, so when they have met their deductible (very fast), the insurance picks up the cost.
She goes back to see Dr. Diamond at Memorial Sloan Kettering (MSK) in April after she has had lots of scans. He told her that she could drop the V dosage to 1 in the morning and 1 in the evening while she is in NZ.
- It appears that some patients may be switching to dabrafenib (D) for maintenance, even though V was the drug that got them better to begin with. V & D are considered competitive drugs, so that V opens up the market for D. It may be that Roche/Genentech don't like the idea and may try to keep the original participants on V as long as they can. A member who is on V, and now in remission, would like to see how D is doing from a maintenance perspective. With V, even if you are on only 1 a day, you will still have issues with the sun. "Wouldn't it be nice if we could be on just 1 D, and be stable forever!"
It was said that "D messes with sun, too" so the future may not be quite as rosy (or as sunny!) as the member would like.
- Balance, or rather the lack of it, was discussed. A member who is stabilized on treatments is still very "off balance". A member who is in remission said that he was "still wobbly". His cerebellum was damaged in the early part of his illness a good few years ago. Recently, he went to some PT sessions to help with balance and walking. Most of the group were 20+years older than him, but the sessions were useful. You need to challenge your balance to improve things. He started standing feet apart, then feet together while cleaning his teeth. His electric toothbrush goes for 3 minutes at a session, so this provided a decent amount of time to practice his balance. Then he started doing the same with his eyes closed!!
- Another said that she walks a lot when in the swimming pool, after she has done her swimming. Also, she has an electric toothbrush, so she might give that a go too.
- Sensitivity to sun was the next topic. One member had managed to get his nose burnt just by walking to the exercise room in the apartment. He was once at a market in San Diego and was

holding an umbrella and it wasn't raining. People were looking to see what was wrong with him!

- The member going to NZ has bought masks to wear in the airport and when she is out in the sun in NZ. Last summer, she was on the beach in NC all covered up with mask, hat, etc. A little girl asked if she was a good guy or bad. The member said that she was a good guy with a bad disease!
When she had been at NIH last April for the possible D and trametinib (T) study, she was told that she would have to slather herself in sunscreen. However she didn't know whether this was because of the D or the T, or both! We were referred to an article "The side effects of dabrafenib include sensitivity to the sun and other skin cancers.," <http://www.cancer.net/targeted-therapy-dabrafenib-keeps-melanoma-worsening-longer-chemotherapy>.
- A member may be switching to D, partly because his liver enzymes became high while he was on the V. He has been off the V for 2 weeks. He hasn't been started on D yet. He thinks that Dr. Diamond may want to restart V. The member doesn't think that this makes much sense since it was V that made his enzymes "out of whack". It was said that if he was on just 1+1, (which he can be because he is no longer in the trial) then he should be OK.
- Exercise was talked about. One member is not working out, he is just working. His job is in a Kindergarten and has no time to exercise (..or desire). One is exercising twice a day, and rowed over 30,000 feet one day this week.
One admitted to getting addicted to indoor swimming. She also does PT exercises for her shoulder and hip. She has had a cortisone shot to her painful shoulder and it "really helped!" The shot was into the capsule around the rotator cuff. She had a classical "frozen shoulder". Now, she does lots of exercises and her PT stretches it out. Dr. D thinks that her shoulder problems are due to the high dose of V, although one member said that V actually resolved his shoulder problems, which were due to the ECD and not V.
- The wife of the member who has just started V came on. He has more energy, some hiccups, and got sunburnt inside the house! They have moisturized "like crazy". He is on 2+2 plus his usual medications. He has been a bit more tired in the last 2 days. They are waiting to see how it all goes. They have moved south to Toronto (her father's place). he raised the question of wearing sunblock while in the house. The dermatologists say not to.
- The topic of bone loss in the mouth was mentioned. A member said that his dentist was concerned that despite his age (he's only a baby, one of the youngest of us) he has some bone loss, and this is unusual. There have been articles about this. One recommended: "Premature alveolar bone loss in Erdheim-Chester disease", <http://www.ncbi.nlm.nih.gov/pubmed/2216355>.
People have said that their teeth break apart [summarizer's note; 2 of the molars in my lower left jaw just sheared off leaving the roots behind!]