

Summary of ECD Global Alliance chat held on Saturday 30th May 2009

9 Present

- One patient had to attend an emergency room this week; the importance of taking as much information as possible on ECD and on your medical history when you attend an emergency room was mentioned.
- There was a brief discussion re: alcohol. One patient had been advised to avoid alcohol whilst on interferon. Other members on the chat who were on interferon had not been given this advice.
- One patient's insurance company had initially denied approval for continuation of approval; the decision was only reversed following appeal by a local doctor. This resulted in a 2 week break in the taking of the interferon which had caused significant problems. One member suggested that you could contact the manufacturer of the interferon in these situations as some have programs that may help in continuing the supply of the drug.
- One member uses pegylated interferon and only has an injection once a week; other members on the chat have experience of non-pegylated interferon and typically have injections 3 times a week.
- One member has to attend the doctor's office each time for interferon injections. Other members on the chat encouraged them to try to move towards self injecting, which can make life much easier.