

Summary of ECD Global Alliance Internet Chat **June 15, 2019**

2 Attendees:

- A US member had a Chest CT this week. Her lungs are not in a good state. She is now off Mekinist but taking prednisone for her lungs. She has a "smart medical and pushy" friend who called the local oncologist office yesterday. She had had the CT a few days before. The friend told the office to see her or she would wind up in the Emergency Department! They saw her and looked at the bad lungs!

At that moment she had a three-year-old grandson playing a tuba beside her! As well as, a then a nine-year-old grandson playing country music on a portable radio, and a five-year-old granddaughter dancing! Her next appointment will be with the pulmonary specialist.

- The Norwegian member has no appointments in sight but would like to get checked out before the Milan trip. She feels like she has gone many months telling the docs that something isn't right.
- The American member is a nurse who feels very well informed but is just realizing how much she needs her "pushy" friend. She was a lab scientist.