

Summary of ECD Global Alliance chat held on Saturday 23rd July 2011

(<http://www.chatzy.com/427437211406>)

13 Present

- 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>).
- Several members mentioned that the time of the chat was a little inconvenient (3pm on a Saturday afternoon Eastern Standard Time). The chats are held at this time so members from Europe and Australia are able to join in, although it may not be the best time for anybody! Members can post messages on the chat room at any time, and, if there are several people who wish to chat at a particular time the chat room may be used for this purpose also.
- The difficulties faced by caregivers were discussed. Mutual support is often very helpful and the organization will try to put caregivers in touch with each other if they wish.
- Members were again encouraged to send copies of their medical records to Dr. Vaglio in Italy, if they have not already done so. Details are on the website.
(See <http://www.erdheim-chester.org/VaglioPhenotypeStudy.html>).
- One patient has had a particularly bad week and alternative medication is being considered. Other patients on the chat discussed medications they had tried. There are patients in the group who have tried almost every treatment for ECD. It is clear that what works for one individual does not necessarily work for another, and that if one medication is not effective, another might be. Known options include interferon, gleevec, cladribine (also known as 2CDA), kineret, steroids, actemra, sirolimus, methotrexate, Tamoxifen, etc.
- One patient has been suffering from 'weepy legs' and has had to have their legs heavily wrapped below the knee. Heavy compression hose has also been tried.
- One patient who has been in hospital for some time receiving treatment for a brain lesion is making a slow improvement. Sensation in the hands/arms and legs is gradually improving. The patient is looking forward to coming home in the next few weeks. The patient has slight double vision caused by a lesion in the pons and the eyes 'jump around a lot' when tired. This patient currently wears an eye patch to help with this, although another patient on the chat mentioned that they have prisms in their glasses to correct double vision.
- One patient mentioned that they have difficulty controlling their emotions and thought that this was linked to treatment with interferon. Another patient (not on interferon) also experiences this.
- One patient is suffering from lumbar spinal stenosis which is very painful and is due to see a specialist shortly.
- The next chat will be held on Saturday 30 July at 3pm EST.