

Summary of ECD Global Alliance chat held on Saturday 2nd April 2011

11 Present

- A question was asked about whether other patients suffer from hip or knee pain. One patient on the chat suffered from knee pain on a regular basis. Another patient described how they experience leg weakness and heaviness but no pain. It was discussed that some patients find pain medication helpful and some have found kineret effective. Several patients in the group have used fentanyl patches to good effect.
- A patient asked about experiences with interferon. One patient said that it was fairly typical to have flu like symptoms for a while after commencing treatment. Another patient who has been on interferon since 2005 suffers from tiredness.
- One patient had a cytarabine injection last week which caused a great deal of pain. It is thought that the pain was probably as a result of bruising from the lower back lumbar puncture needed for the injection.
- One patient, fairly new to the chat, described how they had symptoms for eight years before diagnosis. This patient suffers from poor balance and stiffness in the legs. Introductions took place on the chat with people giving some details about themselves and their history.
 - One patient was diagnosed in 2007 and has had treatment with interferon, fentanyl and testim
 - One patient was diagnosed in 2009 and has double vision and poor depth perception. They wear a patch over one eye.
 - A patient with brain stem involvement is currently being treated with cladribine, They have a weak left side, double vision, dizziness and tinnitus.
 - One patient was diagnosed in 2005.
 - One patient was diagnosed two years ago. They suffer from poor balance, slurred speech and have kidney involvement.
 - One patient has some problems with depth perception and focusing outside when anything changes quickly.
 - One patient was diagnosed in 2009 after several years of symptoms. They have heart, retroperitoneal, long bone and orbit involvement.
- There was a discussion about the difficulty of eating, caused by loss of appetite or choking/difficulty swallowing. Several patients found that they were often too tired to eat. One patient had problems with choking. A patient who has just been discharged from hospital is still being fed through a peg tube. This patient's pneumonia had been caused by food aspiration. It was discussed that a speech therapist/pathologist may be able to help by suggesting exercises relating to swallowing and also by advising on diet. Sometimes just changing the consistency of the diet may help. One patient also mentioned that they sometimes choke on saliva. Several patients had used Ensure (sometimes with the addition of ice cream!) when they were struggling to eat.
- The next chat will be held on Saturday 9th April at 3pm EST.