

Summary of ECD Global Alliance Internet Chat October 13, 2018

13 Attendees

- A member said that it is now "cold here in Kentucky!" She had just taken a little nap while football was on, and there was a fire in the fireplace. She stated that it "got cold two days ago." Another member said that it was cooler where he lives (around 55 degrees), and it seemed like fall. The member that had mentioned napping had undergone a cardiac catheterization and stress test the previous week. Both were fine, but the doctors still cannot figure out her chest pains.

Dr. Diamond really thought it was bad family genes. She is back on her medications and having some side-effects from the dabrafenib. Her femurs have begun to hurt again. She wonders if it could be the ECD "rearing its ugly head." She is overall slower because her hip, femurs, and knees hurt, even though she is still exercising. She uses a hiking stick whenever she walks because of the pain, dizziness, and being off balance. She is supposed to have another PET and MRI in December. She will follow up with Dr. D in January.

- A member has spoken with Dr. Diamond about his recent scans (a PETMRI with no radiation in August; a new type of scan). Dr. D is not at all worried about anything on the scans. He said that in another nine months he will need another one. The member said the scan was "terrible" and he couldn't move for 90 minutes!
- One member is lining up her and her husband's trip to the conference in Orlando, Florida. Another member has started a new job and can't afford to take off any days, but said the conference in Italy sounds attractive. He hasn't been to Italy and the conference is in the summer. He said that it would depend on "if I have a baby by then." He said "it's going to have to be soon. I am 38." He then left the chat to change clothes from attic to closets.