

Summary of ECD Global Alliance Internet Chat **September 01, 2018**

5 Attendees

- A member is taking a nitroglycerin patch for angina. She is off Mekinist for three weeks until she sees Dr. Diamond. The patch seems to be stabilizing her blood pressure (BP), but it gives her a headache every day. Tylenol does help. She just got a call from someone from the University of Kentucky. She is going to be interviewed for a December "letter."

She has reserved a two-room condo at the Holiday Inn Resort to stay at for the Orlando ECD Global Alliance event. She hopes that her kids will join.

She has read a scholarly journal from Belgium that talks about a blood test, a ctDNA, that can measure response to treatment. She doesn't know any details and will ask Dr. Diamond about it this week. She and her husband will be meeting up with another couple (the husband is in ECD remission) in New York City after seeing Dr. Diamond and an endocrinologist at Memorial Sloan Kettering. The other couple are visiting family, not seeing the doctors.

She and her husband are flying in and out the same day although she feels she may be crazy for doing it.

- Members updated each other on children and grandchildren. One member's child just celebrated her 16th birthday. Another member said that her grandchild who just turned one year old just started walking. Another member talks about hoping that her young daughter doesn't take too many steps alone before she, herself, can as well. But she guesses that her daughter will beat her.

She has been doing a lot of walking on the treadmill lately. She has been doing two kilometers. She has gone from 55 minutes for 2 kilometers to 32.20 minutes in a little over a month! She tries to do a bit better each time. She also just had a checkup and is back to where she was before the pregnancy!

- A member has been doing 30-minutes on the bike at the gym. She said that she isn't going fast "but I go." Her left hip hurts on the treadmill or an "arc" trainer. She also uses the warm pool to "move and stretch" three times a week. The local YMCA is only a mile away from her. Since it is so close and very nice, she has no excuse to not go.
- The member who just had the new "no radiation" scan (MRI PET) said that the experience was dreadful. "Pretty much like an MRI of the entire body." No radiation from the machine itself, because there was no CAT scan, but he was injected "with some stuff." He was taken in at 10 A.M. and got done by 1:30 P.M. "They strap you down all over." He had to fast, and the only good thing was that he didn't have to "drink the drink and wait for an hour." He was in the machine for about two hours with no movement allowed.