

## **Summary of ECD Global Alliance Internet Chat** **18 July 2015**

5 Attendees

- A member from the US had his first encounter with a Norwegian when they were both on the Chat. The Norwegian told him that she had managed to go to the NIH twice, and to the ECD conference twice. The US member won't be able to go to Houston. He has had to take too many days off from work this year. Someone asked whether there was anything planned for the Sunday of the conference weekend, but other members thought that there wasn't anything planned. It was said that you are sure you to meet others with this "lovely disease" at the conference. [Editor's note: The ECD Patient and Family Gathering will be held on Friday, October 9 and Saturday, October 10 only. There are no planned activities for Sunday.]
- One member told us that it was 7 years after his diagnosis that he met another patient! He was diagnosed in 2005, and is currently "in remission". He has been taking "low dose" methotrexate (40mg) once a week for a few years. He is still slurry and wobbly, and had to retire from being a family physician 8 years ago (at the grand old age of 45). Methotrexate is an old chemo drug. It has been used over the last few years in rheumatoid arthritis, as it reduces the autoimmune reaction. Rheumatoid arthritis patients also take "low dose" once a week, but their dose is less than 15 mg!! Zelboraf and BRAF status weren't around when he was most ill so he never got into any of that. He needs to get bad again, if he wants to try any of that!!
- The Norwegian woman is 36 years old, and was diagnosed in 2011. She thinks that she probably had it closer to 10 years prior. She has been educated as a nurse, and is now working as secretary part time. Her bad balance and stiff legs are the main problems. She has been on Vemurafenib for 1.5 yrs., combined with "tons of exercise" and there has been a good effect. She used to have a lesion in her spine which gave her extremely stiff legs. This lesion is gone (due to the V), but there is scar tissue, and she has been told that she will always have stiff legs. She also has Diabetes Insipidus (DI), but that is a minor problem compared to the difficulty walking. She has no pain now.
- A member who started V recently told us that he had had awful balance, eye problems, speech issues, and swallowing difficulties. After 2 weeks of V everything is back to normal, even his balance! He ran to catch a train the other day!! At Memorial Sloan Kettering (MSK) he is a celebrity. Dr. Diamond said it's the fastest response to vemurafenib that he's ever seen. He had all of his problems for a little over a month, except his eyes which had been troublesome for a year. It took about a year for him to get a diagnosis. It was said that most of us have taken a few years to get a diagnosis. He was rushed to the hospital with the idea that he had aggressive lymphoma. But all the finding on scans did not present lymphoma. A lot was going on inside him too...although he had no symptoms of that. He was told that "the 'V' drug was your miracle."
- One of the members suffered damage to her immune system from a chemotherapy drug that she took (clofarabine). She asked the member on methotrexate about any effects on his immunity. He said that he had had some "horrible bad chests" [infections]. One was due to ECD in his lungs. Another time he had Respiratory Syncytial Virus (RSV) Pneumonia. You get RSV when your immune system is low. He had to spend 3 weeks in an isolation room. He couldn't go out of the room or have any windows open, and ALL visitors had to "rubber up" with

masks, gloves and aprons (even the Doctors and Nurses)! Although he is now in remission, he will always be slurry and wobbly. No standing on one leg for him! "And I'm NOT going back to work!!"

- A member told us that her problem is the crazy feeling she always has in her head. Since the disease is in her head and orbits, she can't even begin to describe. She has it in her long bones but she has no pain from the ECD.
- One of us said that she has not been sick with a cold or fever all winter and spring. She can't remember the last time she was sick. So her immunity is going strong.
- Members talked about supplements. The member who can't remember being sick, doesn't take anything. She eats healthily and exercises regularly. She managed to do 5 miles on Thursday, a new record for her!
- The member on methotrexate takes folic acid except on methotrexate day, and vitamin D because he has got the "little old ladies disease", osteoporosis. He is on biphosphonate, Bonviva and a calcium supplement. The Bonviva is just once a month!! If you have it into a vein it's only once a year!!! He was placed on it 3 months ago. His DEXA scans show thin bones, he has had long courses of steroids. He broke a rib after a minor fall in the bathroom (Hic!).
- A member has been told to take folic acid, and Vitamin D. She had osteopenia before she had ECD diagnosed. She hasn't had her levels checked in a long time. She needs to start walking. She gets on the treadmill sometimes, but her head won't let her take much of it.
- Someone had recommended Turmeric to a member, but her doctor hasn't said if she could take it.
- A member on V has been super sensitive to the sun. A member on a low dose (1 in the morning and 1 in the evening) can manage the sun for an hour or so with SPF 50 and a sun hat. But she has been outside longer if on walks.
- A number of members praised Dr. Diamond. One said that he "has been awesome!". This member is going to see him once a month now. He goes for his first scan, since starting on the meds, on July 30.
- A member then told us some strange stuff about treadmills. His buddy was recently diagnosed with stage 4 lymphoma, and this "natural doctor" said the treadmill is the worst for you. He said it lets off radiation. He also talked about leaving your wi-fi on at night, and eating only organic foods.

The lymphoma patient had a phone conference with this doctor and recorded it. According to the doctor, treadmills did release radiation. A member said that he thinks that this doctor is a little crazy. He asked whether he had told them to keep away from the UFOs yet. "You don't want to get captured by the aliens!"

- A member came whose husband has ECD. He just had his 3rd 5 day treatment of Cladiribine, the disease was finally diagnosed in May. Years ago she noticed personality changes first. About 3 years ago his eye started bulging. Then, in May, after multiple surgical biopsies, and after having terrible balance and headaches, he was hospitalized and had scans done. It's in his brain, bones, eyes, and sinus cavities. He had a heart attack last Saturday due a blockage in a

coronary artery. He has had a stent put in. She was advised to make sure that they're doing regular blood work on him, particularly checking his white blood counts while on the Cladribine. So far his blood tests have been ok we were told.

- Another member was placed on Cladribine when first diagnosed. The cladribine was working for her but they switched to Clofarabine, because the Cladribine wasn't showing improvement quickly enough. She had only been on it two months. The Clofarabine destroyed her immune system.
- It was mentioned that a member had heard interferon treatment "is rough. One member had it, and was completely exhausted 24/7. Another found that it didn't bother him. He must be insensitive, which probably comes from working as a Family Physician for 20 years. "Must harden you up!"
- A US member said that there is a patient with ECD who only lives 10 minutes away! He was diagnosed in 1998 after multiple surgeries. He's doing well now and is on prednisone for maintenance.