

## Summary of ECD Global Alliance chat held on Saturday 28th August 2010

### 8 Present

- About a week ago an interesting article was published by a group of doctors in France on the use of anakinra (trade name Kineret) as a treatment for ECD. Two patients were treated with good results. The ECD Global Alliance has received a copy of the full length article and the publisher has asked that it be shared with the members of our organization. If you or your medical team would like to see a copy, please email (via the website or the normal email) and we will send you a copy.
- One member described how their three new foster children (aged 3 and under) are keeping them busy!
- One ECD patient described the difficulties and frustrations in being a caregiver for their spouse who has Alzheimers disease.
- A patient commented that ECD was not causing them the problems that it did a year ago, and that possibly a course of Gleevec that they received may have helped.
- One patient is very frail and present and there is concern over their production of red blood cells. It is likely that the patient will be referred for a second attempt at a bone marrow biopsy soon. The patient has difficulty swallowing due to a mediastinal mass and finds soft and moist foods the best.
- One member has experience of making tasty food for people with feeding/nutritional problems and would be glad to share some of the recipes they have found helpful. Please send an email to the usual address if you are interested.
- Several patients reported that they had lost 50lbs or more whilst on treatment with 2 cdA.
- The question for the week was ‘Please share with the group what you as a patient or you as a caregiver do all day. I know that there are parts of the day that are void and drag on. Do you volunteer, have hobbies, work on projects, etc? Perhaps you, as the caregiver has not enough or too much time on your hands. Perhaps, you, the patient has times where you are bored and don't have something to do. Give the rest of us some things we can do.’
  - One patient described how their foster children keep them very busy; they also work on woodworking projects.
  - One patient is a volunteer at a local resource centre for people with nervous system problems and runs a cookery course one day a week.
  - One member described how their grandchildren keep them busy; they are also considering volunteering at a local school.

- One caregiver works full time and is also kept busy with caring for their partner, attending appointments etc.
  - One patient enjoys crafts and has made dolls houses, miniatures and a large carousel from wood.
  - One patient has recently started working on a business venture that may be run from home.
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- The next chat will be held on Saturday 4<sup>th</sup> September at 3pm EST.