

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

**01 Nov 2014**

10 Attendees

- Two members came on before the Chat to say that they would be unable to make it that day. One of them told us that his father, who has ECD, has had it rough in the recent past. He has been declining recently, and so another bone marrow biopsy was done. He has now been diagnosed as having CMML (chronic myelomonocytic leukemia) as well as having ECD. These may be related forms of the same disease. His doctors are starting him on Dacogen. It was raised as a possibility that it may treat both the CMML and the ECD. There are at least two patients with both CMML and ECD being treated in the US.
- We were asked about our experiences with the DDAVP nasal spray. This is used to treat Diabetes Insipidus, so many of us use the spray. A member said that she was having problems giving the proper dosage, and wondered whether this problem was more general. One member said that he couldn't help because his daughter uses the tablet form of DDAVP and not the spray for her DI.  
There was a response from a member who does use the spray. He has noticed that, as the bottle gets to the bottom, the doses are not correct. The amount sprayed out is too little. The brand in question, for both patients using the nasal spray, is Bausch and Lomb.
- We were asked whether anyone had heard of a Dr. Braiteh. A member had been led to believe that he is an ECD knowledgeable doctor, who trained at University of Michigan and had been at MD Anderson in Texas. He has moved to the member's city for about 4 years, supposedly, and the member has been transferred to his care. The member has been unable to find any information about him. The member thinks that his regular doctor (of many years) has given up on any treatments for him. The ECD Global Alliance is a source of information about doctors familiar with ECD. Contacting Kathy Brewer should be helpful, too.
- A member asked us whether we suffer from cold toes and fingers, "or is it just me?". A number of members have this problem. One thinks that it may be related to his chemotherapy, but he had also had a period on kidney dialysis and this may have contributed. Another member attributes this to nerve damage when he spent a week

and a half on a ventilator. One member always wears bed socks. One said that her doctor had said that she shouldn't relate everything that is wrong to her ECD!

- A member who has been having a very difficult time, told us that it looks like he will need surgery to both shoulders. He also said that some sort of tumor had been found on his ankle. He has much reduced movement of his shoulders, and this is thought to be due to narrowing of the passageways which the tendons go through. This is thought to be due to the ECD.
- Our woodturning member has just finished a goblet made from apple wood. He varnished it that morning and is very pleased with how it looks. He will get some pics done and circulate them to those who are interested. The woodturning member has had a lot of doctor appointments during October as a prelude to him starting on Vemurafenib (V). The doctors decided that, with his shortness of breath, he should be on oxygen part of the time. He has been told to use it while sleeping, and after exertion. He started this week, and slept much better, woke up more rested, and not as tired as he usually feels. He said "It seems to be a big help".  
A member said that her grandfather was told he needed oxygen, and when he uses it correctly it helps greatly.
- A UK member was hearing the sounds from the first fireworks of this year. Nov 5th is the UK's BIG FIREWORK NIGHT!