

Summary of ECD Global Alliance chat held on Saturday 14th May 2011

6 Present

- One patient who had an MRI recently has received the good news that the disease is stable at present.
- Most patients with ECD see quite a number of specialists. It was discussed that it was often useful to ask one doctor to be the 'primary doctor' who takes on the role of co-ordinating care.
- A patient with a brain lesion has had their treatment changed to interferon. So far there is cautious optimism that the treatment is holding the situation. The lesion has affected the patient's right hand side so walking is difficult and hand/eye co-ordination is not good. Rehabilitation treatment is due to commence shortly.
- One patient mentioned that they suffered from an itchy rash on their right ankle and calf, which only appears after radiation treatment. Another patient said they had also suffered from a rash which was diagnosed as 'lichen ruber planus' after a skin biopsy.
- A patient experiencing light headedness and dizziness asked if anyone else suffered from this problem; one other patient had experienced this occasionally.
- One member who has written an article on ECD will probably have the piece published in their local paper soon.
- The next chat will be held on Saturday 21st May at 3pm EST.