Summary of ECD Global Alliance
Internet Chat 09 Mar 2013

5 Attendees

- Before the Chat started, Kathy had posted a question; "Do any ECD patients suffer from cataracts that have developed early, or quickly, and thus possibly be linked to ECD?" A member replied after the chat, saying that "Our son, who was diagnosed with ECD in 2009, after receiving CDA chemo at the age of 44, quickly developed cataracts, and had surgery." No-one else mentioned having cataracts, although bilateral retro-orbital swellings have been present in members.
- A member came on, who has just returned to Europe, from Florida, and admitted to being very sleepy. The member did not sleep, at all, on the journey. Help had been arranged at the airports, and the member was picked up in a wheelchair. Wheelchairs, and help, make such a difference, because there is such a long distance to walk at the airports! A member, who used to travel a lot for business, would walk at the airport carrying a 10 kg backpack, AND go the long way round!
- Our member, in Australia is doing well, and currently visiting his, much loved, mother-in-law, to keep her company, for some of the time, while she's on her own. The weather is beautiful and company is good.
- A member came on who has just returned from a second trip to the NIH. This time, there were two other ECD patients there. They were the first fellow patients the member had ever met, in person. This trip was, essentially, a repeat of the tests that had been done in November 2011. The good news/bad news was that there was essentially no change. The member is pleased that the disease appears to have stopped advancing, and hopes to reduce it. There was mention of Dr Haroche's work with a new drug. This is a BRAF inhibitor. About 50% of ECD patients appear to be positive for the BRAF mutation. The member's original biopsy slides are being tested.
- A member has seen a neurologist, but nothing was found that could point to the cause of poor balance.
- A member, whose wife has died from the effects of ECD, said that "no change" was usually good news with ECD. His wife had had periods of years with no change. Slowly, deteriorating balance was a problem, even before the lesion in her brain started. She managed to continue with most of her interests, but needed more and more arms to hold on to get around.

- One member told us that that he had been stable for 4 years. Another was only diagnosed 2 years ago, and the doctors say that last year has been stable, but the member feels much worse. Interferon has been used for almost 1 1/2 years now, and things have worsened over the last 9 months.

  The doctors don't want to try anything else, since, mainly, only the nervous system and skeleton are affected, so they say that stronger medication is not needed.

  Balance is a particular problem, and walking is barely possible, without holding on to something or someone. Fatigue, is such that exercising is not really exercising, anymore.

  It has been hard meeting somebody for the first time after a few years, and being hardly able to walk now. Another member said that needing help to walk is a big thing, and means that there is a need to rely on others.

- A member asked whether it was possible that the current problems stem from the treatment, rather than the disease. When this member switched treatment, from interferon to kineret, both fatigue and balance issues went away. But interferon did seem, thankfully, to have thwarted advance of the disease. Interferon seems to have different results, in different people, and one of the difficulties that the doctors face, in the earlier phases of ECD, is knowing when to stop a treatment, just in case the lesions start up again. In Norway, low dose naltrexone (LDN) is currently being focussed on, and is being used for MS and other rare diseases.

- A member's physical therapist recommends going away to a rehab/training place for 3 weeks to see if that will help. There is a long wait for this, and the member does not want to go to a place in their home town, because they will have met too many of the patients and nurses. The member is a nurse. It was said that rehab/training can make a big difference, learning new ways to coordinate and having help to strengthen the vital muscles.