

Summary of ECD Global Alliance Internet Chat **26 Dec 2015**

7 Attendees

- It was mentioned that the ECD Global Alliance has put some videos of the 2015 conference on YouTube and they are subtitled. To access click on the CC (Closed Captioning) button to turn it on the subtitles. <https://www.youtube.com/channel/UCYR3skR>
There was some discussion about the CC button! You have to click on the button in the menu at the bottom. In the settings, there are options to read it in other languages or to change the font size. Some editing needs to be done to remove typos. The CC have been automatically generated. It would be great if anyone knows of someone who would like to volunteer to edit the CC to get them corrected. Someone suggested that it would be good to get in touch with the people that CC live performances in theatres. This is called open captioning. They transcribe each word live. The Hearing Societies may be able to point us in the right direction.
- The new member in Canada saw Dr. Pagnoux in the previous week. He specializes in blood disorders and is a rheumatologist as well. Our member is his 6th ECD patient -- he has 3 in Canada and 3 in France.
- The member and his wife had found that it was "amazing how one hour and half makes a difference". They are now in the stage of getting more tests. The doctor was able to view the X-Ray and MRI images of the member's kidney, heart, and legs. They will have more test results when they go back in February, and should get a treatment plan. He has a high platelet count which has been going on for many years. There is some concern that vemurafenib (V) may not work in this case, and so he is in consultations with doctors in USA who are examining all options. His platelet counts are extremely high, and this is controlled/treated with baby aspirin.
It was easy to ask for a PET scan, and easy for the doctor to order it. Some other things need to get checked out -- his kidneys and his heart. The problem isn't getting the scan, the problem is getting the doctors to agree to request it.
He is to see a local rheumatologist in a few weeks, who will offer him the medical care he needs if he needs it locally. V is being considered, and interferon and Kineret were mentioned, but Dr. Pagnoux may have to explore the use of a new drug. They will have the answers in February, including a better idea where the inflammation is, and hopefully get some treatment plans for other issues bothering him. He used to take vitamin B12 tablets for anemia, but this has been stopped.
They feel "tons better" having someone looking after the ECD and pointing them in the right direction to get help in other ways. The doctor said that the ECD was "very slow moving", which is in their favor. On another matter, the member is enjoying the use of his Christmas gift of an IPAD stand.
- A member who has been on V, and is now in remission on a low dose, said that he was doing well. He doesn't know if V is still doing anything anymore as he has not tried to stop taking it. "Maybe it's really not doing much these days."
He has found that driving gives him the best indication of whether he is doing better. He also told us that he had tried to maintain a colder body temperature. So he would chill down his hands, feet, eyes, etc. during the day, and even in the middle of the night!

- A member who has also been having V treatment said that he had not been so good this week with some chills, low grade fever, and headache. He said that he has been getting headaches, numb feet, and sore legs on a dose of 3 in the morning and 3 in the evening. (Another V patient said that he had got all of those, too.) When he was on 4+4, it was about 6 months before his first side effect.

His original symptoms were from the ECD and V helped to resolved them. "Nothing is there now". On a previous Chat he had mentioned some of the SUV's (Standardized Uptake Values) seen on his recent PET scans. The scans from September had SUVs of about 2.3. This was in the bones.

The doctors use the SUVs to get a rough idea of whether a tumor, or lesion, is benign vs. malignant. Usually, 2.0-2.5 is the cutoff. Different lesions or tumors may have different values on the same scan.

- The member in remission said that on his last scan, a few of the lesions/tumors are no longer visible, and one of them had dropped to 1.3. If the treatment is working, they will continue to drop over a long period of time.
- Members discussed the length of time that they had had symptoms, before ECD was suggested. One thought 8-9 years, another 10. Another said that there were a lot of little signs that something was wrong, but that he had never really thought about it. He would get a funny feeling if he got off the couch fast, and he didn't feel "completely stable" when getting dressed. One had had trouble with his arm for over 10 years. He, now, has full normal motion and range of his right arm. "So V did it!" He also had felt dizzy if he "span his head or did a flip"!