

Summary of ECD Global Alliance Internet Chat

15 Sep 2012

5 Attendees

- A member is "counting the days" until a planned vacation in a "warm" place. What with work, and exercises at the gym, a vacation is needed.
- A chatter's son, who is an ECD patient, has recently been to Houston, and seen the replacement for Dr Kurzrock. His eye problems have got worse. Hopefully a new prescription for contact lenses will improve things.
- Another member has recently seen the oncologist, and had been told that everything looked good. A visit to the NIH was made in January.
- Problems with sleep were discussed. The responses ranged from "no trouble" to "very disturbed nights". A patient goes to sleep straight after taking his Gleevec. His mother, who does not have ECD, does have problems getting to sleep!
- Bladder problems are a cause of sleeplessness. One member has to go to the bathroom many times. Three members have been put on DDAVP for diabetes insipidus. This has improved matters a lot.
- The member, who brought up the subject of sleeping difficulties, uses a fentanyl patch. This makes a lot of patients drowsy, but that doesn't happen to this patient. Melatonin has also been tried. A regular sleeping tablet causes too much drowsiness on the next day. He has one "call of nature" per night, and the dog wakes him up for the same reason!
- Metformin, and its effects on the bowels was mentioned. If you are on it, you need to be able to "get to the bathroom, fast"!
- A Chatter has been following a patient from Pittsburgh on Facebook. She has been at NIH getting tested, and doing some sightseeing while there.
- A member has a video on You Tube and this is the link:
http://www.youtube.com/watch?v=Zv5Rv-py2_s&feature=em-share_video_user