

Summary of ECD Global Alliance Internet Chat **August 4, 2018**

6 Attendees

- A new member joined the chat. She said that she is new to chat rooms and was recently diagnosed with ECD. She wanted to know what her future would hold. She is very weak in her lower extremities, but has no pain.
- A longstanding member, who has been having chest pains that are being treated as angina, came on the chat. She feels as if her concerns are not being taken very seriously. A heart doctor put her on a nitroglycerin patch two weeks ago, but she still had acute pain yesterday that went away after 20 minutes.

She had a brain MRI and a total-body PET-CT scan this week. These were previously scheduled before the chest pains started. Maybe the PET will show what is going on. She says that she is most frustrated with doctors saying that this is serious, but then looking the other way. She thinks that she has "too many doctors."

- A French member said that it was very hot (almost 100 degrees Fahrenheit), which made his pain worse. A US member was experiencing a "true summer day," no rain, blue skies, and mid-80's outside. She had eaten a juicy, stone-free peach from Georgia, and her grandkids had a lemonade stand. The French member said that the "juicy ones make you want to go swimming all day."
- The US member ask if the French member had any heart issues associated with ECD or chemotherapy. The French member said that when he goes to Paris they check to make sure the ECD is not affecting his heart. He can have a heart PET-CT scan every six months. The pain that he has around his heart are mostly pain from his rib bones. He said that he has got a family doctor, all other care is done by the hospitals, but sometimes he has to wait three months for the results. The results are sent to himself, his rheumatologist and family doctor by mail.
- A US member said that most of her doctors are at MD Anderson. She has a family doctor and Dr. Janku "controls the rest."
- Another US member finds that NYC is "just too far away." She is going back again in September to see Dr. Diamond and a pituitary specialist. She is trying to make reservations at a French restaurant in New York at the moment. At the time, she is going to be in New York with her husband. Another longstanding member will be local, and they want to meet up.
- Another US Member came on and said that he is in New York as well. He is seeing Dr. Diamond this month, then goes back to Memorial Sloan Kettering to get a "special test" done! It is a PET-MR, which is a scan with no/limited radiation. It is new, and he thinks they only have one machine.

He is a kindergarten teacher and has just got a new job teaching first grade in a town close to where he lives. He will not have to wake up at 4:30 am anymore. "I can sleep until at least 6:30." He will get ten hours more sleep a week and save ten hours on the commute.