

Summary of ECD Global Alliance Internet Chat 20th April 2013

6 Attendees

- A member told us that they had suffered a broken hip. He said that his doctor had told him that he was "too old to break his hip", but he had managed to anyway.
- A new member introduced himself. He is originally from Manchester, in the UK, but has been in California for many years. ECD was diagnosed in 2010, when he was aged 68, although he believes that he has had it for many years. Symptoms have been severe fatigue, loss of muscle coordination (especially swallowing), kidney disease, vascular problems, and diabetes insipidus. He is unsteady, but can still walk. The diagnosis of ECD, in October 2010, was made "by accident". He had gone into hospital with pneumonia. X-rays of his lungs just caught the top of his kidneys, and these were encased with a 2cm rind of fatty tissue. He had been diagnosed with Idiopathic Diabetes Insipidus in 1992. He still manages to play a bit of golf, but finds 9 holes a struggle.
- A member mentioned that 2CDA (=cladiribine in the UK) had caused the "masses", that were causing problems, to stop growing.
- A member has just spent a few days away from home, and has read, and thoroughly enjoyed, "Down Under", a travel book about Australia, by Bill Bryson. This member has managed to be away from home for 6 days, which, for him, is a record!
- A member, from Australia, told us that he hopes to be at the San Diego conference in November. This will, probably, be part of a "round-the-world" trip, and will need to be planned and booked. He has relatives near Nottingham, in the UK, and may be able to also make a visit to a member, who lives in Yorkshire.
- A member, whose wife has recently died due to the effects of ECD, has recently taken a "car load" of Ikebana vases and other pots, and 8 boxes of quilting material around to a local school market and spent the day selling them. He made \$450 from it (which adds to \$3000 already made), which will all go towards ECD research. The sale has also made a little more space in the garage!
- Members then spoke about the range of symptoms that they had had, the ages at which they had been given a diagnosis of ECD, and what was difficult now.

One member, diagnosed at 45 with "the wobbles", has taken medical retirement (trying to work as a family physician, and trying not to fall over, at the same time, had become too much!).

Another, diagnosed at 32, is still managing to work.

Another suffered with stiff, aching, and painful legs, and fatigue for 10 years. Also she would easily catch the least illnesses, and these would take 6 weeks to get better.

- We were reminded that it is important to keep doing things, but tailoring activities to what is possible.
- A member, new to us all, came on after we had finished. This member's father, who is based in Nottingham, in the UK, was diagnosed with ECD about 3 years ago, after falling very ill. He has many complications, particularly with respect to his kidney function. He was told,

yesterday, that he has a degree of renal failure, and will need to have dialysis at some stage. We were asked whether any of us have had similar complications.

(Editor's Note: Kidney issues are not uncommon with ECD. We have members who are or have been on dialysis. At least two members have had kidney transplants.)