

Summary of 8-15-08 ECD Chats

Chat Date:

8/15/08

Time:

3 pm Eastern time

4 Attendees

Summary:

Participation in Our Online Chats

A short discussion was held about why we seem to be having some chats that are not heavily attended? Are we having them at the wrong time? Wrong day of the week? Are people too busy with summer activities to join in? Are we having them too often? Are people not interested? Would formal agendas help? We will continue to have them as long as anyone wants to meet. But if people have ideas on how to make them more meaningful we certainly want to make them worth people's time.

Treatments

Participants shared their experiences with various treatments. Interferon; 2CDa; remicaid and methotrexate ; and another cancer treatment (not named) were all discussed. One patient has had personal success in stopping the disease from spreading using interferon, another has had success with 2CDa. A third is hoping the recent (5 months ago) initiation of interferon treatment will show good results.

Side effects of interferon and 2CDa treatments were discussed. The flu-like symptoms and mood swings (treated with Paxil for one patient) associated with interferon treatments were talked about. Also one patient experiences diarrhea occasionally and dry mouth.

The first treatment series with 2CDa did not seem to cause any bad side effects with the patient in the chat room. However, the doctor did monitor the patient throughout the treatment to ensure all blood indicators remained in an acceptable range.

Monitoring

Sharing of each patient's monitoring plans took place. The following were noted as different patient's monitoring plan:

- eyes checked every 6 months by an eye doctor to watch for any masses that might be forming in the eye area.
- CT scan of the body and a MRI of the head every 6 months. The frequency used to be every 3 months but has now been change to every 6 months.
- CT scans without dye because of reduced kidney function. For this patient MRIs are not an option because the scans don't show

anything if the gadolinium contrast agent isn't used. In this case the reduced kidney function prevents the gadolinium from being used.

- Eye doctor appointments every 3 months. Checkups every 6 months with the other doctors on the 'care team', including: haematologist, ophthalmologist, nephrologist, and endocrinologist, and local General Practitioner. Yearly checkups with the cardiologist.

Getting a Diagnosis

The difficulty in getting a diagnosis of ECD was discussed. The following were shared:

- One patient was told they could spend millions of dollars and still not find out what they had.
- One patient was diagnosed only because the pathologist had seen the same signs in an autopsy.
- It was brought up that Dr. Kurzrock said it took 3 years for her first ECD patient to get a diagnosis.
- One patient was diagnosed only because the doctor had seen a previous referral with the disease.
- Prior to diagnosis one patient had a scan of white blood cells in an attempt to diagnose what was causing them to have chills. The patient says the pathologist 'panicked' and ordered another test. He never heard anything more.

Some patients have literally multi-million dollars of tests performed and still do not get a diagnosis. This is partly what our group hopes to change in the future.

News from the HAA

- The HAA has recently received 3 completed questionnaires for the ECD Registry. This is great news! The more information the researchers have, the more they will be able to learn. The more they learn, the better the treatments will become. Thank you to those who have gotten their information into the HAA. (Remember, keep a copy of all the information you send in to the HAA. Next time someone asks for all this information, you will have it!)

A question was asked about when the new shorter version of the ECD Registry Questionnaire would be published. We don't yet have an answer to that. As I understand it, there is an international registry that is in work to track information about all the histio-diseases. It is planned for this registry is to become functional in 2009. A shorter questionnaire will be used at that time. It may be that the shorter questionnaire will be used for the ECD registry sooner than that, but I

don't know. If you haven't yet completed your questionnaire, please keep working on it. If it is just too much to do, call the HAA (1-800-548-2758) and ask if you can complete the shorter questionnaire.

A suggestion was made as to whether the HAA could use the data we have collected in the patient log. That information has been made available to the HAA, although names were not given. Contact will be made with the HAA to see if they can use the information in any way.

- The HAA is busy at work getting a chat room facility added to their website! If all works as planned, this will enable us to continue our chats without costing us anything.
- Dr. Kurzrock's team at MD Anderson in Houston is now on the HAA referral list of ECD knowledgeable doctors. Her team submitted the paperwork recently and the HAA can now refer patients to her team. This seems like good progress!

Getting Word Out About ECD Global Alliance (that's us!)

It is still difficult for people to find our group. We have had a couple new people contact us in the past month. Although we never want anyone to need us, when they do we would like it to be easy to find us. One patient in the chat room said it took much researching on the internet before they discovered how to contact our group this past spring. Until they found our group they had only had contact from CORD and HAA, neither of which was able to provide much in the way of helpful information.

We are busy trying to find someone who can build us a professional-level website. Since we have no funding source we are searching for a way to do this without cost. One of our members suggested contacting schools. We have started an effort to find a university that would like to partner with us. We would get a website and they would get training. So far we have not found success, but we just started and we will continue to try. If YOU have any ideas on how we can best get a website developed with little or no funds, PLEASE speak up.

In the meantime, a friend of our group is working on developing a prototype website for us. This will not be anything fancy, but may prove to be a starting point. As progress continues, we'll keep you notified. If you would like to be a part of this activity, please speak up.