

Summary of ECD Global Alliance Internet Chat

21 April 2012

10 Attendees

- A member came on before the chat and left quite a lot of information. He had family duties to attend to, and so could not be with us. Garden work is keeping him busy; planting new plants and soil preparation. Also he is having discussions with his landlord about keeping warm this winter. He is getting ready to give a "lesson" at his church in June. It's about enjoying life and God's gifts, even when times are hard (e.g. when someone has a chronic illness). Recent blood tests showed that the "good" cholesterol is still low, but everything else is good. Looks like fish AND fish oil caps will be on the menu for a fair while!
- A member came on who had not been with us for a while. Chemotherapy has now finished, and there have been 2 clear MRI scans. A blood transfusion had been needed but now things were just being kept an eye on.
- A member is finding that the new job is OK, but it involves a lot of sitting down, which results in a lot of stiffening of the muscles.
- Our member, who had been given a "gyro exerciser" recently, has managed to make it work, after only 2 weeks of trying!! He was congratulated by another member whose son uses one. It is about the size of a tennis ball, and consists of an outer plastic shell, and a smaller ball loosely held inside. This ball contains a gyroscope. If it is all started off and spun correctly, it exercises the muscles of your hand, forearm, and upper arm. It also helps to get the joints more mobile. It is also called a Powerball. It is on the Net, and on Amazon, where you can see the product, and read reviews.
- The member with the Powerball also "tries" to play the trumpet. It was generally felt that this must help us, especially those with chest problems. It must be good for breath control, and having to blow forcefully. It helps psychologically too.
- A member, who recently hurt her back, has felt well enough to restart harp lessons.
- A member was pleased to report that when her radiologist had reported some fibrosis on a chest xray, her regular doctor had said that "she had ECD". The radiologist replied with "Oh, that explains that", instead of the more usual "what's that"!!
- A new member came on, having been given information about the Chat by Kathy. Her 50 year old daughter has ECD. She lives in a very small town in Missouri. Her daughter has been on weekly shots since being diagnosed in December. Eye problems are particularly troublesome, with nystagmus, and bulging of the eye tissue. She has been advised to tape the eyes closed at night to stop them from drying out.
- She had heard about poor survival in ECD, and was surprised that some of our members have had it for 20 years. It was explained that the MEDIAN survival for ECD is 3 years, but this is NOT the same as the MEAN survival. The MEDIAN survival of 3 years means that 50% of the patients who are diagnosed with ECD have died within 3 years. The MEAN survival is the AVERAGE time that people survive after diagnosis, and may be much longer for those that get through the first 3 years.
- After we had finished another person came on the Chat. She said that her husband has ECD with growths in his heart, bases of both lungs, and stomach. He is on prednisone and interferon, and requires dialysis due to kidney damage.

