

## **Summary of ECD Global Alliance Internet Chat** **19 April 2014**

11 Attendees

- A member came on before the chat started and said that he had been diagnosed with ECD about 6 weeks ago. He had just begun taking interferon injections, three times a week. He said that he had been told by the doctor that he would have flu-like symptoms every time he gave himself the injection. So far he has taken it 5 times, and only had flu-like symptoms the first 2 times. He hopes that this is "the end of that". He hopes that the interferon will control the disease, but he is also hoping that it will help improve the terrible fatigue that he has. He asked whether others were using interferon, and if it had helped with the problem of fatigue.
- A new member, from Turkey, came on. He asked some questions; how do patients feel? What is the exact time for chatting? How can he get tested for the BRAF mutation? Where can the test be done and how much does it cost?
- Dragon Dictate then decided that the member who is using this program wanted to say "good afternoon cheddars"! Luckily the "cheddars" did not take offence at this and they stayed on. Perhaps they thought that they would taste better once they had matured a little by spending time Chatting!
- There were chatters from Dayton Ohio, Houston Texas, and the UK. Two of the US members are going to try to "get together". The member from Houston is planning to retire to the mid west. "The land of lakes and snow" said one member. After living in Houston for some 30 years, he has been hot enough for long enough. He really misses the seasons.
- A member told us that he had been to the NIH the first week of March. They had found a 100% blocked heart artery! This has now been stented, but he has had to stop working. This has been hard to adjust to, but he is glad to be able to rest.
- A number of Chatters commented that Dr. Estrada (NIH) was "awesome". One member has been told that Dr E will try to get a biopsy to test for BRAF. A biopsy taken before had no ECD tissue in it. A member advised us that, if we were planning to have the BRAF test, then ensure that the doctor talks to one of the doctors at MSK first. One member had a positive biopsy at one hospital, but then had to have another in New York, because they didn't get enough tissue the first time.
- The member who has been having shoulder problems is hoping to find out something in the next week. His doc is supposed to have scheduled an MRI.
- Members discussed the "delights" of riding on the great big medical merry-go-round. One thought that it was more like a roller coaster if you go to NIH! One member needs a large spreadsheet to help keep track of everything. The timing of MRIs was mentioned. 6am is usual for one member. 7am on a Sunday morning had been used at MSK! And 8.30 pm brought up the rear.
- Members said that their spouses were all very supportive and appreciated. The medical team, at the NIH, was praised. It was noted that what the local Dr's were missing, was knowledge about ECD. One member had started his ECD journey back in 2000. He finally got a diagnosis in 2007. A Long Road!!

- After the Chat had finished, one member came on and wished us all a “wonderful week-end!” Then another came on to apologize for missing the Chat. She had been out “detailing my car and helping my dad with his”. She has been having some bad back pains, but is otherwise doing OK.