

Summary of ECD Global Alliance Internet Chat

25 Jun 2016

7 Attendees

- Before the Chat a message was left. A member would not be with us because he was having "a biblical dinner" with friends. He meets people of all faiths and finds this rewarding. He has been talking to his doctors about treatments, and also with insurance.
- The recent death of Gurnal Jones was discussed. A member said that he was a shining light with the ECD awareness. <http://keenanfuneralhomes.com/jones-gurnal-a-iii/>.
- A member logged on from Georgia. She was on the first leg of "sister's escapades" around the country. The only time she uses a cane is at airports. This week she and another sister fly to Mississippi where the oldest sister from DC, will meet them.
She is going to forget about ECD for a month ("have chemo, will travel"!). She is supposed to get another PET in NYC in August, but may just have an MRI in Lexington because her insurance is "wacko".
- There was then a discussion about the merits of keeping the body/blood more alkaline. A member has been shown water that you can buy that has a higher pH than usual. Plant greens powder are alkaline, too. She said that the health food "gurus" say that alkaline blood is better to fight diseases.
Another member said that his father-in law tests water for something, but he didn't know why. This member only drinks Poland Spring bottled water (no matter how bad it is!).
- The Australian member had a good experience when seeing an endocrinologist on bone metabolism last week. It was "great being listened to, and finding agreement".
- A member mentioned that he is having some difficulty in getting travel insurance for the trip to Paris. The BREXIT (the UK possibly leaving the European Union) may make more difficulties.
- A member told us that a medical article was written about him when he was diagnosed. He said that he might print them out and autograph them. He said that it was scary to see how much was wrong with him., but it was corrected by taking a few pills.
- Insurance came up next. A member has heard that BCBS of MN is getting out of the individual insurance market in MN that covers extensive networks. He wonders whether it would be the same elsewhere. UHG has already done it where he lives.
People wondered whether there were annual limits on the number of PETs that you can have. Some policies only allow for 2-3 scans a year, except on clinical trials.
- A member told us that he was having problems with the University of California, San Diego (UCSD) billing department. They keep making mistakes and over-charging him.
- A member's blood pressure has been varying a lot for no obvious reason. She is on a beta blocker and a calcium channel blocker, and has decided to lower the doses. "So far, so good." She is also decreasing the dose of statin that she takes. "It's my body and I can play with medicines with the best of them", although she doesn't play with the vemurafenib!