

Summary of ECD Global Alliance chat held on Saturday 17th April 2010

12 Present

- One patient reported the good news that they are improving without treatment at present. They have been having Reiki treatments which they feel are beneficial.
- Another patient has been off treatment since April 2009, when they finished cladribine, and feels they are improving.
- Another patient is in remission and has been off all treatment for ECD since August.
- Sincere thanks were expressed to the webmaster who does all the work on the website for the group on a voluntary basis. It is hoped that an update for the website will be available shortly. The website will include an address for sending donations to the group, and work is continuing on adding a memorial page for donations to be given in memory of loved ones. It is also hoped that a video clip will be available on the website in the near future. There will be a new link shortly providing advice for those who use wheelchairs.
- The question for this week's chat was
**'I am at my worst when.....
and I am at my best when.....
Please share with the group the whys and whens of your answer.'**
 - One patient said they feel bad when suffering from the side effects of interferon.
 - One patient said they feel worse when reminded by their difficulties of what they can no longer do. They feel best when with good friends.
 - A caregiver said they felt worst when the patient they care for is upset and best when they are happy.
 - A caregiver said they feel worse when they think about what they can no longer do due to ECD.
 - Another caregiver said they had felt worse when tired, they felt forgotten and didn't know where to turn.
 - Several patients said they felt best when they had a project or work to do.
 - One patient mentioned they felt worse when in pain or when having to walk a long way.
 - A caregiver said it was frustrating when people suggested they have an easy life because they work part time.
 - A caregiver said they gained support from their medical team.

The next chat will be held on Saturday 24th April 2010 at 3pm Eastern Time.