

## Summary of ECD Global Alliance Internet Chat

June 29, 2019

### 6 Attendees

- The chat began two US members; one in Ohio and the other in Kentucky. One mentioned he was fairly stable with his ECD. The "stable" patient had been taking a lot of Zelboraf (V) and was losing weight. He was reduced to 1 + 1 (one in the morning and one at night), and his weight loss levelled off. His breathing, balance and walking ability are all affected. Everything makes him tired. His mind wants him to be active, but his body says no.
- The other member stated that her four years of stability were not so "stable anymore." She stated that her "check engine light has come on." The previous day she had an echocardiogram. She said they sent her a survey about "how they did." Jokingly she said that she was going to wait for her results before responding. She has a lung test this week and has been on Mekinist since 15 May.
- A Norwegian member with the young daughter came on. More photos had been posted online and were being admired by the group. She is having a busy time. They are going to her partner's parents for a couple of days, then to the hospital for a PET scan and MRI. She will be home Friday night and then off to Milan on Saturday. She is prepared to hear that the scans show that things are a bit worse; it "will be good to know what's going on."
- With US temperature of 91 and 95 degrees, one member said that she is still able to get to the pool twice a week and uses a recumbent exercise bike. It was suggested that possibly a buildup of ECD tissue in her chest wall was affecting her ability to inflate her chest.
- Another member came on. She stated that she had finally "got word from Eli" about meds for Diabetes Mellitus. {Not sure if this is in reference to Dr. Diamond or the drug company} She took her first pill that morning and already felt a difference. "At least I may not be wetting my pants all the time."

She stated that she was sorry that she wouldn't be able to go to Milan, but she couldn't leave her husband. His dementia is getting worse.