

Summary of ECD Global Alliance Internet Chat

02 Mar 2013

6 Attendees

- A member will be going to Tennessee this week, where his son has been building a house for him.
- A member from Europe was asked whether he was planning to go to the NIH. He was advised to look on the GA web-site for further information, and encouraged to go to the NIH by other members.

Dr. Estrada's e-mail is: juvianee.estrada@nih.gov. For more information see:

<http://clinicaltrials.gov/ct2/show/NCT01417520?term=erdheim+chester&rank=1>

- The son, of a member, has just been for his second visit to NIH. They have given him many helpful tips. He was low on Vitamin B-12, so he is now getting B-12 shots. His testosterone is low, so they are giving him a patch to wear, and his triglycerides are high, and they have suggested dietary changes. No white flour or pasta, change to Multi-grain or whole wheat. No butter, no Canola oil. AND they have told him to sign up at a gym, and start working out. A good point was that the lesions on his heart are gone.

NIH said they could see a tiny bit of improvement. He is still working, but does not drive out of town or at night. A member was "alarmed" by the "NO BUTTER!" suggestion. This member has a very low vitamin D level. It was suggested that this member should ask for the doctors to send him to Tenerife for some sun!

There were three patients at the NIH who got to meet each other.

- The "Spit for a Cure" study was mentioned. A member and her husband have already "spat". It had been a simple thing to do. They were mailed some paper work, giving permission for the test to be done. Then some tubes were sent, to be spat into for 10 min, and then the tubes are mailed back. A UK member has volunteered for the study, but is having difficulties arranging for the samples to get to the US because he is in the UK. He was e-mailed, at Christmas, to let him know that there was a problem, but no-one has got back to him yet. He was encouraged to e-mail them, himself.

For more information about the "Spit for a Cure" study, see:

<http://txch.org/cancer-center/histiocytosis-program/research/spit-for-a-cure-new-study-to-define-the-role-of-inheritance-in-histiocytic-diseases/>

- A member, who has not been with us for a while, joined, and told us that he is going to the gym regularly, for the hip that was replaced, and to get "in shape".

- A member is soon off to the seaside, for a short “birthday” holiday.
- A member, who has had a lot of trouble, with pain, recently, has had a return of this.