

## **Summary of ECD Global Alliance Internet Chat** **December 9, 2017**

5 Attendees

- One member has recently returned from a meeting of polyarthritis patients. This member also said that they had been taking codeine for the past two weeks to address their pain.
- A member who has been off medication for some months said that they are improving everyday with exercise.
- It was discussed that ECD presents in so many different ways, making it difficult to understand.
- Several members related how they had first presented to their doctors. One said that it was pain, shortness of breath, and tiredness that were amongst their first symptoms. Another patient said that it was the protuberance of their eyes that first led them to see a doctor.