

Summary of ECD Global Alliance chat held on Saturday 9th January 2010

12 Present:

- A message was posted prior to the chat relating to the previously discussed issue of the recall of interferon injectable pens. Pens for this patient had been recalled and they had been replaced with the normal injectable type, which have no needle supplied. Needles had been purchased at the local drug store. The patient is still doing well on interferon and is taking a reducing dose of prednisolone, which they hope to stop by mid February.
- Two patients on the chat take aleve to reduce leg pain. One patient had tried aspercream but this had not been much help. A member commented that some patients have used the fentanyl pain patch for pain relief with good effect.
- The benefits of exercise were discussed. One patient finds walking highly beneficial and walks five days a week, which helps them to keep mobile, increases the feeling of health and aids pain relief. Another patient commented that since they have increased the amount of exercise they do, many of their symptoms have become easier. Another patient attends physical therapy sessions twice a week. However, one patient commented that even walking a short distance gave them considerable pain in the hips.
- A patient who has been experiencing stomach problems has now stopped taking Gleevec and is undergoing investigations.
- Recently the newsletter editor requested that pictures of patients and caregivers be submitted for inclusion in the next newsletter (the email address for the newsletter editor is 'stanceforlance@hotmail.com'). To protect the organization, lawyers have advised that we should not post anything on the website without a signature giving permission. Therefore members are asked to sign a form (which is attached) giving their permission for the picture(s) to be used in the newsletter and then on the website. You can do this by printing the form, signing it (everyone who appears in the picture needs to sign the form), then scanning it into your computer and sending it as an attachment to the newsletter editor. You could also post (snail mail) the form, or take a digital picture of it and send this electronically. Whichever way it is done, a copy of a physical signature is needed before the picture may be used.
- A patient who is due to begin Medicare in February asked if anyone had any advice.
- A member who is looking at raising awareness of ECD in connection with Rare Disease Day asked for ideas. Any suggestions would be very welcome and may be emailed to 'tjcmorgans@wildblue.net'. NORD has some material that may be used to help get articles in the papers and politicians interested. The group also has material which could be sent to interested members to help raise awareness of

Rare Diseases and ECD. (This will material will be sent in a follow on email.). It would be useful for members to send a letter to all their respective governors asking them to proclaim Feb. 28 as Rare Disease Day. A letter is already available, so it should not be difficult.

- A recent email from the HAA indicated they were initiating a project which will include collection and analysis of data for ECD and other non-Langerhans rare diseases. There are no more details at present.
- In terms of the status of research projects, Dr Vaglio is still progressing his project. Dr Haroche's project is further along; he has received funding and should be working with us in the next few months. At present he is looking into the logistics of taking and transporting blood samples. The group was recently invited to join in an effort with Euro-Histio-Net who are trying to develop an international registry.
- A new movie on rare diseases and a family's fight to find a treatment has recently been released; it is called 'Extraordinary Measures'.