

Summary of ECD Global Alliance Internet Chat 24 August 2013

8 Attendees

- Some of the members from the US mentioned they were being affected by the wildfires that are raging at the moment. Some are affected by the smoke, and some outdoor activities have had to be cancelled.
- A member's daughter has just restarted teaching. She has been teaching, now, for 7 years (5 at 3rd grade, and 2 at 2nd). He also has three grandchildren, that are busy getting married, or getting ready! One had got married on the previous day, one had the wedding reception that very evening and one had a bridal shower booked for the next day.
- A member has just returned from a 10 day cruise to Alaska. He had taken his children and grandchildren too. He has been "fairly stable" recently, meaning that he is bothered by fatigue, but is able to get about. However, he does have some balance problems, and is losing the use of the right hand. He lost a tooth when it corroded, from inside out, and he also has some speech and swallowing problems.

He has not yet contacted the NIH, and was encouraged to do so. The contact details for the doctor leading the study are; Juvianee Estrada-Veras MD.

juvianee.estradaveras@nih.gov, Phone 301-451-7963, National Institute of Health Bethesda, MD.

We were reminded that they do not treat you when you go to the NIH. They run lots of tests to learn more about how ECD is affecting you. These run, usually, Mon.- Fri from 6am to 5pm, and you are busy the whole time.

You get a complete examination, including assessments of your eyes and teeth. You are given a thorough knowledge of what is going on with your body. You get copies of all the results. Currently, they even pay for the flight (originating in the US) and a room for the patient and traveling companion. Any ECD patient is eligible to enroll in the study, no matter where they may live.

- A new member, from Chicago, came on for the first time. Her husband was diagnosed with ECD the day before the Chat! He has an eroded jaw, long bone pain, and fibrotic Interstitial Lung Disease (ILD). He is 60 years old, and has had symptoms for about a year and a half. He has just had a bone biopsy, and this gave the answer. He has had a lot of pain in the long bones. The doctors treating him hadn't seen this disease before, and other members said that their doctors had said the same! She was advised to check out the ECD Global Alliance website. This has a lot of information about doctors, and also lists different treatments.

- The new member then asked about possible treatments. Interferon had been mentioned. A member said that he had been taking interferon since November 2005. An injection on Mon, Wed, and Fri. It leaves him feeling tired and exhausted all the time. A member said that he had had 2-CDA (cladribine) chemotherapy, and was now taking anakrina (Kineret). This is a drug that is mainly used in the treatment of rheumatoid arthritis. It is taken as a subcutaneous (just under the skin) injection, twice a day. There are a range of other treatments, and it seems to depend entirely on the patient, which one is effective. One member has tried interferon, cladribine, cyclophosphamide, and azathioprine. He has been taking methotrexate for the last 3 years and is stable.
- Another member, who is the mother of a 48 year old man, who was diagnosed 5 years ago, said that it had taken 10 years to find out what his problem was. He has had 2CDA chemotherapy, which, he feels, stopped the progression of ECD. He now takes imatinib (Gleevec), and sees Dr. Janku at the MD Anderson Medical Center in Houston TX.
- A member is having problems with Medicare regarding getting treatment. She was advised to email support@erdhiem-chester.org to see if the ECD Global Alliance can help.
- A question was raised about the Chat. It happens every week, but the people that sign on tend to change. Members from all over the world participate.