

## Summary of ECD Global Alliance Chat On 23 June 2012

9 Attendees:

- A new member from South West Virginia came on. Her husband has just been diagnosed with ECD. He is retired from the military. Members talked about the area of the US in which they live (or elsewhere in the world!), and gave the length of time since their diagnoses. They also gave short details of how they were diagnosed, and also whether they were working, or how long ago they had retired. They understood the difficulties that the new member was going through, especially finding doctors who had even HEARD of ECD! Bone abnormalities had been the problem, which were mistaken, at first, for cancer. Type 2 diabetes was also diagnosed. MRI of the brain is going to be done next. John Hopkins Hospital is organizing this.
- Members also talked about their treatments. These were varied. Interferon, and 2CDA (cladribine) were mentioned quite a lot. The doctors at John Hopkins have mentioned interferon after the MRI, and cladribine as a "down the road" option. Members described some of their experiences with interferon. Flu-like symptoms were the commonest problem, and the length of time for taking the interferon may be indefinite ("till it stops working", one doctor had said, when asked "how long?" by a member). One member has gone into remission and takes no treatment at all, at present.
- One member had used kineret, and had very good results, and much reduced side-effects, after a number of years using interferon. The disease has not advanced for years now.
- It was said that it might be useful to get involved with a V.A. hospital for those patients who are veterans. The VA will help pay for the treatments. It was also suggested that the ECD organization ([support@erdheim-chester.org](mailto:support@erdheim-chester.org)) or Dr. Estrada-Veras, who is heading up the ECD study at NIH, might advise as to a doctor close by who will treat ECD. (Traveling for healthcare can be very difficult, and expensive).
- A member, who had been suspected of being diabetic, has had the diagnosis of Type2 diabetes confirmed. Treatment has started, but diet and exercise are the most important areas to attend to.
- A number of members remarked on how generally fatigued they feel. It was said that this could well be due to the treatment being used (especially interferon) or it may be due to the ECD itself.
- A member, who has wood-turning as a hobby, asked another "turner" if he had started on anything. The answer was "No". The lathe still needs a clean!
- A member about to get married told us that things were "under control". The member has found the iPhone has helped her access the chat room in spite of blindness.
- A member said that they were getting SS due to the illness. Histiocytosis has, recently, been added to the SS Compassionate Allowances List of disabilities and illnesses. Everyone is hopeful that this will make it much quicker for US citizens to move through the SS disability process.