

Summary of ECD Global Alliance chat held on Saturday 30th October 2010

7 Present:

- Members commented on the recent update letter (sent on 29 October) which outlines the financial status and organizational activities of the ECD Global Alliance. It is extremely encouraging to see how the organizational side of the ECD Global Alliance is progressing. The amount of money already raised is considerable. It is hoped to award \$50,000 this fall to fund an ECD based research study.
- One patient reported that they had been suffering from chest pain recently and also severe cramps in the legs and toes. Two other patients represented on the chat also suffer from cramps. Some doctors recommend magnesium supplements.
- One patient who has diabetes (thought to have been caused by drugs used to treat ECD) has been asked by one of their specialists to take part in a diabetes study.
- The next chat will be held on Saturday 6th November at 3pm EST.