

Summary of ECD Global Alliance chat held on Saturday 4th July 2009

9 Present

- One patient has recently had a consultation with Dr Kurzrock in Houston. The drug Gleevec has been prescribed and the patient has just started taking the drug. Some side effects have been experienced; leg pain and a short episode of numb fingertips.
- Another member has been taking Gleevec for seven months and would be interested in making contact with others who have taken this drug.
- One member has benefited in recent months from improved diabetes control, which has led to improved energy levels.
- Two members on the chat discussed problems regarding foot pain and how it has caused problems with mobility. One member finds that wearing crocs has helped. Another wears modified sandals.
- There was news from one patient who was in a wheelchair 18 months ago. About 9 months ago he was able to walk with the aid of a walker. He is now walking with the aid of a cane. More recent issues with double vision and stroke-like symptoms are also improving greatly. We celebrate this improvement!
- One member is traveling extensively later this year (October) and would like to meet other members en route. The route will cover Montana, Dakotas, Idaho, Wyoming, Colorado, Utah and Houston (November) Please contact Kathy in the first instance at the normal email address if you would like to be put in touch with this member.
- Much of the chat was spent chatting about family and 4th July celebrations!