

Summary of ECD Global Alliance chat held on Saturday 19th June 2010

11 Present

- A new member was welcomed to the chat. They are in their early 60's and were diagnosed with ECD aged 56. They have been treated with interferon since 2005 and CT scans have indicated that the condition is stable. They suffer from fatigue all the time and have difficulty breathing.
- One patient currently on Gleevec is doing well and has more energy than they have had for years. This patient saw a urologist recently who was pleased that the patient's kidneys were functioning well. A stent has been removed and another one replaced.
- One patient is currently in a lot of pain and is very tired. Much of the day is spent in bed, and the patient has no appetite. It is thought that the tiredness is due both to the disease and the treatments (interferon and prednisolone).
- A caregiver mentioned that their relative is doing well but sleeps most of the day.
- One patient has recently been receiving radiation treatment (to the head) and has been suffering side effects from the radiation.
- One member is involved in organizing a fundraising event to be held on July 31st. Funds raised will be shared with the American Heart Association.
- One member has a friend who is the General Manager for a Single A baseball team. A piece on ECD is planned for the next team newsletter, which has a circulation of 10,000.
- A patient has recently enjoyed running a cooking course for people with coordination/balance problems at a local Nerve Centre (a resource centre for patients with neurological problems). The aim of the course is to help people cook safely and to promote healthy eating. Further sessions are planned. Two of the participants are severely disabled and are in wheelchairs.
- One patient has an electric scooter; which they ride when taking the dog for a walk! Several other patients in the group are thinking of getting a scooter to improve mobility and independence.
- Several members discussed their poor balance. Some patients use a walking cane while others need a chair.
- The next chat will be held on Saturday 26th June 2010 at 3pm EST.