

## Summary of ECD Global Alliance chat held on Saturday 14<sup>th</sup> |November 2009

Number Present: 8

- One patient had recently been experiencing fluctuating white blood cell counts due to taking cladribine; this had made them feel ill and unable to work. Another patient had experienced similar problems in the past and had needed transfusions.
- One patient had recently suffered from significant chest problems; steroids have helped a lot but have caused a huge increase in appetite! The patient has recently started treatment on methotrexate.
- The patient who had been suffering with problems with their knees reported an improvement; they now need to be very careful when walking and stretching.
- There was a brief discussion on stomach problems. It was agreed that it is sometimes difficult to tell whether symptoms are due to the disease or due to the treatment. One patient finds that stomach pains may occur if they do not take drugs with food/before food/after food, in accordance with the instructions. Another patient has been given a drug to reduce stomach acid whilst on steroids.
- Four patients on the chat had experiences of being treated with cladribine; it was interesting that three different dosing regimens had been used in these four cases.
- A patient who has had a recent head MRI reported that one side of the orbital masses appeared smaller. Another patient reported no change after a recent scan.
- A member who has been working hard on producing Christmas cards to be sold in aid of ECD Global Alliance has recently completed the art work for the cards. If you would like to view the cards please e-mail [rjcmorgans@wildblue.net](mailto:rjcmorgans@wildblue.net).
- A member asked whether patients have one doctor or several doctors responsible for their care. If there are several, what are their specialties and is one doctor responsible for the overall co-ordination of care? Members on the chat named a wide variety of specialties. Some have one specialist who acts in a coordinating role; others have a local doctor who acts as coordinator. Some had a number of doctors but no-one who acted as coordinator.