

Summary of ECD Global Alliance Internet Chat **12 Sep 2015**

8 Attendees

- We were left a message by a member who has been on Vemurafenib (V). She was going to a wedding and would miss the Chat. Her recent PET scan showed her lung lesion and legs are better. Her MRI shows that her brain lesions are stable too. She is on a dose of 3 pills in the morning and 3 in the evening of V.
- Another V "user" told us that she had been on a mountain climbing walk, 7.2 km. It had been quite difficult but she made it! Although it did take 5 hours! She had needed her boyfriend in one arm, and a walking stick in the other! She can do shorter distances on her own, but she has bad balance and stiff legs, which is a bad combination. She takes Vemurafenib 1+1, having started on 1+2 and after one year reduced. She has a checkup this coming week; she hasn't had one since February. She was asked her age, and said that it was 36 (summarizer's comment: "Believe that if you will; I thought that all women knock 5 years off, don't they!"). Other members claimed to be 35 and 53 (he was only 43 when it all started).
- A member who responded VERY well to V is back at work, teaching kindergarten children.
- A UK member has just started a 10 session, walking and balance class run by physiotherapists. He is the youngest participant by about 20 years!
- Another member who has done well on V said that he is "Feeling a bit better everyday". He has just had a visit at UCSD with blood tests. They are trying to determine genetic mutations from blood. This could be a very useful tool to quickly determine if a patient is BRAF+ or has another mutation.
- They are also trying to use urine to ascertain BRAF status and levels. The member who has just been to UCSD had done many urine samples when he was at Memorial Sloan Kettering (MSK). This is a different technology from using blood for tests. It is possible to have multiple mutations, and the technology to diagnose a mutation is further ahead than the availability of treatments. It was said that it wouldn't be very useful to over analyze mutation types unless/until drugs and treatments are actually available to deal with them.
- Another member has been having V treatment for a good while, and has responded well. She said that training and exercise has worked wonders for her. She feels like most of her spare time goes on exercise, but she is motivated by the fact that she is getting better.
- We were asked whether those on V had noticed any hair loss on their legs, hands, feet, etc. One member said that he hadn't had much hair on his legs, hands, feet, etc. to begin with, so he could not really tell. A female member had lost hair on her head. This has grown back, but she is now "all curly". One member had lost his "hairy bits" (or rather the hair ON his bits, not the bits themselves!) although he has never had V!
- We were reminded that there is an ECD page on Facebook. It is only visible to members.
[Editor's note: see - <https://www.facebook.com/groups/784637751599933/>]

- The "gathering" in Houston was talked about. It is coming up soon (October 9-10). Some will be arriving in the days before it starts. There is a meal on Thursday evening when people can meet and put faces to names.
- A member who has had a lot of problems with her eyes (macular edema) told us that her latest OCT examination showed no edema again! This the 3rd week for which it has been clear. She is hoping that this is a sign that the Sorafenib (she is ARAF+ and that is why she is not using V) that she is on, is doing the job!! But her vision is still "pretty crazy". She has 20/20 vision in the left eye, and 20/30 in the right but doesn't see clearly. She wonders whether this might be due to damage caused by years of the edema. She is hoping to have an MRI of the brain and orbits, to see if there's any improvement.
- A member, who had an eye biopsy in April of 2014, is still experiencing after-effects from the surgery. The surgeon who did the biopsy at Mayo knew that ECD was the diagnosis even before the procedure. He is now living in California and sees Dr. Kurzrock. He saw her in July, and won't see her again till Dec. He is having blood tests along the way to monitor his health.