

Summary of ECD Global Alliance Internet Chat 13 April 2013

7 Attendees

- A member whose father has ECD came on before the chat session started to give an update on his father's condition. The patient had recently been in the hospital for pneumonia that was suspected to be the result of aspiration. His pneumonia has fully cleared and he is going on week #5 of Interferon (pegasys). He seems to be doing well and is tolerating the medication with no noteworthy side effects. He is mentally sharper and seems more like himself of old. His dexamethasone dosage was also increased while he was in re-hab so that may be behind the improvement instead of the interferon, but something seems to be working. Walking and balance are still an issue, but the family expects that. The patient is going for physical therapy 2x a week (also includes pool therapy) and swallow therapy. His next series of scans will likely be in 4 more weeks. He wishes everyone well!
- A member who has been missing the chats recently explained that he had spent the last 3 weeks in the hospital with a broken hip. He was turning off a lights, turned to get his walker, lost his balance, and fell.
- Another member said they had fallen on their hip and arm one night, but had been lucky because nothing was broken. This member explained they had physical therapy for 5 days in a row this week, from 1:30-3pm. Afterwards they found they were able to walk around in a store by themselves without holding on to something or someone. It had been a few months since that was possible! The patient has 2 more weeks of everyday training! With all the therapy, it doesn't leave much energy for the patient's normal bike riding exercises!
- A third member said that he is on Bis-phosphonate infusions for his bones. This member had fractured his spine previously when he fell in the shower.
- A fourth member said they had experienced similar falls. As a result, they were sent to physical therapy where the therapist says he is very pleased with the patient's progress! The patient goes to therapy from noon-1pm, 3 days a week. The therapy is helping the patient's leg feel better. The biggest concern of the patient's is healing a tendon that is making it difficult to walk. The patient is taking 6 ibuprofen tablets a day to help with the pain.
- A caregiver mentioned that once their loved one's balance was affected by ECD, many falls were experienced.
- One member said they had an MRI yesterday.
- It was mentioned that sometimes it is the simple things that are the hardest, yet mean the most.