

## **Summary of ECD Global Alliance Internet Chat** **January 5, 2019**

### **4 Attendees**

- Members began the chat by asking about each other's health as 2019 got started. The doctors working on ECD were praised. One member is heading to Memorial Sloan Kettering in January to assess her progress. Dr. Diamond and Dr. Janku (from MD Anderson) were mentioned.
- A member had carpal tunnel surgery the previous week and a cyst on her finger dealt with. This had reduced her to one-handed typing! She gets a sacro-iliac joint injection in mid-January. She is 62.
- A member and her husband ended up in the hospital at the same time for four days in December. She had pneumonia, which messed up her medication because she had to come off the vemurafenib (V) for 10 days. Her husband, of 55 years, is her main caregiver and has just been diagnosed with Alzheimer's disease. So, he ended up at the hospital also. She is 76 years old and was diagnosed in April 2018 when she presented with a lump. However, she has had diabetes insipidus for some years before.
- Another member said that his creatinine had increased a little on his last hospital visit, and Dr. Janku had stopped his V. That was four months ago, and he will see what has happened at his next visit. He said, "for the record, I might or might not be 68."
- Members discussed where they were. One is in New York. Another said that her youngest son did an internship at Sebonack a few years ago. He is a professional golf manager.
- There is a member who also lives in New York and sees Dr. Diamond. He and his wife are in their late thirties, and only live one hour away from New York City. They met up with another member when she was on a visit to Dr. D. He usually comes on to the chat, but his Saturdays do get filled with other obligations.
- A member already has a foot of snow with more forecast. Another has been inundated with rain and just wants "decent weather in NYC this week."
- A member came on, who lives in North Carolina. He said that he is supposed to go to the doctor later this month to get new glasses. "Then, maybe I can see." He is 58, married, and "very much in love" with a woman that is 13 years younger than him! He said that he went to the doctor in 2008 and was diagnosed.