

ECD Global Alliance Chat 01 October 2011

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9 Attendees

- One member came on briefly, before the Chat had started, and said that her son had been taking Sprycel since June. Things had improved according to scans, and 3 months more of treatment was planned before another PET scan.
- Sprycel was looked up in the literature and it appears to be used in leukemia patients who cannot tolerate Gleevec.
- A new member came on after we had finished. He has ECD and was seeking more information.
- 2 members were asked how the preparations for their trip to NIH were going. The first patient will go to Bethesda this week. He isn't a "Chatterer", but has kindly sent Kathy the details of his schedule at NIH. Many members were interested in this, and Kathy has sent out a copy to everyone.
- One member was getting better after having a colon and gall bladder infection. Antibiotics have been prescribed for a Clostridium difficile infection.
- Another member had had minor surgery to remove a small cyst this week.
- A member who has been suffering with back pain has made some improvement.
- A member who has had a lot of difficulties with swelling of the legs thinks that there is a bit of improvement.
- It seems that it is taking about a week for Dr. Estrada-Varas at the NIH to get back to people about the timings. If anyone is having difficulties, then please get in touch with Kathy.
- Kathy said that the most important document to send to NIH was the report in which ECD is diagnosed. This will probably be a combination of a pathology report, and a report from the doctor who gave the diagnosis.
- Travelling with interferon was discussed. Members have normally not had problems flying while carrying their own interferon. It is necessary to think about how it will be kept cool during the journey. One member has used a frozen "cool block". A suggestion was made of taking a zip-lock bag, and asking for some ice from the aircrew. It was thought that it was best to contact the airline regarding all this BEFORE traveling!

- Dr Gahl, the senior researcher at the NIH, has just been awarded a Public Service Award. Congratulations from us to him.
- A discussion took place about the bronchoscopy that is going to be part of the work up. This is usually done under sedation. One member has had it done this way and reported that it had not been too bad.
- We were not able to say, at the moment, whether travel costs to NIH will be met, or how any assessment will be made. Some members are planning to take a train for some of the journey, and this choice was approved of by people who had used the trains for other trips.