

Summary of ECD Global Alliance Internet Chat

13 Aug 2016

7 Attendees

- A French member is going to start Pegasys in 2 weeks. He hopes not to have the same problems he has had before trying to see the same specialist. He had had to wait for a year for advice. After being seen for the first time, the doctor immediately took the situation in hand. The doctor was surprised that he had diabetes insipidus for 10 years, and so he may have had ECD at that time.
- In the US, a member went to the wedding of the daughter of a friend. The friend had died when her daughter was just 5 years old. It had been a lovely wedding.
- A member confirmed that she was still on vemurafenib (V) and doing well. Every couple of months she gets some joint pains and nausea, but mostly feels OK. She started on a dose of 3 pills in the morning and 3 in the evening, but has been on 4+4 since 15 Feb. It was remarked that this was a big dose for a long time, and must have cost a GREAT deal!! Her MRI scans have been the same as they were before the V. She only has MRI scans, and told us that PET scanning had not been recommended. It was said that the main reason for having a PET scan is to see whether tumors/lesions are active, relative to normal cells, (i.e., benign vs malignant). If the drug is working, it should turn a malignant lesion into a benign one and shrink it over time.
She thinks that she does not have "enough knowledge" to know if she should request it. She was advised to try and seek out a doctor who is knowledgeable about ECD. A member who has been on a V trial said that the PET scan was the "standard" to monitor progress. She is going to get in touch with Kathy at the ECDGA.
She has renal stents in place, which she has exchanged every 4 months. Her only skin issues have been with an increase in moles, which so far have been benign. Her dermatologist has recommended a mole study. She has had no pimples or boils.
<http://erdheim-chester.org/knowledgeable-doctors/>
<http://erdheim-chester.org/care-centers/>
- The member who has been having difficulties with her insurance company, told us that "My insurance company actually approved payment without a stink for the PET scan on Thursday!!" She is wondering what it will show, since she is more dizzy, has more joint and bone pain, and a cough. Her brain MRI is essentially the same after 15 months on V, but the lesions could be "shells". Her pituitary gland is still "screwed" and she has fluid in the mastoid air cells.
- A member from Norway said that she was going to try to see Professor Haroche for her follow ups.
- A member who is in remission after V said that he thinks that 2+2 V is the best dosage during the therapeutic phase. A dose of 4+4 is good for a short period at the beginning for 3-4 weeks, (he only managed one week at the higher dose). He is now taking 2 V a day and doesn't have any side effects except sun sensitivity. But he does have other issues to take care of. He has had colitis (an inflammation of the large bowel) for over 15 years. This could have long term effects like bowel cancer, so he "can't afford to spend all my \$\$\$ on just ECD".