

## Summary of ECD Global Alliance Internet Chat

June 28, 2014

### 8 Attendees

- A message was left for us to say that a member would not be able to attend the Chat, but she told us that she was doing fairly well. Her doctors think that her shoulder pain may be due to a torn rotator cuff. This would need to be repaired surgically.
- A member who has not been on the Chat for a while, is hoping to be able to attend the conference in September. He would like "to be able to meet face to face." He went to NIH in March. The doctors were "great", but the stay was exhausting. He has a big problem with bone pain in his legs. There has been more pain over the last 6 months, especially when walking. He stopped working 4 months ago. Another member said that he had to retire at the age of 45, and another had to stop at 56. The one who retired at 45 said that he was on a good pension. He had always worked for the government! The one who had got as far as 56 was in the US Army, in Vietnam, so his medical care is paid for.
- A member who has been on V (vemurafenib) for 6 months now, popped on to say hello, before she went out for the evening! She had been for her 6 month Vemurafenib check-up that week, and "everything stable and doctor is happy".
- A member had just been to the NIH. A LONG week! But the member said that it is definitely worth going through the NIH program although it is exhausting. "There are so few options for we ECD folks, and it's terrific that Dr. Estrada and team are very focused on the disease." He was introduced to the drug Flexeril (cyclobenzaprine; a muscle relaxant used to treat muscular pain). He finds it beneficial for his bone pain, and sleeping difficulties. They also gave him some exercises to do to help his pulmonary function.
- A member who recently fell and broke a rib is getting better, with the great help of his caring wife. He has not fallen again. Last week they had managed to go to see Wynton Marsalis and the Lincoln Centre Jazz Orchestra starting out on their Blue Note Records 75th Anniversary Tour.