

## **Summary of ECD Global Alliance Internet Chat**

**Feb 25 2017**

4 Attendees

- Members talked about how they were getting along. Exhaustion due to exercising was mentioned.
- The recent NIH report was mentioned. It reports on 60 patients hospitalized between 2011 and 2015, with details of their treatments and the location of the disease. Follow the article here: [The clinical spectrum of Erdheim-Chester disease: an observational cohort study.](#)
- A member's wife said that he had had a fall in his wheelchair. He is okay himself and "fine today". She thinks that the wheelchair protected him. He uses the walker upstairs and for short distances. The wheelchair is for support and he uses his feet to move around. He has been having more issues with his balance. The wheelchair has made getting around safer in the last years.
- A member is due to return to the hospital in Paris for more examinations in two weeks. These will be check-ups to see if there have been any changes in the course of the disease, and to find if he is BRAF positive. He does blood tests every month because of his medications. He sees a good physiotherapist who relieves some of the symptoms.  
He has a few chickens, and thanks to them, he feels obliged to go out every day. He is glad to be able to take care of them. If he feels too tired when he is feeding them in the morning, he goes home and returns later when he feels better.  
He will soon attend an interreligious meeting. He said that "whatever our religion, when we are sick we are all on the same boat".
- A member left a message after the Chat. He has had a busy week. His father is in the hospital with pneumonia, so he has been spending a lot of time with him. To make things even more interesting, his refrigerator is freezing food in the "non-freezer" part. He is looking for a new refrigerator!