Summary of ECD Global Alliance Internet Chat
30 Aug 2014

8 Attendees

- A member who could not be with us today suggested that the ECDGA could raise awareness (and maybe $$$) by picking a weekend and posting on FB about our dealings w/ ECD. If even some of the people who get the link sent to them, spread the word, and it grows, then something good should happen.

- A member told us that she is still having pain in her lower back, and the doctors would like her to have an MRI as soon as she can. She has been having therapy for her shoulder. This is still hurting, but it is doing better and she is getting more motion.

- A member came on for her first time. She was diagnosed in January, lives in Pennsylvania, and is on the venurafenib (V) trial at Sloan Kettering. She is on the Diamond side, and is going back to see Dr. Diamond just after the ECDGA gathering. She hopes to meet up again with one of our other members. She thinks that she gains a pound everytime she goes to Sloan Kettering. Her dose is 2 tablets in the am and 2 in the evening. She started with 4-4 and developed numerous skin tags - some very large that needed to be removed.

- A member has just finished his second round of cladiribine chemotherapy. He has 4 more to go.

- Another member told us that he is also on the V trial at Sloan-Kettering, and is going back to see Dr. Diamond this month. He has been on V for 3.5 months, and it has worked particularly well on his eyes; "almost a miracle". He had very significant orbital involvement, and was probably going to lose his vision if nothing was done. Also, bone involvements have all been reduced significantly. As far as side-effects are concerned, he has the "hand and foot syndrome" and sensitivity to the sun. He has also gained 8 lbs! He had no treatments at all before the V.

- Members talked about their experiences with treatment. For one member, there was improvement after 1 year of interferon treatment, and his condition has been stable for 5 years. His doctor doesn't want to risk taking him off the treatment.

- Another has been on interferon since Nov 2005. This has kept him stable, but he feels "tired and exhausted" all the time.

- A member told us that he has significant orbital involvement. He lives near Toronto and there are no trials of V being done there. He is BRAF positive. It was recommended that he should try hard to get onto V. He was advised to check with Genentech, as they offer V for free if you're qualified from a financial standpoint.

- Members who are going to Sloan-Kettering said that they are not getting financial assistance with their traveling expenses.

- We were asked whether we were experiencing red, and painful welts. A member on V is getting these. They go away after a few days and then “show up somewhere else”. She can stand them anywhere but on the bottoms of her feet. Another member on V wondered whether this may be the same side effect that he is having. He suggested using cold compresses during the day, and occasionally at night, to help control the pain.

- A member asked whether it was possible to take V if you had already had a kidney transplant. Nobody came forward with any information. [From an ex-physicians point of view, I would think that if you were taking anti-rejection drugs and/or steroids to keep the kidney healthy, then V may well be “not allowed”. The patient is urged to talk to his doctor about possibilities.] A member told us that he has a kidney that is “virtually non-operative”. He has had treatment with V that has been “highly successful”.