

## Summary of ECD Global Alliance chat held on Saturday 14<sup>th</sup> August 2010

### 8 Present

- One patient has had an especially difficult 2 weeks. They have recently had three chemotherapy treatments (with 2CdA) and have required hospitalization due to multiple problems. The patient is at home now. This patient has received the treatment intravenously in very large doses. Several other patients on the chat had received the drug in the past, one intravenously over a two hour period each time, one received the drug subcutaneously. Both these patients had six cycles of treatment , one cycle a month for six months, each cycle consisting of a daily dose over five days.
- One patient who is stable at present is deferring treatment with leustatin at present. Doctors are concerned about the drug lowering the blood count and consider this an unnecessary risk at present as the patient is stable. Another patient who had received the drug described how their blood count was reduced but not enough to require intervention.
- A patient has been approved for assistance through the Johnson and Johnson programme and will be able to obtain leustatin with no charge.
- A question was raised as to whether people experience problems with the increased heat. One patient is cold all the time and usually needs to wear a jacket. Several patients reported heavier sweating than normal. Several patients reported that the increased heat made their balance worse.
- The recent fundraiser was a great success; thanks and appreciation were expressed to the organizers.
- Sleeping problems were discussed, several patients on the chat described waking and then not being able to get back to sleep. One patient took Ativan to aid sleep. Other patients described how they often fall asleep during the day. Several patients reported needing more sleep than normal.
- A website has been found that will allow allow donations to be made to the ECD Global Alliance by internet without any charge. This means all money donated would to the organization for its use. This website is being tested and if all goes as hoped will be added to the ECD Global Alliance website soon.
- Two grant applications have been received this week and will be forwarded to the Medical Review Board.
- The next chat will be held on Saturday 21 August 2010 at 3pm EST.