

## Summary of ECD Global Alliance chat held on Saturday 30th April 2011

### 8 Present

- One member responded to the request on last weeks chat for information on experiences with Gleevec. The patient concerned has been on Gleevec for one year and four months and has had a good experience. They immediately felt they had more energy when they started to take it. There have been no side effects. Tests indicate there has been no change in disease status.
- A patient who has had kidney problems recently is improved; the kidney function is better and dialysis has not been necessary recently. However, the patient still feels very weak which is causing difficulties with transferring, for both patient and caregiver.
- It was discussed that some patients in the group use fentanyl patches for pain relief. However one patient (on a fairly low dose at present) is finding them ineffective for pain control.
- Three more patients are in the process of collating medical records to send to Dr. Vaglio. This is positive, but he needs many more in order to make the study meaningful. Dr. Vaglio is intending to write a piece to share with members to explain more about the study, and it is hoped that this will encourage more members to respond.
- One member met with several doctors this week interested in doing research into ECD. The doctors expressed interest in both seeing patients and/or obtaining tissue samples. More information will be forthcoming as it is received.
- The 91<sup>st</sup> patient registered with the group in the last few weeks.
- The next chat will be held on Saturday May 7<sup>th</sup> at 3pm EST.