

Summary of ECD Global Alliance Internet Chat **28 Mar 2015**

6 Attendees

- The first part of the chat involved a US member asking a UK member about the word "fortnight". This is used often in the UK, but not in the US. It is used to describe a period of two weeks. It most likely derives from there being FOuRTeen NIGHTs in two weeks and so a FORTNIGHT.
- A member told us that she will be going to the NIH later in April for two weeks to begin the trial of dual therapy (dabrafenib and trametinib). She is BRAF positive. She said that enrolling on the trial was not too much work. She just had to fill out papers, and is looking forward to getting started. Her legs and shoulders really hurt and, at the moment, she is not even taking OTC medicines.
- A member on the Sloan-Kettering (SK) trial has just come back home. He had been there for the whole week, including a few days of sightseeing and visiting Long Island. Sloan-Kettering has been getting a fair bit of publicity from the trial (vemurafenib). They are not working directly with NIH. The drugs being tested are different, but they will be exchanging information.
- One member is putting her stomach problems down to the steroids that she has been taking for her eye problems. She had to go off her ECD treatment drug for almost a week. She is ARAF positive and not BRAF positive, so she is the only one on this drug! Her eye had worsened and she had to go back on steroids. Now she is back on the drug, but only on half the dose. She will be having an OCT (a test that looks at the retina) at the end of April or beginning of May.
- A new member said that she was diagnosed "by accident" on January 21st. She had symptoms which the doctors could not explain for years (skin lesions, that were taken off and biopsied, and called xanthogranulomas or reticulohistiocytes). Last fall she began to feel dizzy and started slurring her speech; so she saw a neurologist who reluctantly ordered an MRI. This showed lesions that he couldn't identify, so off she went to Duke. She is now waiting to start a study at the NIH. The doctor at Duke, who 'accidentally' diagnosed her in January, wanted to prescribe Pegasys (the long acting interferon alpha injection). Even though he told her 4 times that he had NEVER prescribed it before! He didn't want to test her for the BRAF mutation. She "kindly" told him that she would check into the NIH study, and she contacted Dr. Estrada-Veras directly.
- Another new member came on. She is from BC in Canada. Her sister, who lives in Ontario has ECD. She has sent her sister information on how to join the ECD-GA, but she does not seem interested at the moment. She and her husband are very trusting of the medical system even after waiting so long for a diagnosis. She is in "bad shape" and has had many health problems over the years. She fell out of bed almost 2 years ago, and has not walked since. She has lesions on her spine, and problems with her sight, but she has no pain. She had "everything" tested for a year. Last October she flew to Toronto where a team diagnosed ECD. The sister on the chat thought that she has been tested for BRAF, but was not positive. She is being treated by an oncologist. She is on her

fourth round of chemotherapy, but there is no change in her condition. Cladiribine chemotherapy is just given once a month for 6 months (although it is one injection every day for 5 days in a row). The member had sent the doctor the article about Alice Nilsen, our Norwegian member, and her doctor was interested in Alice's treatment. To be on the treatment that has worked so well for Alice, you need to be BRAF positive.

- The question of a "cure" was raised. It was said that ECD is like cancer. You haven't been cured until you die of something else (like a truck, or a bullet), and there is no sign of the cancer in your corpse. This means that something else "got ya", and not the cancer!
- Some members said that they had been prescribed anti-depressants for their symptoms. It made one member feel like it was "all in my head".
- Two members are both going to SK. One will probably go back at the end of April or beginning of May to see Dr. Diamond. He wants to do testing to see if her drug is helping at all. He wants to do another PET-CT. She had one in January and asked whether having one so soon after would be OK. For the people on the clinical trial, the schedule is to have MRI, CT, PET, etc., every other month, so she should not worry.
- The other member, who goes to SK, will be going back again in late April. They may meet up with each other!