

## **Summary of ECD Global Alliance Internet Chat** **April 28, 2018**

3 Attendees

- A member told us that she had had some minor surgery for trigger finger, carpal tunnel, and a lipoma on the back of her hand. Her husband had wanted to go hiking at a nearby reserve that day. She thinks that she crept along more than she hiked. She also fell a month ago and sprained her ankle. "A hiking stick is always near me, now!"

She is now just taking trametinib. Dr. Diamond took her off dabrafenib (D) at the end of February. She likes not being on vemurafenib (V) any more, because she can walk in the sun.

Her blood pressure (BP) had gone up to 200/100. She wonders if the D caused this spike. She has a brain MRI and Echo in two weeks. Her BP is about 120/74 now. She is on two medicines/day for BP, but she has been able to reduce the doses by half and her BP is stable. She is having a colonoscopy next month, and is scheduled to see an endocrinologist/pituitary specialist at Memorial Sloan Kettering (MSK) in September. She usually catches an early flight on Thursday morning, has her appointments on that day, and then flies out from LaGuardia on Friday night. She stays at the midtown courtyard that is attached to the MSK building where Dr. Diamond is located. She gets her scans done in Lexington before she goes. She has previously met other ECD Global Alliance (ECDGA) members on her trips, and may meet some more this time.

- The French member will be going to Paris in early May. His trains will be running, although there has recently been an industrial dispute affecting them.

He put out some plants last week. A US member said that it would be Derby Day on the following Saturday, which is when they are told that its safe to put out annuals! The French gardener still has some seedlings in his greenhouse.

- One US member is just taking one V a day for maintenance. He still got his lips burnt slightly after being in the sun for a few minutes. He has now got a permanent itchy spot, which is growing larger. Otherwise, "I am ok."
- The French member sometimes meets Professor Haroche in the hospital corridors and can greet him quickly. Prof. Haroche rides a motorcycle, so that he can travel more easily in Paris. A year ago, he had just returned from vacation in the Himalayas with a backpack.
- A website was recommended, called [Genetics Home Reference](http://genetics-home-reference.com). A US member prints it out and gives copies to her doctors. (This is also found on the ECDGA website on the Resources page: <http://erdheim-chester.org/resources/>)
- Insurance difficulties were raised again, especially regarding scans and maintenance drugs. One member said that "if you are in complete remission and doing very well, even a PET scan is hard to get pre-authorization."