

Summary of ECD Global Alliance Chat

6 May 2017

5 Attendees

- A very limited chat this Saturday. Apart from people saying it was the Kentucky Derby Day, only one comment was made.
- A member who started treatment with vemurafenib (V) two years ago, said that his skin, hand, and foot problems went away, after a while, and haven't returned. He still has some joint, muscle, and bone pain, but doesn't know if it is ECD related. His scans, for the last two years, show no further activity, although he had "pretty active" disease before V.