

## Summary of ECD Global Alliance chat held on Saturday 6<sup>th</sup> June 2009

11 Present

- One member is now on their 2<sup>nd</sup> cycle of chemotherapy (cladribine) and described that they have not experienced any serious side effects, apart from feeling a bit tired.
- One member has received a blood transfusion this week due to low red blood cell count. The patient seems to have a little more energy following the infusion.
- A question was asked about whether anyone had noticed their hair becoming dry and brittle. One other member had noticed this; another member said their hair had become fine and soft. A possible link to interferon was discussed.
- One member had recently met Dr. Vaglio in Parma, Italy. He is planning to contact Dr. Haroche in Paris shortly and begin the process to formalize his study using the medical records he has requested. We should hear something more from him then.
- It was mentioned that Dr. Haroche is looking to collect HLA test results. He would really like blood samples but this is proving difficult logistically. To participate in this research you need to talk to your doctor about the possibility of having the test performed. From the patient's perspective, a simple blood test is all that is involved. Dr. Haroche has received blood samples from three patients in the group at present.
- The side effects of interferon were discussed. One member said that when first taking it, they experienced fever and aching the morning after the shot. These symptoms were relieved by taking a painkiller. This patient has few problems with taking interferon now. Another member described nausea and dizziness and another member, stomach problems. One doctor had suggested that the side effects of interferon were reduced with the pegylated form of interferon. One patient had been advised to drink plenty of water the day before the injection and the day of the injection to lessen the side effects.
- Three members described their experiences with pericarditis. Symptoms include pain and shortness of breath. Another member described how windows had been put in to drain the fluid around the heart. These members had received differing information as to whether the pericarditis was related to ECD.