

Summary of ECD Global Alliance chat held on Saturday 21st May 2011

10 Present

- A question was posted prior to the chat asking whether anyone had experienced problems with broken blood vessels in their eyes. Two patients had experienced this in the past. It was mentioned that the blood vessels at the front of the eye may be broken and although this looks alarming, it is generally not serious. However, bleeding from the vessels on the retina is much more serious and may damage eyesight.
- A question was asked regarding swelling of the feet and legs. A couple of other patients had experienced this. One patient found that the swelling was reduced if they raised the legs when sitting, so that the feet were higher than the pelvis. The patient used pillows to rest the feet on when lying down in bed.
- Two patients on the chat mentioned that they did not have much energy at present.
- One member asked whether any other patients had suffered from crumbling fingernails. No-one else on the chat had suffered from this although a patient had lost three molar teeth (and another one is crumbling), even though they have always taken good care of their teeth. Other patients in the organization have also had this problem.
- There was a discussion on the subject of social security disability. One person asked what percentage of patients with ECD were receiving social security disability. If it were a high percentage, might it help others to get benefits? The answer to this question is not known but it would be an interesting point to look into further.
- The next chat will be held on Saturday 28th May 2011 at 3pm EST.