

Summary of ECD Global Alliance Internet Chat **January 27, 2018**

4 Attendees

- The interview with Dawn Damuchi, regarding ECD, was discussed. This article can be found on the ECDGA website <http://erdheim-chester.org/news/the-fresh-faces-project-stands-with-eed-survivors-these-are-their-stories/> .
- One member described how they suffer from pains that come and go. On the positive side, they are still able to travel independently.
- One patient is a member of a committee scheduled to work with Dr. Diamond regarding patient quality of life. The main symptom that bothers this patient is low energy.
- It was discussed that the significant medical progress in ECD means that patients are now doing better with the disease.
- It was mentioned that patients often look well, and that the suffering is hidden.
- One patient is taking kineret, another patient was on kineret for some time and is now on vemurafenib.
- The issue of low testosterone in ECD was discussed. One patient said that a doctor had said to him, "Ordinarily we worry about a man your age when the testosterone falls below 160. Yours is 9."
- The importance of meeting other ECD patients was discussed and that this can help with feelings of loneliness when you have a rare disease. The value of the ECDGA Annual Symposia was emphasized in this regard.
- One patient has been asked by a local TV station to do an interview on ECD and their experience of the disease in the spring.
- A patient mentioned that they exercise daily; which helps, but they still suffer from back and hip pain.
- A member asked the other chatters whether they had the problem of a frequent cough. Other patients on the chat had suffered from this. One patient thought that it may be linked to a medication they were taking.