

Summary of ECD Global Alliance Internet Chat **11 April 2015**

10 Attendees

- A message was left for us by the wife of a European ECD sufferer. She asked whether there were others who take Neoral or interferon (intronA). She said that her husband had symptoms from ECD outside his kidneys for 3 years, but there are now signs that the ECD is active within the kidneys, and they are only functioning at 11%. She asked whether others had such problems.
- Another member left a message. He could not attend because he has "had a horrible few weeks with a chest infection". Not getting any sleep, and coughing when lying down.
- A member is going to the NIH this coming weekend, and will not be able to chat. She was diagnosed in January, but has not had any formal treatment yet. She lives in Kentucky, but grew up in Texas. She has had all kinds of "crazy symptoms". It was all put together by accident a few months ago. She had been at Mayo in MN last summer, but was incorrectly diagnosed. She has severe leg pain (with lytic and sclerotic long bones). She is not taking any pain medicine (even Advil or Tylenol) because Dr. Estrada asked her not to before she goes to NIH. She has lesions in her cerebellum, and her balance is not good. She coughs a lot, and is thinking that there are histiocytes in her lungs. She also said that she had "occasional heart issues" which nitroglycerin takes care of [summarizer's note; probably anginal chest pains]. She has never been to NIH before. She is going to be in the phase 2 study. She thinks that she has had some degree of ECD for about 10 years. Odd lesions began popping up on her legs and when they were biopsied, histiocytes were found in the mix. Her symptoms really accelerated last summer.
- A member told us that she has been to the NIH twice already. Her main problem has been poor balance and stiff leg muscles. Luckily, she is not in any pain. The tumor in her spinal cord has completely shrunk, after some months on vemurafenib (V). Now there is just scar tissue left. She will be going back to NIH later this year.
- A member, who has also entered the phase 2 study, told us that he had just finished an "intense" week at the NIH. They kept him very busy with lots of tests and such every day. This was his first visit. He takes V, 2 in the morning and 2 in the evening, and has enjoyed a gradual improvement. He had first presented with a tumor over his right coronary artery. This is getting slowly smaller. This tumor was discovered in his home town. He attends MD Anderson (MDA) "Wonderful place".
- A member who has had a particularly difficult ride on the ECD Helter-Skelter, (she had a lymphoma as well as having ECD) has just had another PET. She visits her oncologist and Dr. Janku at MDA next week. She hasn't been able to get to the NIH yet. On the first time that she was going her husband found out that he had cancer, and needed treatment. On the next time she found out that she had lymphoma.

- The Houston conference was mentioned. Most of the chatters were planning to be there. Some had signed up already.
- Nursing in general was discussed. One member said that a nurse had told him that "nursing is not an occupation, it is a calling". Another agreed, and told us that her nurse mother had met her father during WWII in India. Her mother was at Walter Reed Hospital most of the time during WWII...right near the NIH!
- The benefits of exercise, and some of the difficulties involved, were mentioned. For one member her goal for the next year is to walk around the block. Up until last fall she could walk 15 miles/week! Another also wished to walk but his right ankle "doesn't agree". He asked whether anyone had any good ideas for the relief of ankle joint pain. He is trying to include a 30 minute "brisk" walk each morning in his "program". A member, who has ECD and Rheumatoid Arthritis, said that her doctor has her taking Glucosamine for joint pain. The wife of one member is a violinist, and she seconded the idea.
- A member has recently fallen due to his balance problems. It was his 16th Wedding Anniversary, and he lost a gourmet meal, wine, champagne and dessert. But after 16 years, "it sort of looks like you guys are going to last!" said one member.