

Summary of ECD Global Alliance chat held on Saturday 25th June 2011

8 Present

- A member posted a question prior to the chat asking whether other patients had experienced problems with insurance companies refusing to pay medical bills. Several patients in the group have had to deal with this issue. Whilst there are no scientifically approved treatments, there are treatments that small studies have shown help slow/stop the progression of the disease. In past cases, once the insurance company has been made aware of the literature, they have often been willing to listen and there are members who have been successful in persuading insurance companies to continue/grant funding.
- One patient has deteriorated significantly in the last three weeks and is now completely dependent. The lesion in the pons/brain stem keeps reactivating, causing loss of control on the right side and a little loss of control on the left side. This cause the patient to lose sense of where their arm and hand is in space. The patient is currently being treated with 6mg/d of dexamethsone with 3MIU of alpha interferon/day. The dexamethsone will be slowly reduced. So far this year it would appear that it is really only the dexamethsone that is controlling accretion of the histiocytes and the interferon is being very slow to have an effect. Twice now when the dexamethsone has been reduced below 4mg/d, the lesion has reactivated and the patient has worsened.
- A question was raised about information for carers. Does anyone know of a good book or website for full time carers? One member has found being a member of a local carers group very helpful.

(Post chat session information: The following websites have been helpful to some caregivers in our organization:

- <http://www.videocaregiving.org/caregiving.php> (be sure to scroll down on the window)
- www.nfcacares.org/caregiving_resources/tips_and_tools.cfm
- www.familycaregiving101.org/manage/messages.cfm
- http://www.ama-assn.org/ama1/pub/upload/mm/433/caregiver_english.pdf
- <http://www.agis.com/caregiverkit/caregiverkit.pdf>
- <http://www.ndrf.org/Caregiving.htm>

These and other links can be found on the ECD Global Alliance website with a selection of the “Caregiver” menu option on the left side of the window. See <http://www.erdheim-chester.org/CaregiverInfo.html>. If you can recommend a book on caregiving, please send your recommendation to support@erdheim-chester.org.)

- One patient is continuing to successfully lose weight (gained when on steroids) by exercising regularly.
- The next chat will be held on Saturday 2nd July 2011 at 3pm EST.