

Summary of ECD Global Alliance Internet Chat 25th May 2013

7 Attendees

- Kathy left a message, telling us that she was helping with the filming of an ECD documentary. She hopes that this will help raise awareness of ECD.
- A member came and told us that through Humana's RightSource, he has been able to save \$66 per order of a prescription drug (testosterone). The cost of this medicine was not being covered under insurance previously. But, through their own program, he can get it covered and save \$\$!
- A patient reported his leg is gradually improving. There have been some visual problems too; "the grass is too bright". Reading glasses from the store are being used. A routine oncologist's appointment is due soon.
- Another member also has major issues with vision. The optic nerves have been damaged by pressure from ECD lesions. She can see a bit. She noticed that there were lots of colours, when she was next to a cyclist dressed in bright bicycle gear. She was in Valley Forge National Park, and could see a green haze.
- We were recommended to read a patient's blog, "Without a Manual". (see: <http://withoutamanual.blogspot.com/>.) The author writes with humour and bravery. She has good friends and a daughter who is a strong part of her life.
- Another member also has a blog; Minkey's Place. (see: <http://www.minkeysplace.com/>.)
- A member told us that he had recently joined the group of ECD patients who have lost teeth! One had broken straight off at the gum level! An appointment had been made to see the dentist. [Breaking news; it was a crown that broke off, not a "real" tooth. The dentist is planning to "pull out" any remaining root in a month!]
- A member has recently had a spinal tap. This was to help with dizzy spells. A meeting with the doctor had also taken place to discuss the results of some memory tests. The member does very well on the hard questions, but when under pressure, memory is poor.
- A new member came on. She is from Queens in New York. Her son, aged 21, has ECD, and she is trying to get him involved with the chat.
- A member is about to start a diet called VB6. "Vegan before 6" has been written about by an American food writer (Mark Bittman). You eat only vegan foods until 6pm. Then you can have anything you like, during the evening. He thinks that it helps, because you start to change the way you eat (not by sticking the food in your ears, or up your nose, but by eating different things). Vegan foods are usually low calorie, and low fat. And people seem to change their eating patterns in the "vegan-free" times too.
- A member was asked whether "school's out for summer" yet. The member is 1/3 of the way through one summer class. Then, after taking 2 days off, 2 more summer classes will start.