

Summary of ECD Global Alliance chat held on Saturday 3rd April 2010

16 Present

- A new member, diagnosed in October 2009, was welcomed by all to the chat. They have lung problems and a double lung transplant has been suggested as a possibility by doctors. Members suggested that the patient's doctor may find it useful to contact other 'ECD knowledgeable' doctors who are listed on the website. One patient who had lung problems mentioned that their condition had improved on Gleevec.
- One patient is due to start the first round of radiation therapy this week.
- A patient had a doctor's appointment this week and their condition was assessed as stable. This patient is doing well on Gleevec and has more energy than previously.
- There were some very positive developments for the organization recently, with a number of doctors expressing interest in research. See the email dated 3 April for further details
- It was suggested that some members might be interested in having a mid week chat. Various times were suggested 1. Wed at 10am EST 2. Wed at 6pm EST 3. Thurs at 10pm EST. If you are interested in this idea please send an email to the normal address specifying your preferred time.
- One patient continues to do very well without any ECD drugs at all.
- One patient is feeling a bit weak post chemotherapy.
- One patient is doing very well; they have dialysis three times a week which is going well. They are considering a cruise with dialysis facilities.
- The question for discussion this week was:
'If you are the caregiver, how has this illness changed your life? If you have the illness what changes have you seen in your caregiver or other family member?'
Responses were as follows:
 - The caregiver feels they now have little free time due to their caring role and their efforts in raising awareness of the disease.
 - The caregiver feels they have had to learn to be more patient; they don't do as much traveling with their partner as they used to. Several caregivers mentioned that they stay at home much more now and travel much less frequently.

- One caregiver has had to increase their working hours for financial reasons. Another has reduced their working hours so that they can cope with their caring responsibilities.
 - One caregiver described how emotionally difficult it was to deal with the illness of their child.
 - Attending and transporting patients to hospitals for appointments is extremely time consuming.
 - Two ECD patients on the chat are caregivers themselves and described how difficult and tiring this was.
 - One caregiver had retired from their job two years early to help their relative.
 - It was commented that it is easy to stay so focused on the patient that the caregiver forgets about themselves.
 - One patient is very aware of needing to give their partner ‘alone time’.
 - A caregiver commented that their role had changed; while they ensure they are near or around the patient, they also try to ensure they follow their own path/vocation.
- The question for next week’s chat is ‘ When you are feeling especially down, in more pain, depressed etc, what are some things people do for you that helps you manage? How did the things they did help you?’
 - The next chat will be held on Saturday April 10th at 3pm EST.