

Summary of ECD Global Alliance Internet Chat On 16 June 2012

9 Attendees

- A member, whose daughter was diagnosed with ECD last year, came on before the Chat to give a progress report. Interferon is the treatment at present, and a recent review showed that there had been "no change" in her condition. Great news! There is still eye protrusion, but, unless she loses sight or gets double vision, there are no plans to operate. She is going for re-assessment in December. Her mental state is a problem; it is difficult to get her mind around the whole idea of this disease. It is "one day at a time" quite often! The essay, "The Median Is Not The Message" by Stephen Jay Gould has been helpful. There is a lot of good information in it. (See http://cancerguide.org/median_not_msg.html)
- There was one more message left before the Chat. This was left by a member, who works at the same time as the Chats. This is almost the only time that working is possible. Severe right elbow pain has been present since early February. Physical therapy has been tried, as have a number of medications, including steroids. Lidoderm (lidocaine) patches are being used, but aren't working. More sessions of physiotherapy will start on 26th of this month, as this "took the edge off" before.
- A member, whose son has ECD, told us that her son had had a good week. He had called and said he that would be visiting tomorrow, to BBQ for Father's day
- Our member, who is soon to be married was reminded "that wonderful wedding is getting closer and closer".
- A fairly new member asked someone how long they had been retired. The answer was 5 years.
- A member told us that last Monday was the sixth-week anniversary of his prostate surgery, and the prohibition of exercise ended, to his dismay! He was encouraged to try to find another reason for not doing exercise!
- One member had managed to join the Chat using an I-phone.
- A member had not heard about a recent MRI scan, and was strongly encouraged to call to find out the result.
- A member has started alpha interferon shots 3 times a week. Possible side-effects were mentioned, particularly chills and fatigue, although one member had had no

side effects at all. Another had only felt a bit tired. The member, starting the interferon, has also just had a first MRI. The machine was new and very swish.

- A member has just had routine blood tests, and the results look like Type 2 diabetes (the type that you tend to get when you are old/mature and fat/well built), and the cholesterol and lipids were abnormal. "Diet, diet, and more diet AND NO SUGAR!!" is the "medicine" that the doctor will prescribe!