

Summary of ECD Global Alliance Internet Chat

20 May 2017

6 Attendees

- A member has had surgery on her painful shoulder and is now "chilling" and allowing it to heal. It is painful after the operation. The bicep tendon was cut and reinserted outside the shoulder, because there was so much inflammation. Not moving it for a while helps with the healing of the new insertion point. It is unknown whether all of this is due to the medication or the ECD itself. She has been off dabrafenib (D) since April 11, in case it was the chemo, but the pain only got worse. Now, she is wondering what chemo to go back on. She saw Dr. Diamond at the end of March, and won't go back until October when the ECD conference is scheduled. Normally, she goes every four months, but if she was on his trial she would have to go every month. She is also changing to a new oncologist at University of Kentucky. He had called her, on the day before the Chat, to ask her to choose between three new drug trials. She spent the rest of the day crying because she was in so much pain from the surgery and doesn't want to make decisions.
- A UK member came on and started to use his version of text-speak!
FTSOTP=From This Side Of The Pond
FYSOTP=From Your Side Of The Pond
SOS= Same Old S***
- The "joys" of grand-parenting were discussed. Some members remarked on their inability to do the standard grandparent things (zoo trips, playing in the park) because of their illness.
- A member said that he is only 60 years old, and feels like he has another 15 in him. Another is only 37 and has been sick for at least 10 years. Her balance has been poorer recently and has not recovered.
- A member was looking forward to a meeting on the next day with communities of other religions. "We are brothers and sisters despite our differences, and when we work for the peace of the world, we can understand ourselves."
- The "text-speaker" ended things with these "Thoughts for the week". They are in Latin, too! Rene Descartes, the philosopher, said "Cogito ergo sum" = I think, therefore I am. A graffiti writer in Cambridge wrote on a wall "Cogito ergo non bibi satis" = I think, therefore I haven't drunk enough!!