

## **Summary of ECD Global Alliance Internet Chat**

**9 April 2016**

7 Attendees

- Before the Chat started a new member came on who has recently been diagnosed with ECD. So far, this person only has ECD in the eye tissues. Starting treatment has to wait for healing after thyroid removal. This new member then asked what treatments others had had.
- A member came on who had been in a trial at the National Institutes of Health (NIH) for all of last year. In January of this year, she had no disease in her brain, but it recurred 7 weeks after stopping dabrafenib and trametinib. She goes back to NIH soon, and hopes that she will be put back on the trial drug. She has a few changes and her arms and head shake. But she feels "fine, just a little slow with my thinking".
- We were given an update by the spouse of a member, who has recently started vemurafenib (V). He has just visited his doctor who saw that the member had surpassed all the doctor's expectations with V, after 6 weeks! There are improvements in gait, balance, speech, and swallowing. A request to have hospital based PT rehab has been put in.
- Two members, who have already had treatment with V, both said that they were feeling good. One of them likes to exercise as much as possible, the other said that a couple of years ago, his wife was training for a half marathon and he used to jog with her. He feels "so out of shape now". If he runs a half mile he is exhausted. Before ECD came along his longest jog without stopping was 6 miles.
- A member came on who has not been with us for a long time. His 36 year old daughter is now in remission, but her vision has been severely damaged, and her balance is very poor. She and her husband have a special tandem bicycle which they ride.
- Members discussed the way that "sick days" were allocated. They are limited in many professions. One member was in the V trial, so he had to take 1 sick day each month. A member, who is a retired teacher, said that he had accumulated over 300 days by the time that he stopped working. Public schools in PA allow for that. He didn't need the sick days but they were a good "insurance" against sickness!