

Summary of ECD Global Alliance Internet Chat **23 July 2016**

9 Attendees

- A member left a message saying that she hoped to Chat later. She has been doing well, apart from having some stomach pains for which she is having tests.
- Our gallivanting member logged on from her car. She and her husband were driving back from a NC beach to Lexington, KY (terrible traffic south of Charlestown, WV!). She has a brain MRI in Lexington booked, a PET scan, and an appointment with Dr. Diamond on August 18. She had got in the ocean for the first time in two years! It was calm and she was covered, but her lips and face look bad!
- A French member has seen Professor Haroche and will start treatment with Pegasys (a long acting version of interferon) in August. He asked about side effects. It was suggested that he look on this site for information: <https://www.drugs.com/pegasys.html> . He still has some tests regarding his diabetes insipidus.
- A member who has changed from vemurafenib (V) to dabrafenib (D) due to liver problems is doing "extremely well". His scans in July show that the disease is 99% gone! He is taking a dose of 3 pills in the morning and 3 in the evening each day for a little over 3 months. He has no side effects except for a little keratosis on his arms/shoulders, and his "beauty spots" are darker. The sun doesn't seem to bother him now, and he recommends D to all. The dose that he is on is the max. The doctor talked about a patient of his that has come off completely, just takes one methotrexate pill a week, and is doing well.
- A member said that she has an ongoing problem with fluid retention. Another said that she also had this problem sometimes, and she wondered whether certain foods might make things worse. The member who first mentioned it said that in the past, the only thing that helps is hospitalization & IV lasix (frusemide). She was taken off treatment for Diabetes Insipidus because it appears that she no longer has it. She takes V 4+4. She does have other kidney issues. She has renal stents, which are exchanged every 4 months. She also needed a pericardial window (a cut made into the sack that surrounds the heart and can fill with fluid, making it difficult for the heart to work) 2 years ago which released 1000ml. Her fluid retention seems to recur every 12-18 months.
- The Rareconnect website was mentioned. One member goes on regularly and others just occasionally. <https://www.rareconnect.org/en/community/erdheim-chester-disease>.
- Members talked about skin reaction to interferon injections. One gets red patches around the injection site, and it also gets dry and itches "like crazy". She is BRAF negative and takes Pegasys once a week.
- The health uses of cider vinegar were discussed (believe it or not!). A member had applied some to a mole that had gotten bigger and had a rash around it. This took care of it, and now it's all gone, including the mole. The cider causes a mild acid burn. It hurt a bit at first, but he put a drop on the site a couple times a day for a few days, then stopped.
- Members were asked whether they drank vinegar (some people do!). One member used "to do a

shot of it per day". Then someone told him that it's not good to do that, so he stopped. Apparently many people have used it to remove moles. But you need to be careful, if you use it on your face and don't do it correctly, you may leave a scar.

- A member has connected with another patient via Facebook. She has seen the local oncologist that the member also sees. Our member told the doctor that if she gets 3 more patients, she will be an expert. The doctor rolled her eyes!
- The member who has just started Pegasys interferon was asked whether she felt any better. She said that her eyes feel better. Side effects were a problem at first, but seem to be getting better now.
- The wife of a member, who has been being treated with V, said that he has been bothered by a skin irritation that hasn't gone away. Some of his medications have been changed, and he has been taking more pain killers, so he is more tired than usual. A member suggested that he might try triamcinolone acetonide 0.1% cream on the rashes. And he should try to not scratch them.
- A member said that she has just started taking Trametinib and has fluid retention for the first time. She has swelling of her feet and ankles, and there is swelling under her eyes. She also has a bad pain in her back and pelvis. She thinks that she will probably need to go down in dose due to these side effects. Another problem is that the doctor ordered 2mg tablets, that can't be cut in half, although she was asked to take 1mg at first. It was suggested that she just take it every other day. She has only just started it, and has only taken 3 pills in 1 week.
- We were told that the husband of one member (he happens to be a psychiatrist!!) is going to be on the ECD caregivers Facebook page as "Ask Bob"!