

Summary of ECD Global Alliance Internet Chat **20 Aug 2016**

5 Attendees

- A member left a message to say that he was going to his nephew's 3rd birthday party that day. He said that his ECD status was the same; "Same medicine...same feeling".
- Another said that she was doing well, and had a great turn out at her fundraiser a few weeks ago. She was treated with venurafenib (V), but has been off all medications, specifically for ECD, for a few months and is doing well. She has not had any issues with being off of her medications. She never did have chemo, she was treated with interferon and anakinra at the University of Chicago. She did well on the interferon with just occasional redness at the injection site.
- A member has just returned from seeing Dr. Diamond at Memorial Sloan Kettering Cancer Center (MSK). Her dose of V is being reduced to 2 pills (240mg) a day, and this reduction happened two days ago. She is hoping to have less side effects, like another member with a reduced dose seemed to have.

Dr. D thinks that her dizziness is not due to the lesions in her cerebellum. He thinks that she should get some Vestibular Rehab from a PT (the vestibular system is part of the inner ear, which helps to control balance). Her scans show that she is "stable". She did have to see a dermatologist while she was there to have something taken off her arm. After a few days the biopsy result will say what it is or was. It had "come up" just 2 weeks ago. She has also developed many boils, so the dermatologist suggested that she should use clindamycin lotion (clindamycin is an antibiotic) on her body. She is trying to stay clear of oral antibiotics since she had a C-diff infection the last time that she took an oral antibiotic for a sinus infection. She also drinks probiotics (from a drink called Goodbelly or from Kiefer) to keep the C-diff away.

The excess skin on her feet is from the V, and she feels like she is walking on marbles. The dermatologist also wants her to see a foot orthopaedic in Lexington for the excess skin below her toes. Her local oncologist in Lexington has been asked, by Dr. Diamond, to become a referral center!
- We were told that one member on V had been found to have a longer QT interval (a measurement of the passage of the electrical wave through the heart, tested on an EKG). So the doctors have reduced his V from a dose of 2 pill in the morning and 2 at night to 1+1, and also reduced the dose of his antidepressant. So far he is "doing fine" and will go back next week to see what the EKG says.