

Summary of ECD Global Alliance Internet Chat on 12 Oct 2013

6 Attendees

Daylight Saving Time Changes soon, BUT on different days in Europe and the US. In the US the change is on Nov3. In Europe its Oct 27.

It means that the non-US folk will have to use their brains to work out when the Chat will be happening.

- Weather was the first topic (like it is for most people!) Snow in Scotland, and in parts of the US, but still "very, very warm" in the Southern US.
- A UK member is going to Leeds soon to see the Doc that has been sorting out all his care. Since the member's last visit, 2 other ECD patients, from the North of the UK, have also started to see the same Doc. This is all the "fault" of our member. It was suggested that the Doc "will commend you for being able to find all the ECD patients in the UK!" But in the UK, Docs working for the State Health Service get an annual salary, and don't get paid any more for the individual patients that they see. So the Doc might show his "gratitude" for all the extra work that has come his way, by ordering some "nasty" tests.
- A member, unfortunately, had a seizure recently, and an Electroencephalogram test showed activity in the right frontal lobe. This probably means that the member will need to restart medication (Keppra). The oncologist indicated that, going back on Keppra might have a beneficial effect on her balance. She is able to walk, but is shaky and has to take her time. She makes good use of her blind-person's cane. Good news is that the scar tissue of the tumors in her orbits is smaller.
- A member has discovered, after a long wait, that she is BRAF positive. She is very interested in trying a BRAF inhibitor. If she can get into a trial (1) the drug is paid for by the pharmaceutical company, (2) the trial allows scientific data to be collected to see if the drug does really help. The disadvantages are that (1) you must be seen at an institution that is included in the trial and (2) you have to have follow-ups very frequently (about once a month in the beginning). She is European, so going to France frequently is easier than the going to the US. She lives very close to an airport, and that will help too.
- A member went to the Doc this week, and his blood test is showing an increase in white blood cell activity and platelets, and something else that "wasn't good". He goes in for his first bone scan since starting interferon. He is in the process of scheduling his bone biopsy.

Dr Estrada-Veras has been in contact with his own Doc and requested it. He thinks that Dr E-V wants him in to be in the BRAF study, but he is worried about the traveling that would be necessary. He wants to schedule a "vacation" at NIH, but is concerned that the study is a "non-essential" in the eyes of the US government, and may be affected by the shutdown. We were told that the government shutdown has affected the NIH, and we are going to have to wait and see what the long term impact, if any, might be. Patients already registered with the NIH will be harder to turn away than new patients, and anyone thinking about someday going to the NIH, should call them now and become a registered patient. The actual visit can be scheduled into the future.

- A member asked about the reimbursement of travel costs involved in being in the BRAF inhibitor trial. Participating in the natural history study includes travel, but the set-up for the trial isn't yet known. The NIH recognizes that travel is difficult, and will do what they can to help.
- A member has recently received \$233 from bonds that her grandmother bought her every birthday. She was informed that the amount would be deducted from the \$700 that she gets from SSI. This is her only income. Her food stamps have been cut from \$149 to \$79. It was said that "SSI has some draconian limits". (Summarizer's note; what a word!). She cannot have any more than \$2000 to her name. If she has any more, this is deducted from her monthly benefit.
- A member took his children to a truck show last week, but it didn't turn out very well for him. His good leg gave out on him, going into spasms. He took a step and there "was nothing there". No feeling or control. He didn't fall but couldn't walk for a couple of hours. His eldest son was, fortunately, able to get a golf cart for him to sit on.
- A member has moved nearer to his son, but the son has a 7 to 6 job, so that the only time to visit is when he comes to supper, or at Church. Luckily, his wife likes to cook and his son likes to eat! This probably makes everyone's day a bit brighter...
- A member, who organizes a "lunch club" at a local resource centre for people with long-term neurological illnesses, was asked how this was going, and whether his wife was also "lunching" on days when she had time to come too. We were told that she hadn't been for lunch yet, but that when she does come that she will have to help with the washing up. "Can't have the poorly folk doing the chores!" In fact, she already does do all the shopping and packing up, and she helps to choose suitable recipes.

There is also going to be a garden built there, with raised beds so that people can reach them. The plan is to start growing flowers, fruits and veg.

- A member mentioned Bakewell tart, and others asked about it, as they had not heard of it. It is named after the town where it was first made, Bakewell in Derbyshire, UK. It has a sweet pastry case, then a layer of raspberry jam, and has a sponge topping (with ground almonds in too).

Some members asked for the recipe.

- A member told us about her present work schedule (which will be changing later this year). She works 40 hours a week, and said that this was hard. The other members were not surprised!!!
- A new member, who lives in Vegas, was asked after, but there has been no contact. Kathy only has an e-mail address for him.
- A member said that, although he wanted to go to the San Diego conference, this will probably be too difficult. He could probably get there, but organizing a suitable motel room would be difficult. He said that he was lucky "if I can handle doing the laundry around here, let alone anything else or work...no matter how much I try".
- Difficulties with SSDI were mentioned. One member has a son with special needs, and has been trying to get him SSI and disability all his life! But the member has "too many assets".
- A member, who had succeeded with her claim for benefits, had Docs who wrote any necessary letters, and her parents would make the phone calls that were needed. Other things that helped were the loooooong list of docs that were involved in her care, and all of the various specialties that they came from.
- The Chat ended then, but later a member from Australia came on. Daylight Saving to blame again! DST has just started in Australia (cos their seasons are all upside down), and we had all gone.