

## **Summary of ECD Global Alliance Internet Chat** **May 19, 2018**

3 Attendees

- One member had his eight year old grandson staying overnight. He has just started on double the dose of his medication. He now has to have his injection twice a day, at two different sites.

He is preparing a plant exhibition for the 2nd and 3rd of June. This will be of plants that existed in the 8th century, with the theme of Europe under Charlemagne (a ruler of large parts of Europe in the Middle Ages). This has changed many things, including his writing and he had gardens and vineyards installed. The member finds that he learns a lot as he goes along, and his passion for the subject "makes me forget the pain." It was said that "It is good to have a hobby that takes you away from reality."

He is keen to cook with the different plants that he learns about. These are from different cultures; Jewish, Muslim, and even Chinese. He isn't able to get involved in sports other than walking. He feels lucky to live in the countryside, and yet not too far from the big city.

- In the US, on that day, horse racing was the big thing. It was said that horse racing could be an expensive hobby, but the US member only bets on the big races. There is a racetrack, called Belmont, near to where he lives (a 45-minute drive) that he goes to once in a while. The track at Saratoga is five hours away, and he goes every year.
- In France there are horse races, with betting, almost every day and with special prices on weekends. Many people have horses just for walking. They are kept in the meadows until the owners want to ride them, and are not used for racing. The US member is afraid to ride horses. "I'd be the clutz who falls off." He said that walking is good exercise, and that his job is about a 12-minute walk from the train station.
- The US and French member both have stable ECD now. The Frenchman is 61 and the American is 38. The Frenchman's eldest daughter is older than that!
- The US member said that he can now lead a normal life. He doesn't have pain, "Thanks to Dr. Diamond and dabrafenib." He just gets tired from time to time. The drug hasn't caused problems, not even sun issues. He had had no issues while taking a dose of four pills in the morning and four in the evening of vemurafenib for six months, except that it was very bad in the sun, and it ended up affecting his liver enzymes.
- A US member came on late because her son and his wife and their three-month-old son had come visiting.