

Summary of ECD Global Alliance chat held on Saturday 20th February 2010

10 Present

- There was a discussion regarding the medications used for orbital problems. Two patients take Imuran, one has not seen any results as yet and doctors are considering prednisone. Another patient on Imuran had taken prednisone but the side effects outweighed any benefits.
- A number of patients are taking prednisone for orbital involvement but also to relieve pain.
One patient finds a 20mg/day dose helpful in pain management. One patient takes a dose of 10mg/day which they find helpful. If they have a special event planned, they increase the dose to 20mg/day for a few days prior to the event and then taper the dose to 10mg/day after the event. This helps them in being able to do the things they want. One patient is currently tapering from a 40mg dose of prednisone but noticing that pain increases as the dose is reduced. The patient's doctor is considering the use of kineret.
- Kineret has been used by another patient in the group for bone pain relief to very good effect. The drug is given as a daily injection. The patient has found that pain levels have reduced to almost nothing, but if the injection is missed for a day the pain returns. It took about a week before the reduction in pain levels occurred. The only side effect has been some minor irritation at the injection site.
- One patient reported that they take diflunisal for leg pain.
- One patient diagnosed in 1992 uses a wheelchair as their balance is very poor. A patient diagnosed in 2004 described their main health problems as leg and hip pain, visual problems and balance problems. It was discussed that symptoms differ widely, and that it is very useful to share information. Work is continuing on a patient log to gather this type of information which could be used for research purposes.
- The member coordinating actions relating to Rare Disease Day for the group reported that they were excited about the responses from our group to Rare Disease Day. Members were encouraged to continue with their excellent work in promoting this day.
- The group is still waiting to hear from the government regarding the tax exemption status. In the meantime, please continue to share your fundraising ideas with the group.
- A patient commented that they thought a skin rash was related to ECD, although this view was not shared by others, and biopsies had not provided any further information.

- A patient has been paying for a health insurance policy which they have recently found has been unnecessary and is now looking into obtaining a refund.
- Those who have not submitted pictures and/or photo release forms to the newsletter editor are encouraged to do so as soon as they can. The address is 'stanceforlance@hotmail.com'.
- One patient shared their thoughts on having a rare disease. Most patients have some idea of possible treatments, prognosis and where to go for information; having a rare disease is like living in limbo and it is difficult to know where to go for treatment, how long it will take and it is hard to find out about possible medications. The patient described the value of the chat room to them in terms of being able to discuss issues and gain support from each other.
- The next chat is scheduled for Saturday February 27th 2010 at 3pm Eastern time