

Summary of ECD Global Alliance Internet Chat **Saturday 29 Sep 2012**

10 Attendees

- A new member came on before we started and told us the story of her husband, who has ECD. He has been on kineret and prednisone. He feels he has seen improvement since he started eating the parsley from the garden! He has fibrous growths on both lungs, on the right side of his heart, in his stomach and his kidneys. His attitude is very good. They have just moved to Texas, so he could crab and fish. He goes to dialysis three times a week. As well as having to try to cope with this, she discovered that she, herself, was ill, with cancer of the breast, and 2 lymph nodes. She went through chemotherapy and radiation, and has been doing well. She encouraged us to try to keep our lives as normal, as possible. To “live life”.
- Another member also came on early. She is in the middle of a house move and so was unable to join us. There has been a slight deterioration in her health, after several years of stability. She is setting up an appointment with Dr Janku.
- A member is going to NIH tomorrow, and is getting excited by the prospect.
- A member told us that she wouldn't be at the Chat next week because she will be busy getting married! A poor excuse (😊), but we all hope that everything goes well and the couple is very happy together!
- A member is going to SC to visit his family, who mostly live there.
- We were told that about 13 new patients have registered with the organization in the past few months. There are now 140 patients who have registered with us from approximately twenty-one countries.
- Kathy then told us about her recent trip to Europe. She had met with the teams of Dr. Dagna (in Parma), Dr. Vaglio (in Milan) and Dr. Haroche (in Paris). She said that it had been great to have a chance to talk with them face-to-face!
- The Doctors that Kathy met with told her that they would be interested in attending an ECD-GA Medical Symposium in San Diego in October 2013. We

could bring together all the ECD-research specialists. And then perhaps, if some of us could make it, the following day we could have a patient/doctor get-together. The Board is looking into what is needed to make this happen! We were asked to begin to think about whether we might be able to travel to San Diego in late Oct/early Nov in 2013.

- A member, who has been suffering with depression for a while, has an appointment to see his doctor coming up. It was suggested that he should make a list, in advance, of how he feels, in relation to the depression, so that the doctor can more easily understand its magnitude. Also he was asked to consider local face-to-face support groups. Getting together with people to share experiences can be helpful. There are no local ECD groups, but maybe joining another group like MS, cancer, Parkinson's, etc. would provide help. It is something worth considering anyway.

NOTE: ECD associated medical journal articles can be found at:

<http://www.erdheim-chester.org/TechnicalPapers.html>. Please feel free to share these with your health provider.