

Summary of ECD Global Alliance chat held on Saturday 30th July 2011

11 Present

- Several patients on the chat mentioned the problems they have with fluid retention in the feet and legs.
- One patient has little strength at present and is finding it difficult to transfer between wheelchair and chair.
- Several caregivers mentioned that they find it hard to encourage their loved ones to work at therapy sessions. One patient said that they find it helpful to work towards goals e.g. planning a family wedding, being able to spend time with grandchildren. A caregiver mentioned that they work along side their partner during therapy sessions which has helped.
- One patient reported that they stopped interferon in January and is now doing well on kineret. Another patient in the group was on kineret for over a year, which got rid of the patient's bone pain completely (which had not been achieved by the use of narcotics previously). The patient is now being treated with Actemra, another drug used in the treatment of rheumatoid arthritis that is a once a month infusion. This has also resulted in complete relief from bone pain.
- A question was asked about the side effects on kineret. One member mentioned that the only side effect had been a slight injection site reaction, and this had been infrequent. Another patient had suffered from high blood pressure whilst on kineret and this was controlled by medication.
- About six members in the group have experience with Kineret. A doctor in France (Dr. Auoba) wrote one of the first articles on the use of kineret and is interested in talking with other treating doctors using kineret. This doctor has reported good results with patients.
- One patient reported that they have had poor balance recently; balance problems are experienced by a number of patients in the group.
- Two members are due to take part in an interview with the producers of a US TV show.
- The email regarding matching of donations was mentioned (email dated 23 July 2011). Donations may be sent to ECD Global Alliance, PO Box 775, DeRidder, LA 70634, USA. Donations may also be made via the website (<http://www.razoo.com/story/Ecd-Global-Alliance>). It was suggested that this information could be spread via Facebook in order to maximize funds raised.
- The next chat will be held on Saturday 6th August at 3pm EST.