

Summary of ECD Global Alliance chat held on Saturday 29th August 2009

11 Present

- A patient who had not joined the chat before was welcomed to the group. They described how they were suffering from fatigue, thought to be due to taking interferon. Other members on the chat mentioned they also suffered from fatigue when taking interferon, although some patients find that the side effects of interferon (fatigue and flu like symptoms) decrease with time as they get used to the drug.
- One patient had recently seen Dr. Arceci and felt very positive about the consultation. Various treatment options are now being considered.
- Two patients on the chat have been prescribed Provigil to help deal with fatigue, which may be due to taking interferon. Both patients felt it helped improved their energy levels and helped them do more than they would be able to do otherwise.
- One patient has recently suffered a significant level of bone pain. Some patients use fentanyl patches to help with pain control, although some have commented that this has made them sleepy. One patient on the chat uses hydrocodone to relieve pain and commented that keeping moving also helps. Another patient had been prescribed oxycontin plus percocets.
- There was a discussion regarding patients' experiences of abdominal masses. One useful site is <http://health.groups.yahoo.com/group/Retroperitoneal.Fibrosis/>. A patient described how an abdominal mass has compressed the ureters and a nephrostomy was necessary. As there is arterial involvement in the mass, surgery is not an option. For another patient, the masses are entwined with the retroperitoneum so again, surgery is not possible.
- Dose levels of interferon were discussed, with patients on the chat having dose levels ranging from 1.5 MU 3 times a week to 5 MU 3 times a week. Some patients are able to tolerate a higher dose, others not. Two patients had been advised to take Tylenol before their shots and drink plenty of water.