

Summary of ECD Global Alliance Internet Chat **July 21, 2018**

7 Attendees

- A member stated that he has a lot of pain when it is too hot, and things are better after storms. He has been on a double dose of Kineret for two months, with no positive side effects.
- A member on maintenance vemurafenib (V), taking one every other day, said that it's too early to tell, but maybe he should go back to one a day. He will probably ask Dr. Diamond in the next week. He stated that he had been experiencing some facial neuropathy even on one V a day. He stopped taking V for a week and the symptom went away. Now, on one V every other day, he is "feeling great." He said that his mind has not been this clear for a very long time, and wonders whether the V has been making his head feel funny for the last four years.
- A US member said that she had her grandkids to visit with her in Kentucky. She also said that she would be going to Alabama in early August for her niece's wedding.
- A French member also had his grandchildren visiting. The youngest was only two months old and this would be his "first visit."
- A member said that she had "fussed a bit" at her local oncologist last week. She had seen him, a cardiologist, and a dermatologist, and also had a lot of blood work done. Her echo and EKG looked a bit abnormal, so the cardiologist put her on a nitroglycerin patch for the chest pains. She thinks that the Mekinist is "getting the best" of her. She is already on the lowest dose. She emailed Dr. Diamond, as well as told her cardiologist and her local oncologist to contact him too. Dr. Diamond did not respond, which is unusual. The cardiologist said that she should have a cardiac catheter test and stent, then she would have to be on blood thinning medication. The cardiologist wasn't sure about that with the ECD.

A friend had given the member fresh eggplants. She roasted them with garlic, onions, herbs, and added tomatoes. She will be having it with noodles tonight. Our French gardening member suggested "Zucchini in different ways." Such as raw and grated with vinaigrette, like cucumber, or steamed/ grilled. They are also good when cooked on the grill and then seasoned with olive oil and herbs.

- The member who went back on V after the birth of her baby is now on a dose of one in the morning and one in the evening (1+1). She is mainly fine, but does get occasional pain in her fingers, wrist, and arms that will only last a day or two. She has a checkup in one month. She doesn't sunbath and wears 50 SPF when outdoors and it is sunny out. She has only gotten really burned once this summer.
- At the end of the chat session a US member logged in. He is having difficulties arranging a follow-up with Dr. Diamond. He is a Kindergarten teacher and just got a new job at a school closer to home. He cannot take any time off for doctors' appointments, he'll have to schedule one during Christmas or February break.