# Summary of EDC Global Alliance Internet Chat
# 11 Jul 2015

13 Attendees

- A member had left a message to say that he was going out to eat so he didn't expect to be on the Chat. He is in the UK so Chat time is 2000hrs (prime time for scoff!).

- A member came on the Chat for her first time. She has previously followed people on Facebook. She has ECD, and has been ill since 2008, but only got a definite diagnosis in 2011. She is BRAF positive and goes to Barnes Jewish, which is located in St. Louis, MO. She has to go there every 28 days, and sees a doctor that knows about ECD. She has been on a vemurafenib (V) trial for a year, and started by taking eight a day, but she got the hives and so backed down to six. (Another member who has been taking V said that she had been on 2 in the morning and 2 in the evening for the last two months, because she got a rash from 4+4 after 2 days!)

  She has no pain, but her immune system is down and she "gets sick easy". She has had low immunity since about 2008. She doesn't take regular antibiotics. When the disease started up it was in the fall of the year. Her biggest allergy is to ragweed. She lives on a farm, and her husband tries to keep the weeds down.

  Her main problem usually is with her breathing, as the ECD has affected her lungs. Her pituitary gland is affected so she has diabetes insipidus (DI). They recently found this out after a stay in hospital of 14 days. Her hormones are "screwed up" so she has to take T3 and T4 (T3, or triiodothyronine, is one of the two circulating Thyroid Hormones and is the more metabolically active one (relative to T4). Used as therapy for hypothyroidics, T3 may hold some promise as being a short-term fat burner and cognitive enhancer vicariously through the effects of thyroid hormones.). She was first put on Kineret shots. Other things were tried but they did not work. The trial seems to be helping. It seems like she has more energy and people say she is looking better. Her husband is her chauffeur and finds this tiring, but he says Barnes Jewish is a nice hospital.

  Her only side-effect from V is that she can't be out in the sun, or wind. The wind is actually worse than the sun. She has a callus on her left thumb and another on her left big toe. She thought that they were warts, but the dermatologist said they were stress points in her body. If she has any pain it is in the right side of her body.

- A member had seen a dermatologist the previous week, who "burned" off about 10 growths, that the doctor said were warts. A member, now on just 1+1 V, told us that he applies salicylic acid lotion to his feet/soles often. A prescription is needed for this as you can't use just any concentration. The one he uses is 6%.

- Herbals and supplements were discussed. A member asked whether anyone had ever taken Turmeric or Ginger for pain/inflammation. One said that she had started taking Turmeric, but then stopped and asked her doctor if it was okay to take. She is still waiting for an answer. One member had just started taking (along with vitamins B, D, and a multivitamin) Turmeric with Pepper (said to aid absorption) and Ginger. A member has a friend, a physician, who is "very into natural stuff". They met at the Co-Op yesterday and she showed the member which herbals she thought would help the pain.

- Our member who is now on 1+1 of V is doing well so far. She was recently away for 3 weeks at rehabilitation, where exercise was the main focus. She "felt great". She even went bike riding on an electrical bike! She then had a vacation for 5 days so now her legs feel worse again. She had done lots of walking in Copenhagen, but not enough. It has been a lazy day today, but she has to go to the gym in the morning. She did notice that when her bottom lip had got sun burnt it swelled up, and looked like she had had LOTS of botox. Another member who has gotten down to 1+1 doesn't have much trouble with the sun now, but did when he was on the higher doses.

- A member who is ARAF+ is still on sorafenib, but is "taking a short break" due to side effects. She asked whether any of those on "V" had ever had a hemorrhage in the whites of their eyes (an ex-doctor writes; this is a subconjunctival hemorrhage- these never affect your vision, but look very dramatic!). She has had two in the last two weeks. Her drug is a "cousin" of V and has similar side effects, so she was just wondering if others had similar problems.

- A member has had a "small" town week with her sister. They have been to about 5 tiny towns around Lexington to festivals, outdoor plays, etc. She is good for about 2-3 hours then needs a nap. This member has just got a special SPF sunscreen through Amazon for her face. It is a sunscreen that her Dermatologist recommended.

- A member asked how to access all of the current chat summaries. He gets the emails for current summaries, but doesn't know where to get the older ones. (The 2015 summaries will be added with our next website update, hopefully sometime in August.)

- Two female members discussed hair and treatment. One had had completely straight hair before starting on the V. Now she looks like Shirley Temple! Her hair had got thin during the first year of V, but is better now and the curls have just "exploded"! The other is on sorafenib and hers is "really thinning out".

- Our member who has continuing 'puter problems has got an offer, from a FB friend, of a modem for $40. He is going to take this offer. "It could be a block of wood, and work better than this one." This member has an ophthalmologist appointment this coming week. He still hasn't been given his BRAF status.

- Night sweats were discussed. Many patients get them, although they have often reduced in those who have had treatment. One member had even had the night sweats in the daytime!! And one used to have fevers, but not since she went on V.

- Our new member told us that she doesn't get a fever, not even the last couple times when she has been sick. This makes it harder to know when she is getting ill. Her husband watches her "like a hawk" for signs. She does get some infections but it is hard to know when she has got one. During this spring, she had an upper respiratory infection, but the only sign was that her voice was hoarse.

- We were told that the member with the tandem bike is out on it (with her husband, naturally) quite often. Someone said that if they start now, they can stay with them in Lexington, and be in Houston by the beginning of October! Four of the chatters are going to Houston this year.

- The new web-site was praised. Thanks to all who helped develop it!

- We were told that, according to some of the ECD doctors, ECD may eventually be reclassified as an autoimmune cancer.

- Members talked about the attitudes of other people, towards those of us with ECD, and what was not helpful. Being told that "you can overcome ____" (fill in the blank), "if you just keep trying", or that "you look good" (should we all look like someone from a POW camp?). It was said that because "Folks see double amputees running marathons on prosthetic legs, they assume that everyone can do that." These stories get news coverage. It isn't news to write about the people who are so "emotionally beaten up" that they can't do the same.

- Finally 2 members came on with their stories. For one, her husband is BRAF positive. He was due to start his 3rd round of Cladiribine in 2 days, but he has had chest pains, went to the ER and had a mild heart attack. Tests showed a 95% blockage, and a stent was inserted. He is feeling better now. His ECD symptoms started with a bulging eye 2 years ago, but she had noticed a difference in his personality 4 years before. He was finally diagnosed in May. His doctor is Dr. Schiller at UCLA. Her husband is not sure treatments are working, and Dr. Schiller is not very talkative. Her husband has had 2 operations on his eyes to relieve pressure, but he has no sight in left eye. The ECD is in his brain crushing the pituitary gland, and in other places. His balance is not good either.

- A member came on also has an ill husband, who may have ECD. She said that his "x-ray has shown positive". They are awaiting other tests to get it confirmed. At the moment they are dealing with a kidney stone that he has. She thinks that he has been dealing with this (the ECD-like symptoms) for the past 5 yrs., and is trying to get some more information on this.