

Summary of ECD Global Alliance Chat

02 July 2016

6 Attendees

- The member who is having a trip away with her sisters was in the Grand Tetons of Wyoming. She was having a great time, and ignoring the joint pain as much as possible. An altitude of 10,000 feet was "challenging" her lungs. She did admit to having turned down the opportunity to ride horses that morning!! The "galivanting" member is now on three Vemurafenib (V) a day, but wants to reduce it. Dr. Diamond wants another MRI of her brain first. She is caught up in a dispute with her insurance over MRIs or PETs. She is going to have an MRI this time, which she can have in Lexington and she is not sure that she wants "more radiation right now". She is just going to have an MRI of the brain, but her left hip is hurting so much that she thinks that she may need an MRI of that, too. She has been walking a fair amount in Wyoming and her hip feels like it is almost collapsing! She has not heard whether the MRI is scheduled yet.
- One of our French members had a week without pain, but has had leg pain when he bends for the last two days. Professor Haroche will be sorting out a treatment program for him soon. He had all the necessary examinations done in Strasbourg. The doctors sent the results to Professor Haroche in Paris (450 km from the member's home). He has stairs at home, and is concerned about the way that his illness will affect his ability to climb them.
- A member who has had V therapy told us that she had not had a PET scan in two years. She used to have an MRI every 6 months, but now will be once a year. She isn't sure whether she is satisfied with only this amount of follow up. She has been on V for 2.5 years with no break.
- Another member, who is in remission after V treatment, opted out of having a PET scan in April. He is trying to reduce his spending this year, so he can pay off the earlier bills. He is now at a point where he might as well just take his two V's a day and not worry about scans or switching medication. Nothing has changed for 1.5 years and he has not taken a break from V since May 2014. He is keeping up on his daily rest, exercise, and diet program to stay well.
- A member asked whether all "the hoopla" in Europe will keep Americans from going there (although the Euro will have dropped a lot, so things will be cheaper!).
- A member came on who is BRAF negative and has been taking sorafenib. This has been stopped and she starts Trametinib soon. Her shoulder is back to normal, but her eyes are not doing so well. She sees Dr. Diamond and last saw him at the end of March. She is not sure when she is due to go back. She is due to start tramatenib (T) once she has had an echocardiogram and her lab tests are complete. This will probably take a couple of weeks. Sorafenib "did a nice job" on her bones, reducing lesions between 25 and 50 percent and helped a bit with her eyes, but not enough. Dr. Diamond wants to try T.
- Another member who was being considered for a change to T had a stress echo (this is an echocardiogram along with being on a treadmill to get the heart rate up) a couple of weeks ago. She gets the sense from Dr. Diamond that she is not progressing like he wants.
- Members talked about having blood pressures that go up and down a lot. One had had a reading that was so high that the doctor wanted to send her to the ER! She went home instead and her blood pressure was fine!

- Members talked about having regular lab tests. For one, the doctors had wanted to monitor his blood monthly, but nothing has changed for 1.5 years. He thinks that that is a crazy amount to check. He was advised that it was probably a good idea to get it checked occasionally, just to be sure liver and kidney functions are ok. One member said that she did have monthly tests also.
- The difficulties of looking after relatives (and especially your parents) with Alzheimer's were discussed. This is even more difficult when you are ill yourself. Nursing homes are often not a great option. One member said that her mother recognizes her daughters, but not her husband. She rings to tell them that "there is strange man in house".