

## **Summary of ECD Global Alliance Internet Chat** **January 19, 2019**

### **3 Attendees**

- A new member came on who had been diagnosed in April 2018. She presented with a chest lump and went to a breast center. After much testing and 14 biopsies, one was sent to Memorial Sloan Kettering for further testing. She was then seen by Dr. Diamond.

She was then started immediately on vemurafenib (V), two in the morning and two in the evening (2+2). After three months the dose was raised to 3+3. This dose caused bad side-effects and the dose was lowered back to the 2+2. She realizes that she may not improve considerably but hopefully she will not get worse.

Her husband has early on-set Alzheimer's disease. They went to Orlando last year, but she doesn't know whether they will get to Milan.

- Another member told us about problems between him and his wife, and some new medications. He was diagnosed in 2008 and started V at four a day last April. He found that the side-effects were terrible.