

Summary of ECD Global Alliance Internet Chat

23 Jan 2016

9 Attendees

- The bad weather in the US was discussed. Apparently, driving had been banned in NYC. People discussed whether they had had much of the snow or not. Norway was also reported to be icy. This was limiting the exercise that one of our members can take. She doesn't want to fall.
- A member, who has had a lot of shoulder trouble recently, said that the shoulder is so much better that she had been able to swim a few laps that day. When she was doing breast stroke she couldn't keep her fingers closed on her left hand. She wondered whether this could be due to ECD lesions in her brain or a side-effect of Vemurafenib. One member said she thought it was the vemurafenib (V). She blames the V every time she aches somewhere. Another member who has had V, said that hand/finger problems are caused by the drug. The member who was swimming said that the problem only occurs when she swims, although her right hand shakes when she tries to turn pages or do fine motor tasks. The problem seems to occur on intentional movements, not unintentional.

She was advised to keep her hands cold. A member said that he used to dip his hands and feet in cold water when he was on the high dose of V. This was to chill them down. You don't have to cool down the whole body! With the current weather, she will only have to step outside!

She recently received a phone call from Diplomat Pharmacy (that is the specialty pharmacy that sends the V to her). She was told that since her deductible was \$2000, they would send it to her for \$25! She is on a dose of 2 in the morning and 2 in the evening. Dr. Diamond decreased the dose in December, because her joints were so bad. She will be having a full head to toe scan in April.
- A member has come off of Kineret due to "insurance changes". He is now trying to get V, and will know shortly whether he can afford it! He is not sure if the Kineret was working. He felt some relief but his leg pain didn't subside. He is BRAF+, so he thinks that V is the way to go.
- The recent death of Glenn Frey was discussed. He was the lead singer and guitarist in The Eagles. He had been using a drug for rheumatoid arthritis for over 15 years and members wondered whether this might have been Kineret. Some are saying that this might have affected his immune system and the ability to fight infections, such as pneumonia, which was what probably killed him.
- A member who is on Kineret will be continuing the treatment. Her recent PET scan was reported as good. She is BRAF+.
- A member who has not been able to chat for a while said that "they" were still trying to work out his BRAF status. He was told that Dr. Diamond is now using a urine test to identify BRAF positivity, and may be able to send a test kit, although one member said that the urine test is more useful during maintenance.
- The member said that he needed to "check the mail", but he couldn't even "get to the mailbox". His doctor is Dr. Palmeri at Cancer Care. He has been on interferon since about 2008, and was doing fine. However, about 2 years ago he developed double vision. The doctors are hunting for

a mass that they can biopsy for his BRAF status. He has decided to start using an elliptical trainer to get some exercise.

- Members mentioned that the biopsy can be taken from the bones (sometimes from the shin) if the X-rays point to them as a suitable source.
- A member, who is coming off a V trial, has just had his last scans on the trial. The reports were good although the doctor saw a slight little hot spot on the PET scans of the bones and also around the kidney, since him being on and off V for the last 8 weeks. (A member who has taken V said that these hot spots tend to come and go, and, as long as you maintain a dose of 2 V, eat and sleep well, and exercise, they will go.) He has had 2 weeks off here and there. Apart from coming off the trial, he has also changed to the same insurer as his wife uses. He has just picked up his first supply of V from CVS Caremark. 224 pills \$0 copay!
- A member told us about some recent visual symptoms. She had trouble with the vision in her left eye for about 5 minutes while she was driving. She didn't lose vision, but became a bit cross-eyed for a while. Her eyes have never bulged, but her left eye has sometimes been blood-shot. Her eyes had looked fine when she was seen at NIH last April. She has also had 15 minute periods when her vision looked like "waves of water". This came about once a month and corrected itself. She ended by saying that "I WOULD LIKE to focus when I'm driving down a hill in the snow!"
- Another member had, about 3 weeks before, woken at night to go to the bathroom and thought that his right eye had gone blind. He woke the wife, and by the time she had "gathered her senses" it was over.
- Another member finds that every time that he gets sick, his eyes will bulge from all the scar tissue behind them.
- A member, who has been waiting for PET scan results before he starts treatment, has learned that there are more masses around the body than before, so more tests will have to be done. They found masses in his legs, kidney, brain, shoulder, eye, lower ribs, under one eye, and maybe his heart. But now they are talking about treatment for the first time. They will first need to talk with the social worker. They will try to get this appointment soon, and treatment may start in 4 weeks. They think that key issue will be the result of the MRI of the heart area.
He goes to one of the best hospitals in Canada dealing with cancer or other conditions like that. They have a lot of resources there. They are looking forward to the treatment stage. They are also trying to get the house prepared, so that it is safer there.
- The member who is just coming off a V trial said that he used to have scans every 2 months (a PET body, PET brain, MRI brain) and also an EKG and blood test, and dermatology review. He officially had his last scans on the trial the previous week.
- One member suggested that everybody who sees Dr. Diamond should pick the same appointment and "descend on him"!
- Two female members said that they like to have some "girl time". One goes with some friends to somewhere, a drivable distance from home, and stays a couple of nights. The other is looking forward to a group lunch later in the week.

- One member told us that he had ulcerative colitis before he had ECD, and tries to eat only cooked vegetables. Ulcerative colitis is an auto-immune inflammation of the colon.
- Finally, a member told us that she enjoys typing (and has been doing this for years with friends) because she has been deaf since birth. She did learn to speak before she learned sign language. But she has a hearing family so she communicates by typing.