

Summary of ECD Global Alliance chat held on Saturday 26th June 2010

10 Present

- One patient who had cataract surgery last month is doing well and their sight has improved.
- One member recently attended a family function where funds were raised for the group; thanks were expressed to the member and their family.
- Two patients are feeling extremely tired at present. The effect of the illness (and in particular tiredness) on your emotional state was discussed. It is very easy to be irritable, and it is usually the people closest to you who are on the receiving end of the irritation. This is one of the difficult aspects of being a caregiver. A patient commented that before they had illness, they used to tell stories, laugh and smile a lot and that now it was difficult to do these things.
- One patient has recently received some imaging results indicating that the condition is stable; however they do have some sclerotic growths on the spine.
- One patient has volunteered to give a short speech on ECD and the effect it has had on their life and their family's life, at a charity jam fundraiser at the end of July.
- An interesting question was raised. How can we, as an organization, get the insurance companies to see that we need certain medications? One suggestion was for the patient and/or the treating doctor to follow the documented appeal process of the insurance company. The appeal can point to case studies that have been documented, as well as point out that there is no proven treatment for ECD. Another member suggested that we need to also support research that might scientifically show which treatments are effective; it should then be easier to convince the insurance companies that they must pay for medications for ECD patients. Another member suggested going through your state representative to appeal an insurance denial. One

member who is a veteran suggested that if you are having trouble with your insurance you could contact a VA hospital, as they have been very helpful for that patient in handling insurance issues.

- The possibility of creating a library of appeals/dealings with insurance companies was suggested as a means to help those who are having difficulty with insurance. All identifying information would be removed. If you would like to share any documentation that you have used to get insurance companies to cover costs, please forward these to support@erdheim-chester.org. This might also work for disability issues.
- A patient who has had recent experience of the appeals process with an insurance company found that a personal letter, backed by supporting letter from a doctor (s) to be effective.
- The next chat will be held on Saturday 3rd July 2010 at 3pm EST.