

Summary of ECD Global Alliance Internet Chat

4 Jan 2014

10 Attendees

- A member came on early and left a message that she had been doing well until she started having bad dizzy spells. She said that she was very tired and was going to try and rest up.
- 2 more members have just started on the big V (Vemurafenib). One started last week after approval was given. The medicine came in the mail. He is now officially "on it", Saturday being Day 3. He goes back to the Doc in 2 weeks for a check, and then a scan will be scheduled. He has been having some problems with his stomach, but doesn't know whether that is a side-effect of the V, or something else. He is not part of a trial, because there are no trials centred on the West Coast. He is his own trial! His Doc has been talking with Dr Estrada-Veras (NIH) for the most part, but is now going to start talking with Dr Hyman (MSKCC) also. Dr E-V is hoping to start a trial for ECD patients in the Spring.
- A European member who started on V 3 weeks ago is now in much less pain, and is trying to find the energy for exercising again, after too long a period of inactivity. She has moved her exercise bike into the living room, so that it is easier to hop on it while watching tv (she did this twice today!). The weather has been really bad and rainy, so walking outside isn't possible. Swollen feet have been a problem. Walking on her feet has hurt (does she mean that walking on her hands and knees is OK?) and she has had pain under her heels. She goes for her 1 month check up next week. She told us that she had had her first side effects after a few days from starting V, with bad joint pains.

She has had her dose reduced to 1 tablet in the morning and 2 in the evening, and is now starting to work again. The leg pain is still present, but bearable. She was a little worried that her new dose wasn't enough. She emailed Dr Diamond at Sloan-Kettering. She heard that joint pain was a common problem. To deal with this, a lot of patients had to take V for 2 weeks, and then not take it for 2 weeks (but take steroids for that V free time).

- A UK member has just been approved to begin V. His main problem has been with his lungs.

Dr Haroche told his UK doc that he hadn't treated anyone who had such bad problems with his lungs. He was getting short of breath just lying down, and hopes to be getting better soon. He now has a blue badge for his car (a badge allowing you to park in spaces reserved for "Disabled") which means he doesn't have to pay for car parks at the hospital anymore. A small win! Another member said that shortness of breath was a big problem for him, too.

- A US newbie to the V treatment is on 4 tablets in the morning, and 4 in the evening. He has also been started on tablets to prevent him from having any attacks of gout. Gout can occur when a lot of cells start dying. His Doc is going to contact Dr Hyman at Sloan-Kettering, and may add a steroid if he has any problems.
- A member who started V about 6 months ago said that her balance is much better. She was pretty much immobile last year, mainly due to build up of fluid. She has lost 74 lbs of fluid since. The fluid had been building up for twenty yrs or so. A large abdominal mass had occluded (blocked) the inferior vena cava (the main vein that takes blood from the lower half of the body back to the heart) so that fluid accumulated in her body. She has noticed some small white bumps scattered on her upper body. But no other new problems since then. She started PT in September, and is mobile again, walking unaided! She still can't lift her legs very well, so going up stairs is hard. She is "grateful to be alive". Her Dr told her in September that he never thought he'd see her again! Another 2 members who are on V have noticed some skin bumps. The UK member with large effusions around his lungs, is hoping to lose a lot of weight too. He told us that his wife is making him a list of jobs that he needs to do. [Summarizer's comment; beware folks, there can be a down side to getting better!!].
- Concerns were expressed about the need to avoid sun exposure while on V. One member spends a lot of time in Greece. Another lives in Norway. In Norway there has been no sun in all of December, and January has been "rainy rainy rainy". A UK member will be holidaying in the Lake District (a rainy bit of the UK!) this year. And one member on V lives in Las Vegas! He will "just have to cover up". He doesn't "have any place to hide from the sun". How sad!

- Members discussed balance problems. These were common. One member has recently had falls. Members said that they had to go slow. Normal speed causes "balance issues".
- A member, whose son has ECD, told us that he has been struggling with fluid build up all over his body for a couple of months. His ankles and feet are swollen and diuretics aren't doing the job for him either. He is going to see Dr Diamond at Sloan-Kettering next week, and is having the BRAF test done again. He also itches constantly, and she thinks that it is a reaction to a med or meds he is taking. He itches till he breaks the skin. That means that there are 2 of them in the ECD family!
- Diabetes Insipidus was discussed. Different treatments are used, varying from nasal sprays to tablets. Doses were compared. More than 1 member said that if they are even slightly late with a dose of medicine, they "soon know about it"!
- Many members have had sleep problems. From difficulty getting off to sleep, to difficulty staying awake in the day. One member is taking melatonin, but doesn't want to continue indefinitely as he has heard some bad things about it.
- A member has been seeing a hypnotherapist, and she's taught him how to relax into quite a deep place, and has also been working on meditating the pain away. Unfortunately this hasn't worked this week, when he has been struggling for breath.
- 2 members mentioned that they had problems with low testosterone levels. One has a thickening of some sort around his pituitary. This has caused all his other hormonal problems too.