Summary of ECD Global Alliance Internet Chat on
22nd June 2013

7 Attendees + messages left by 5 others at various times during the week

- The mother of a man with ECD has recently visited him, and noticed that the tremors in his hands have all gone. She wonders whether this has happened to anyone else.

- This is the message left in Spanish; hola soy joaquin paciente con la enfermedad de erhein chester, intentare conectarme el sabado a la charla, he leido que alguien viene a Sevilla y de ahi soy yo,. estaria encantado de quedar conesa persona y vernos para cambiar impresiones, acabo de venir del medico del control rutinario y me ha mandado una resonancia para ver que va haciendo el intrerferol perigrado ahora a esperar que me la hagan que imagino quer sera en unos dos o tres meses, pues lo dicho me gustaria que se pusiera en contacto conmigo mediante el correo electronico esa persona que viene a Sevilla .

  Roughly translated, it is believed this is a person looking to email with another ECD patient they have heard about who is treated in Seville, Spain. Unfortunately the ECD Global Alliance has no way to email the person who left the message. If you are the person who left the message, please contact Kathy at support@Erdheim-Chester.org.

- A member reminded us that she is on a 4 week stay at a rehabilitation centre for MS patients. She has met 2 people who have met the 3rd ECD patient in Norway. He has, mostly, problems with his sight.

- Another member couldn't be at the Chat because they were going out to buy some landscaping adornment. This member has been having problems with his leg, but this is feeling much better, although he has to take it easy, and rest "when his leg says rest". His doctor has said that his optic nerve, field of vision & general vision have all improved.

- A new member came on, a 39 year old professor of physics from Brazil! He had to stop working due to fatigue, memory problems, and inability to concentrate. He has had ECD diagnosed and this has affected his bones and pituitary gland. His treatment is in Sao Paulo, (350 miles away), and this week he is due to have PET and MRI scans.

- Some members told us how their illness had begun.

    - One said that he had become rather wobbly, and developed double vision. A scan then showed masses behind his eyes. Nobody knew what they were, and the doctors were planning to drill for a sample, when he had some fits (seizures), and it all went on from there. ECD was diagnosed in 2005. Initially, this member went to London (200 miles away) but the professor that he went to see had never seen a case! Now he goes to see a Doctor in Leeds (30 minutes by cab) and was treated with interferon and then 2CDA (cladiribine) injections. The interferon was stopped because it was not "holding" the disease. He has been stable on low dose methotrexate for the last 3 years.

    - Another member had developed protruding eyes, and masses were found behind both of them. The kidney area was also affected. He is now on kineret, and, prior to that, on interferon. This member is sure that interferon kept him alive for 9 years, but it had powerful side effects. He had to learn to live with them, but the medicine was effective against his ECD. An article appeared in a medical journal reporting success in France with kineret on ECD patients. His doctors thought that he should give it a try. It was just as effective as interferon in limiting the disease, without the fierce side effects. So he has stayed with it, and his overall condition has improved considerably.

  - The new member told us that his treatment has been Alpha Interferon 3 times a week (3000000 UI) for the last year, more hormonal replacement and medications for leg pains. He has many side effects with the interferon but it still works for him.

- A member, who has just started a course of Cladiribine (2CDA), asked another member (who had previously had 2CDA) why he had not mentioned the side-effects. The member, who had already had 2CDA, told us that the 2CDA had not made him ill! He even stopped having the IV anti-sickness drug because he was never sick. The member, newly on 2CDA, has found it very fatiguing.

- The NIH study was discussed. One member on the Chat has, already, been twice to Bethesda. He told us that he had been treated wonderfully. The testing was extensive, and he said that he left knowing much more about himself and his condition(s). On the second visit most of the same tests were repeated to see if there had been any changes.

- The new member has also been to the NIH, and met another ECD patient! The 2 UK members on the Chat, were both concerned by the distance that they would need to travel to get to the NIH (although a Norwegian member has already been twice!).

- A member has just started sessions with a new physiotherapist. This worked out very well, and the member hopes that the new exercises, that he has been given, will improve things.

- Another member has a PET due this week, and will make a first visit with Dr. Filip Janku at M.D.Anderson in Houston.

- A member came on whose 33 year old daughter has ECD, although she is currently in remission and only takes a small dose of DDAVP. All tumors are gone or are scar tissue. She took prednisone, then chemo (2cda), then interferon. She is now blind because the ECD caused swellings behind the eyes, and this “suffocated” the optic nerves. She also has balance issues. She has learned to cope with being blind. She attends the Hospital of the University of Pennsylvania. It was the cladiribine that helped the most. Her doctor, Sunita Nasta, used it because ECD and hairy cell leukemia have some similarities, and so she "went with her gut feelings." She, herself, went to Bethesda back in early December of 2012. She is one of the few ECD patients who has met another ECD patient. She has met Alice from Norway twice.