

Summary of ECD Global Alliance chat held on Saturday 12th September 2009

13 Present:

- A good part of the chat was spent discussing the issue of insurance companies refusing approval for medication. This has been the experience of one patient recently, with the insurance company refusing a request to fund treatment with cladribine. One other member on the chat had experience of an insurance company refusing approval for interferon, although this was subsequently obtained via a cancer clinic. One member had some experience of difficulties with insurance companies being resolved by the use of personal contact: treatments that were initially denied were subsequently approved when discussed in person with insurance company staff. It appears that insurance companies are looking for precedent for treatments with proven results. This is difficult with a disease such as ECD, when there are so few patients. One member had received information that insurance companies use the NCCN compendium as a reference when assessing whether to approve funding for a treatment: one person on the chat agreed to look into this further. Any suggestions on getting insurance companies to approve treatments would be most welcome; this could maybe be posted in the room or discussed at the next chat.
- One patient on the chat is currently tapering prednisone, and plans to commence treatment with interferon in the New Year.
- One patient is suffering badly with shingles.
- A number of initiatives have recently been undertaken by members to raise awareness of ECD. One member is progressing an order for 'ECD T shirts' to include an ECD logo. Another member has plans to produce Christmas cards with the proceeds going to ECD work. One person has sent a letter to all their contacts describing ECD and its effects and asking them to pass on the information to others.
- A question was raised as to whether anyone connected with ECD has been in touch with the politicians who are working on health care reform. The non-profit organizations, NORD and the Genetic Alliance are working with politicians who are involved with health care reform on behalf of all rare diseases. The web site addresses are: www.rarediseases.org and www.geneticalliance.org. It was suggested that NORD and the Genetic Alliance could provide useful information in dealing with insurance companies that refuse approval for certain treatments.
- One patient asked about information on how patients have done on cladribine. There are a few papers but not many. One of the problems is that there are so few diagnosed cases of ECD, it is impossible for any statistically significant studies to be done, to prove (or otherwise) the effectiveness of a treatment.