

## Summary of ECDGlobalAlliance Internet Chat 25 Feb 2012

### 11 Attendees

- A member who has not been with us for a few weeks was welcomed back. And another member who has been having persistent computer trouble also managed to get online.
- A new member came on and introduced herself. She is a nurse in a Veteran's Hospital, and enjoys the work! Her husband is 48 and has ECD. It is stable at the moment. He has been taking cytoxin for a year now. They had an appointment to see someone at the Mayo Clinic, but this was too far away. They are seeing a local doctor, but, surprise, surprise, he has no previous experience of ECD. A member said that her family member goes to see Dr Kurzrok, at MD Anderson in Houston (in fact, the ECD patient is going there tomorrow!).
- Others in the chat room introduced themselves as:
  - The mother of a 46 year old son who was diagnosed 3 years ago. It took Dr.'s 10 years to give his problem a name. He has kidney involvement with a stint in the kidney. His balance and speech are also involved.
  - A 32 year old female patient who has ECD, nervous system and skeleton effected, diagnosed 1 year ago but having symptoms for 10 years.
  - A male patient diagnosed in 2007 with mostly balance & affected. Symptoms began in 2000-01 and included thirst & fatigue.
  - A male patient diagnosed with ECD in the summer 2005.
  - A 32 year old female patient who was diagnosed with ECD in 2007. The patient is blind because of tumors caused by ECD crushing her optic nerves.
  - A female patient who has had symptoms since the mid 80s and dx in 2000.
- The back problems one of our members has been experiencing are not as bad as they were.
- A member who has recently tried to reduce the stress due to her job, has found things to have improved. She is also been "working out" at the gym. The NIH had advised an increase in activity, but had no specific suggestions. Weight lifting and spinning exercises are the current favourites.
- Members were disappointed in how the "appearance" on the TODAY show worked out. Our member's picture only got a 2 second showing, and Dr Filipovic spoke for 20 seconds or so about histio. Also the show isn't even available in Europe!
- A member asked whether anyone had heard from Charles Oz. Kathy had heard from them a few weeks ago. Tanya's difficulties are continuing.
- The sister of one of our members has recently died. Our sympathies were extended.
- Our "bride-to-be" member has managed to get her weight down to under the 150 lb mark. Well done!!
- Rare Disease Day is happening this week. One member is trying to get some coverage in a local paper. Another is attending a local meeting for interested doctors in the area. The Official Rare Disease Day video can be found here: <http://www.youtube.com/watch?v=LBVug-GVLg0>
- A member had recently been visited by her grand-daughters. They had worked out how to use a new cellphone. Her To-Do lists, and grocery lists are on it now! Her swollen legs have gotten to tree-trunk size, so she has to wear floppy pants!
- A member reported a rather alarming symptom related to his bowels. He is having his first proctoscopic exam next week.
- A member's son, is to be presented with Policeman of the Year where he works.
- One of the members of our "wood-turning chapter" has been working with his lathe on some hickory and cedar wood.
- A member has just come back from a few days by the sea in the North of the UK. It was relaxing trip, which will be to be repeated next month, when he turns 50.