

Summary of ECD Global Alliance Internet Chat **May 12, 2018**

5 Attendees

- Members talked about their gardening exploits. One saves her coffee grounds for a neighbor. They are used to help grow tomatoes, and she gets some of these in thanks. Another had done a little planting, but then felt too tired. But he has had his first radish of the year, and the carrots, beets, and potatoes are growing. He also grows flowers that are edible and others to help the bees and get his plants pollinated.
- A US member said that her brain MRI this week showed no change. Her heart echo was "good" and blood work normal. Her pituitary gland is still not functioning properly so she will see a specialist when she goes to New York City in September. She was at the local oncologist at University of Kentucky on that week. He has four ECD patients now (two are BRAF negative). Now that he is in touch with Dr. Diamond because of her, he is also consulting with him about these other folks.
- For a French member the pituitary stem is also not working properly, but hasn't got any worse. His testosterone level is now normal. The doctor is happy with his treatment although his legs are still sore and he thinks that he is lucky to be able to move. He quickly becomes tired and the treatment for his legs has been doubled.
- The UK member, who broke his neck eight months ago, is also off to see an endocrinologist because of a low growth hormone. This is one of the few types of doctor that he has never seen! He has been back at home for nearly six months now, but is still sleeping on a hospital bed on the ground floor as he can't manage the stairs!
His legs are painful, too. He has grown bony deposits in the medial ligaments of his left knee (like having an extra kneecap!) which reduce his movement and hurt a LOT. Yet another problem that he'd never heard of when he was working as a doctor! He had a PETCT last week and the doctors are going to be in touch with Dr. Diamond.
- For the US member, weight gain has been an issue in spite of daily exercise and a healthy lower calorie diet. She drinks lots of water (60 ounces /day). And now they want her to have a colonoscopy!
She has recently had hand surgery for a trigger finger and carpal tunnel. Two weeks before the surgery, a small lesion appeared on the back of her hand. So they took that off as well! The pathology report was that it was an angioliipoma. That is yet another rare condition!
- Our Norwegian member still needs to hold on to things for balance, and has recently tried an electric tricycle, which she is going to get. The UK member said that he has had a TGA Supersport for some years. It is also a 3-wheeler, so he calls it his "Harley"! It is allowed on the roads and does eight miles per hour. It goes on pavement too, (only four miles per hour) and in big shops.
- The member in France is alone for two weeks. His wife has gone to visit their daughter. Her baby is due soon, and she lives a 4-hour drive away. This is the first child of his youngest daughter. He already has five grandchildren.
- The Norwegian is doing articles for a magazine and a newspaper. The Frenchman is preparing an exhibition on the gardens with plants of the 8th century. It was said that it is great that

people around us see "that with this diagnosis, we don't simply live to exist."

- Horse racing was the next topic with experiences of the Kentucky Derby, and results of members betting discussed. And then they discussed the information that they had got about their ancestry.