

Summary of ECD Global Alliance chat held on Saturday 15th May 2010

7 Present

- One patient posted a message at the beginning of the chat to say that lesions in their cerebellum had worsened and that they were due to start a new chemotherapy treatment (vinblastin).
- One patient continues to find Kineret extremely effective in the treatment of bone pain. This patient is now able to do much more around the house than they used to. They have had very few side effects with this medication, in contrast to previous medications.
- There was a brief discussion about cladribine. One patient who had received a course had experienced a positive response. Other patients in the group have also had a course.
- The group has been encouraged by interest in our organization by the medical community. It is hoped that a new research project might be started before the end of the year. It is also encouraging that doctors have found the group via the internet and, because they now have a source of patients, are better able to consider doing research. Before, they may have had an interest but had no available patients.
- Any suggestions for fund raisers, or offers to organize fund raisers, would be most welcome.
- The possibility of the group having its own Facebook page was discussed. It was agreed that if this page is associated with the group, it needs to be regularly monitored and facilitated. It is very important that anything the group starts should be run professionally.
- It was agreed that fostering communication between doctors is important.
- It was suggested that an 'ECD Convention' might be held sometime in the future and various suggestions for sponsorship were discussed. It might be possible to hold this in conjunction with a medical workshop so that information could be shared between patients and doctors.
- The group is now a member of Euro-Histio-Net, has applied for full membership in NORD, and Orphanet (the European version of NORD) now has information posted about the group..
- The next chat will be held on Saturday May 22nd at 3pm EST.