

Summary of ECD Global Alliance Internet Chat

26 Mar 2016

7 Attendees

- The wife of a member who has just started vemurafenib (V) treatment, said that he was continuing to do well. He is using his arms and hands more. He is doing some writing which he hasn't done in 10 years. A new wheelchair has been ordered which will provide more support, and offer him more independence. He has had to make slight changes in his medications due to some extra heart activity.
- A member told us that he and his wife would be celebrating their 17th wedding anniversary on the next day. He had a busy holiday weekend lined up with trips to his and his wife's families. At the moment he feels like he is living on a boat, his head is swimming so much.
- Another member said that every holiday is busy for him and his wife. They go to see both families splitting the time between them.
- A new member came on for her first Chat. She lives in Fort Lauderdale, FL. She is 46 years old, was diagnosed in Nov 2014 and her symptoms began at the beginning of 2010. She sees doctors locally. It took them over 4 years to make the diagnosis. Initially, she was thought to have some sort of auto-immune disorder and was treated with methotrexate for 18 months and then, just before the diagnosis was made, she took another medicine (but could not recall its name). She is now on V, and has been taking it for 14 months. She sees an oncologist, a nephrologist, a urologist and an oculoplastic surgeon. She has tumors behind each eye, abnormal brain tissue, a mass in the right atrium, and tumors on her kidneys. She has had bilateral renal stents put in place. She also has inflammation in the abdominal wall and lymphedema.
She has found that her joint pains have increased while on V. She was due for a CT angiogram (for her heart) in the coming week to compare to the two she had 6 & 12 months ago. She has had MRIs of other organs, but has not had any PET scans yet.
She asked about other people's medications. A number were on V like her. One has been stable on interferon for about 9 years.
- A member who had problems with his liver enzymes rising while on V told us that these were now almost normal again after taking a break from V. He is now going to take V for 2 weeks, and then have a week off treatment to see whether he tolerates this regimen better.
- The member who recently went to New Zealand said that it had taken her 2 weeks to get over the jet lag, but that it had been "worth it!" She said that it was a beautiful place to go, and the people were very nice. She was now at home with her husband and four grandchildren!
Her shoulder, which had been very troublesome, is now better, but her hip is now the problem. She also said that she was "growing" little cysts under the skin on both her legs and arms. She had begun to wonder whether the V was beginning not to work. She is going to see Dr. Diamond in the

next month after scans and she wonders if he will change her treatment.

Other members, who have been on V, said that they thought that this was a side-effect, and that it didn't signify that the V had stopped working. She is on a dose of 2 in the morning and 2 in the evening. It was suggested that maybe this was too much for her. She started on V in May 2015 at a dose of 4 + 4, but could only tolerate this dose for 3 days. She went down to 3 + 3, and is now on 2 + 2.

- The new member asked whether a dose of 2 + 2 V was standard. She is on 4 + 3, and her doctor wants her to go to 4 + 4. The doctor wants to see how she responds to a max dose. It was said that 4 + 3 V is a very high dose, and that not too many people can stand 4 + 4 for more than a week. The dose prescribed depends upon how much a particular person can handle.
- A member who had tumors in the orbits, brain, spine, long bones, etc. started with a week of 4 + 4, but is now down to 1 + 1 and doing well. He has been on that dose for a while now. Another member said that he was on 4 + 4 for almost 6 months, but then started getting rotator cuff pain in the shoulder. Someone knew of a patient who used 4+4 for over a year. She is now on 3+3 or lower and doing OK.
- It seems that most patients on V end up getting better eventually, but "You need to find the comfort zone and try to stick with it."
- A member told us that when he had a sinus infection recently, his first symptom was "bulgy eyes". Scar tissue gets inflamed and he has to take a steroid for a few days for them to go back to normal.
- The prospect of changing diets was discussed. Going vegetarian, gluten free or doing the caveman thing and going Paleo. A lot of people try this, think that it has helped, and go on to try to persuade others to try. There is not much medical evidence behind this.
- The new member said that her lesions seem to have stabilized on the V. No shrinkage, but no growth either. She is not sure whether she is improving clinically. She will have a new set of test results in a few weeks. She can't do exercise because she has lesions all over the soles of her feet, which feel raw when she walks or stands. These lesions are calluses and she already sees a dermatologist for monitoring. She was advised that she should use a callus remover often.
- A member had her visit to a podiatrist this week. She had a large callus under her fifth right toe. The podiatrist cut it and said that there was a bursitis underneath. V accelerates skin growth, which can occur underneath the skin that is already there and hurt the tissues below.