

## Summary of ECD Global Alliance chat held on Saturday 22nd May 2010

### 8 Present

- One patient is doing very well on Gleevec. They cope well at work during the week and use the weekend to recoupe.
- A patient who has been on methotrexate for the last 6 months had an encouraging result from a recent PET CT scan, which showed decreased activity of abnormal tissue in almost all areas. The plan is to continue with methotrexate for another 6 months and then schedule another PET CT scan.
- A patient who had a CT scan of the chest, abdomen and pelvis recently reported that the scan showed that the disease had regressed in size and density in all areas. This patient has recently completed six cycles of cladribine. The doctors are considering what to do next.
- One ECD patient who is also a caregiver for their partner is finding life very difficult at the moment, as their partner has been admitted to hospital this week.
- There was a discussion about how the disease has affected patients' holiday plans. Several patients reported that they only go away for short breaks now (two-three days) and tend to stay fairly locally so that they can get to the hospital fairly easily if they are taken ill. A number of patients require disabled access facilities e.g. walk-in showers.
- One member asked about submitting an article for the newsletter. The address for the newsletter editor is 'stanceforlance@hotmail.com'.
- There was a discussion about fundraising for the group. One member is visiting schools to talk about fundraising possibilities. One member of the board is thinking of compiling a cookbook of favorite recipes, more information will be coming about submitting recipes, but please start saving them now! It might be worth having a separate brainstorming session, aside from the regular Saturday chats, to generate ideas for effective ways to raise funds.
- It was suggested that it would be good to have an ECD convention, including both patients and doctors.
- It was suggested that it would be good for raising awareness to have a press release on ECD for February, to be used on or around Rare Disease Day.
- This week the group became a listed support group on Orphanet (a European group that focuses on rare disorders).
- The question for discussion this week was 'What are some of the things that you have had to give up since being diagnosed? As a caregiver, have you had to give up something you enjoyed? Was it difficult to come to terms with this? How did you get beyond the emotional part of giving up something that you enjoyed so much?'

Responses included:

- The patient and caregiver missed going for long walks.
  - A minister had to give up being a minister in different churches all over the world.
  - A patient who has become blind misses TV, movies and shows; they used to do the makeup for their local theatre.
  - People missed going to the shopping mall
  - Several patients and caregivers said they missed traveling
  - One member missed family picnics
  - One patient has had to cope with significant emotional issues associated with the disease; they have been helped a great deal by working with a psychologist
  - One caregiver has had to change from fulltime work to part-time work so they can be at home more to care for the patient
  - Several patients talked about the major financial impact that the disease has had on their lives, with significant loss of income due to giving up work
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- The next chat will be held on Saturday Mat 29<sup>th</sup> at 3pm EST.