Summary of ECD Global Alliance Internet Chat
13th July 2013

8 Attendees

- Before the Chat started a message was left by Kathy stating that Phill Arnold had passed away. He was a regular on the Chat, and we shall all miss him. The organization and other chatters send thoughts and prayers to Phill's wife and family.

- When the Chat started, we were told that there is a new patient portal for patients, who have been seen at the NIH. It can be found at - https://patientportal.cc.nih.gov. The NIH Clinical Center Patient Portal is designed to provide those patients who have been seen at the NIH, with access to key medical information, regarding care received at the Clinical Center, including test results.

- A member told us that he, and his wife, had met another patient, from Cincinatti, and his wife. They met at the Dayton airport. It was a great visit. They are the only two people in Ohio, known to have ECD.

- We were reminded about the letter asking for donations to the ECD Global Alliance (see attached), and encouraged to send it out to potential donors. We need to do this to support research, and things like the Medical Symposium, and Patient and Family Gathering, and, also, the chat room, website, etc. We all should have received an email, with an attached letter. Members can take the letter and modify it for their needs. The idea is for the letter to be sent out, to help raise awareness, and to let people know how they can donate to the cause, if they want to. Please help. Our organization is a grassroots initiative that is making a difference, but it can only continue with donations.

- The wife of a member is going to give up regular work in three weeks. She will then only work as a temporary staff member, when she chooses. It was pointed out, that she might end up working just as hard, looking after the member!

- A member told us that though she feels good, she is having problems with fluid building up around the ankles. This is keeping her from getting out because it affects her balance. She has had two bad falls, and suffered two broken bones.

- A member told us that a blood test had come back as high on thyroid hormone. There was some confusion as to how this would affect you, and how it should be treated. "An M.D.(retired) writes;

  If your thyroid gland is overactive, it produces too much of the thyroid hormone (thyroxine). This causes your metabolism to speed up. You may lose weight, have a fast heart beat, sweat a lot, and have loose bowel motions. This can be treated in three ways; using drugs to calm the thyroid gland down, chopping out a section of it, using radiotherapy to quieten it. Sometimes, after having it chopped, or irradiated, the thyroid doesn't produce enough thyroxine, and you have to take thyroxine tablets to replace the missing stuff.

  If your thyroid is underactive, you might gain weight, get constipated, have a slow heart rate, and not sweat much. This is treated, fairly easily, by taking thyroxine tablets, and checked with a regular blood test."

- A member, who likes to do woodwork, is doing some stuff. He hopes "to get out after the Chat".

- A member told us that he has been started on another medication, a statin, to try to lower his cholesterol. His thought is, "At least I will be able to have fish and chips, if I'm on the medication!"

- It was hot, and humid, on both sides of the Atlantic. One member (a male) was doing the Chat TOPLESS. He was in the UK, and has no air-conditioning, apart from windows and doors! It's very fortunate that we don't use webcams!!

- One member is having to cope with her own treatments, and with those of her husband, who is on chemotherapy for cancer. He gets chemo treatment next Mon, Tues and Wed. She is still having more tests. She said that she will be glad "when they get me on different medication".

- The story of a UK member is, probably, going to be used in a campaign, called "Raise a Hand", that a new charity is running, to promote research and treatment for Rare Diseases.

- A US member has been trying to persuade a local newspaper to get an article written, and published, about his story. The reporter who wants to do the story, says that she is "swamped". This member asked whether there were any hospitals, near to him, that are doing research into ECD.

- We were then told by a member, that he intended, when the time comes, having his affected organs sent for research. He doesn't want this to involve expense for his widow. He is planning to be cremated, in order to save money, but an autopsy sounds costly. He was told that, if he decided that he was serious about donating his organs, then he should contact Dr. Estrada-Veras (Juvianee.EstradaVeras@nih.gov). He will be able to say what needs to be done, to make it possible to donate tissue for research.

- A discussion was held about ECD-related work being done by Houston-based physician/scientists. Dr. Filip Janku, at MD Anderson, and Drs. Ken McClain and Carl Allen, at Texas Childrens Hospital are all actively seeing ECD patients and interested in learning more about the disease. For more information about the study being performed at Texas Children's Hospital and at other institutions, please see: http://www.erdheim-chester.org/Grants.html.

- Dr. Janku is planning to be in San Diego, and so is Dr. McClain. The talks for the Patient Gathering, in San Diego on Nov 1-2, are being, busily, planned. It looks like there will be a number of researchers on hand, to talk about their work.

- A member who has recently had some more scans, has been told that the ECD, in her cerebellum, has not grown any more. She will be starting a new treatment this week.

- Finally, a member came on, and left a long message in Spanish. The member finds it hard to make the chat sessions, but is interested in communicating with others. If you are interested in emailing with this member, please email Kathy at support@erdheim-chester.org and she will be happy to put you in touch with this member.