

Summary of ECD Global Alliance chat held on Saturday 5th February 2011

10 Present

- One patient asked if others had suffered from itching of the legs. This patient has itching on the front part of the calf, from the ankle up (for about six inches to the mid calf). Their legs itch all the time. One patient said they also had itchy legs, but not all the time. Another patient has had itchy legs for years. One patient described how they had itchy legs for some time after radiation treatment but the itching eventually stopped.
- One patient uses fentanyl patches to ease leg pain.
- One patient received some excellent news recently; the disease is stable/improving in all areas.
- One patient who has been in remission for over a year continues to do well. Their balance is a little better and they have lost a lot of weight (45lbs) over the past year which was gained whilst on prednisone.
- One patient has recently undergone hernia surgery and is recuperating slowly. The surgeon found some material in the stomach which was biopsied to exclude cancer. It is not known whether the material was ECD.
- A patient who was in hospital recently (receiving methotrexate for a new brain lesion) is making a good recovery. They enjoy walking and are now able to walk a mile and a half, whereas last week half a mile was all they could manage. The patient has also found that their double vision is lessening.
- Different ways of highlighting Rare Disease Day, on February 28th, were discussed.
 - Some members are planning to participate in a local blood and bone marrow drive in their community.
 - One member is planning to send a press release to all local TV and radio stations and local newspapers.
 - Another member is helping to organize an ECD Fun Run in their local community. When this is completed, it is hoped that it will be possible to put some details on the ECD website about how to organize this type of event.
 - Some members are hoping to write pieces about their experiences with ECD and send it to local newspapers.
 - One member suggested wearing the ECD Global Alliance t-shirt on February 28th
 - Another idea suggested was to have a 'dress down' day at work or at school and ask everyone participating to donate \$1 in support of rare diseases/ECD.
- The next chat will be held on Saturday February 12th at 3pm EST.