

Summary of ECD Global Alliance Internet Chat **August 25, 2018**

5 Attendees

- A U.S. member said that her newly started nitroglycerin patch (for her chest pain) has been giving her such headaches that she had decided not to put one on that day. She has decided that the headaches are far worse than the "heart pain" sometimes. She was told it needed to be discussed whether she needed to use it regularly or as needed for the pain. She has been off her Mekinist since August 11. She had a stress test recently and apparently one artery may be blocked, and her blood pressure (BP) is much lower in one arm than in the other.
- A French member said that he takes less desmopressin for his diabetes insipidus because of headaches. If he takes more than the smallest dose, he gets more head pain. He is going this week to a "Spa" where he gets the "cure." When he has his BP checked by the doctor at the spa, the doctor there also gets different results in each arm. He will first go to see his daughter and grandson (who is three months old). It is about half-way to the spa and he will start the "cure" in early September.
- The member that is a teacher has not started back to work yet, school starts back in early September. He is due to have a new type of scan soon. It is a PETMRI with no radiation. He had told Dr. Diamond that he would only have a scan if there was no radiation.
- Another member thinks that she will say the same thing. She will also be in New York soon, but will be flying in and out on the same day. She said, "no expensive hotel for me!" When she gets to New York City she will know more about the concept of her Mekinist being stopped. While there, she and her husband will be celebrating 36 years of marriage. She will be 62 in October. She asked for any suggestions of good restaurants in Midtown. Patsy's was recommended: "A little pricey, but delicious food."
- A French member is well beyond school-age, but is starting to write in the language of his childhood: Alsatian. Alsatian is the ancient language spoken by the Alamans of the fifth century. German became the official language only when the Bible was translated into German by Luther.

He has been married for 40 years and is now 61 years old. His wife will soon be 60. They will be having a celebratory meal at the spa as a gift from their children. They are happy to be grandparents and their grandchildren bring them back to life. He has three daughters, the eldest has a daughter (13 years old) and a son (10 years). His second child has three boys aged 11, 9, and 7 years. The youngest has a child that is only three months.

- A U.S. member has four grandchildren where she lives, one in Tennessee, and one in Washington D.C.
- Another U.S. member will be 77 years old this month. Her husband is 70 and they have grandchildren living close by, ranging in age from eight to twenty-one.
- A new member said that she was Israeli living in Holland. Because she speaks Dutch and English she was able to participate in the chat without needing to use the automatic translator. She was pleased to hear about long marriages and having grandchildren. She said that it "makes me feel optimistic." She will celebrate 20 years of marriage in October. She has no grandchildren yet, but has a 16-year-old daughter.