

## Summary of ECD Global Alliance chat held on Saturday 15th August 2009

12 Present

- One patient had a useful consultation with Dr Arceci at the beginning of July. One member who had been trying to get an appointment with Dr Arceci for some time finally got an appointment this week.
- Two members will celebrate their 50<sup>th</sup> wedding anniversaries in the next year!
- One patient had aching legs, which is thought to be a side effect of the biphosphonates. These are used to help build up the damaged bone.
- One patient who has shown radiological improvement recently had been taking prednisone, which the doctor thought had done a lot of good. The patient will continue on interferon and pulse prednisone every 3 weeks for 5 days. No chemotherapy is planned at present.
- One patient has taken prednisone for 10 years for pain control.
- One doctor is considering using cladribine for one particular patient, having first suggested interferon. Another patient has e mailed Dr. Haroche for advice on further treatment, They are particularly interested in the reasoning as to why sometimes interferon and why sometimes chemotherapy and/or steroids are used. Another patient had seen a doctor who suggested taking interferon, prednisone and cladribine all at the same time. It was thought that the cladribine and prednisone would provide a 'jumpstart' and interferon would maintain. However, the patient is on prednisone and interferon only for now.
- Two patients had trouble breathing after hard work.
- One patient had recently suffered a bad reaction to methotrexate, having to spend 4 days a week in bed.
- A patient who had experienced severe pericardial effusion required a pericardial window. ECD cells were found in the pericardium and heart muscle.
- Notes from conversations with Dr.s Kurzrock and Haroche may be found on the website under 'Published Papers'.
- Fundraising: the ECD Global Alliance will shortly be an official non-profit organization able to accept tax free donations. There is a meeting next weekend to finalise the paperwork. Dr.s Vaglio, Dagma and Haroche are currently involved in research proposals. Dr. Arceci might be interested if the funding were available.