

Summary of ECD Global Alliance Internet Chat **16 Jan 2016**

9 Attendees

- A member thinks that he is getting another sinus infection. He had to go to the Acute Care Unit at his local hospital recently to get treatment for one. He finds that his eyes become more pronounced and a bit "bulgy". He puts this down to the large amount of scar tissue behind his eyes, but it doesn't affect his vision. He wonders whether over the counter drugs can help. He asked for info on any home remedies that people knew of. Ginger & lemon tea was suggested (grind fresh ginger, pour hot water through the filter and squeeze in some lemon and honey). The Ginger/Lemon has a good flavor providing you like things a bit spicy. Another member uses Mucinex for her sinus problem.
- The member, who thinks that his sinuses are playing up again, has his last scans for a while this week. He is looking forward to not having so many scans. He is just about to come off the vemurafenib (V) trial at Memorial Sloan Kettering (MSK). He expects to be staying on a V dose of 2 in the morning and 2 in the evening and getting it "off label".
- A member who has recently been diagnosed with ECD has not started treatment, but is hoping to be put on V soon. He has appointments due with a lot of specialists: hematologist, heart doctor, dentist, urologist, and a specialist in arthritis. He also has a heart MRI scheduled for April. He is due to back to the main doctor in February and will get more information then.
He would like to take V if it is possible, but it might not be. They will have to wait to hear what the doctor says. They are also waiting to see if he is also JAK2 positive, because that may well change things. JAK2 is a gene that is responsible for the over production of platelet and white blood cells. He has had a raised platelet count for 20 years, and they are trying to get to the root of this. A positive result means that he does have the JAK2 gene, and a negative result will mean more tests.
- A member who has responded very well to treatment with V told us that she is exercising "more than ever! It's what makes me feel good".
- A member had returned home from Vancouver on the previous night. He was asked about the weather conditions there. "Ups and downs." It had started with unusually sunny days, but then turned into rain.
- A UK member said that the snow was falling at Chat time.
- A member who has been having shoulder difficulties told us that it was now better. She fell recently, and she has some pain in the left popliteal area behind the knee and she has a swollen left shin. Her right knee is painful on the medial side (inside) and she has been told that she has a Baker's cyst.
- A member, who has recently started to see Dr. Diamond, is now on 2+2 V. She sees her local oncologist next week, and goes back to Dr. D in April. She will be having lots of scans etc. She is

exercising gently.

- A member who is in remission, and has started to see Dr. Kurzrock, was asked how he would monitor the situation now that he was not having scans. He is now down to 1+1 V, and only sees Dr. Kurzrock every 3-4 months. However, he has blood work done every month. Although he is not showing any symptoms, he is afraid that ECD may come back in places where it wasn't before. He now gets a full body PET scan every 4-5 months. Some insurance companies limit the number of scans that you can have if you're not on a trial.
- Members discussed whether there was a "best" time to get your blood work done. Someone asked whether 0800 was best, but the general opinion was that it didn't matter (except for fasting glucose tests and some tests for blood hormone levels).
- A member lives next to a neuro/ophthalmologist. This doctor's daughter is a high school student, and is going to interview the member for an article in a magazine. Since this member is the only registered ECD patient in this state, she thinks that it "should be interesting". She has also discovered that one of the medical oncologists that interviewed her at the University of Kentucky lives around the corner!
- A member who changed to his wife's insurance has had no problems in getting V authorized.
- Back to the topic of colds and runny noses... One member said that he never had the flu, or even a running nose, for many years. However, his ECD is under control these days, and he has now been able to catch a cold once in a while, just like a normal person. One said that, where she lives, "you need to give cold - sinus 3 days - before the doctor will say you need to take antibiotics" [most doctors would want longer than that, and worse symptoms than being stuffed up and having a running nose!]. One member said that she had a sinus infection in November, and still has a runny nose (but it's clear). Someone then suggested that it helps to "put some Vaseline on top of the nose bridge before you go to sleep". [Summarizer's note; as an ex-doc, I'm not sure about that one!]
- The husband of a member came on. She couldn't be with us herself. She fell and fractured her shoulder when she was rushing to the kitchen to check on dinner. Her shoe stuck to the tile, and her momentum carried her into the wall, and then down on the tile. She is going this week to see an orthopedic doctor to see if surgery is necessary. Her ECD medicine (Sorafanib) can exacerbate bleeding, and she has bruises in multiple places, so she is having to cut back on the med. She was due for a PET but that has now been delayed because she can't lift her arm. The pain killers are causing constipation.
- The member whose doctors are concerned that his ECD is affecting his transplanted kidney is having a CT scan this week. He thinks that it is quite likely that he will need to start V. It was said that "We all consider V to be the miracle drug" but how many users have trouble after they've been on V. A member who has had V said that everyone on V has some kind of trouble, but the extents are very different. One of us still has numb toes, and hopes that this will go away soon!
- The appointment times given out for scans were discussed. The doctors do scans and procedures 24/7, so it depends on them when the scan times are scheduled. One member had an MRI of her brain at 10:30 pm! And another once had an MRI at 0300!!

- The member who is about to come off the V trial said that his scans were looking a little better each time. He doesn't like being exposed to "all of that radiation". He was told that he may just need to have PET scans, probably every other month to start with, and then going to longer intervals over time. He has been told by his doctor that the scans will be much more spaced out.
- The joys of "waterworks issues" were discussed. One member said that he tended to pass 100ml, and have a residual volume of 150ml still in his bladder. Another member has nearly "got the whole set". He has had, or still has, kidney stones for which he has recently had a percutaneous nephrolithotomy, repeated urinary tract infections, and botox treatment for an overactive bladder. His bladder doesn't look a day over 18!! But he does have to intermittently self-catheterize. Percutaneous nephrolithotomy is an operation where they put you to sleep for 3 hours or so, and stick a big spike (cannula is the posh term) into your kidney. They grab whatever stones they can and take them out, crush some stones up, and zap some with a laser gun, and send all the bits on their way down the pipework. After he had had the operation he didn't breathe adequately after they took out the breathing tube. So they stuck in another one for another 8 hours! Waking up that evening, with a breathing tube still in, was no fun at all!!
- More members said that they have registered for the Paris trip later in the year.