

## Summary of ECD Global Alliance chat held on Saturday 2<sup>nd</sup> May 2009

11 Present:

- One member who was unable to attend the chat asked for the following note to be shared “The treatment of vinblastine, interferon, Aredya, Uramox together MAY help for remission and eye problems”.
- A patient has recently started on Januvia (sitalipitin) for controlling blood sugars (in addition to other drugs taken for diabetes type B). The patient was doing well and had more energy.
- A patient who visited Dr. Haroche in Paris six weeks ago has received the report giving results of the investigations. One new piece of information relates to ECD and heart involvement and the patient will be having an echocardiogram to investigate this further. Dr. Haroche conducted a number of tests, including brain and heart MRI, CT chest and detailed blood tests.
- ECD and heart involvement was discussed. Two patients had experienced fluid build up in the pericardium; both had had surgery to relieve the fluid build up.
- There was a discussion about making copies of medical records to send to Dr. Vaglio in Italy. Some people reported that these copies were easily available at no charge; one person said that a charge would be made. It was suggested that if we explain the copies are required for the purpose of a study, the fee may be waived. Ideally people should obtain one copy and keep a copy for themselves, that way if another researcher wants information there will be a copy readily available.
- One patient reported that they had now been stable for eight years, with no increased uptake on the bone scan.
- A recent increase in pain in the shins was noted by one patient, another person commented that this had occurred to them when they were on a higher dose of interferon.
- One member has just had three sessions of IV cladribine, with (so far) no adverse effects.
- One member is planning to attend the HA conference in Milwaukee this summer. The HAA have recently asked if they can use the ECD Global Alliance brochure at this conference.
- Stress and its negative effect on ECD patients was discussed, one patient mentioned that their pain seemed to increase when they were under stress.
- Members congratulated a couple who were celebrating their 34<sup>th</sup> wedding anniversary today!