

Summary of ECD Global Alliance Internet Chat

16 Mar 2013

10 Attendees

- Before the Chat started, Allie Freitas from NORD posted some new information. She said that she has worked closely, with Kathy, over the last couple of months, developing an ECD online community on RareConnect that can be found at:

<https://www.rareconnect.org/en>

Allie stated the following in regard to the ECD Community on RareConnect, "It is not meant to replace this chat but just to enhance your community! The vision is for the online community to be monitored by patient advocates, patient organization representatives, and experts from within the specific disease community. This format will create a trusted safe space, that can facilitate community building and information-sharing across languages and cultures. The community has been launched as part of a larger project, RareConnect, which is the result of a partnership between NORD and our European counterpart, EURORDIS, the European Organisation for Rare Diseases. The aim of these communities is to connect affected individuals and their families, provide links to medical information validated by patient group representatives, and help direct individuals to other tools and resources that may be of use to them; including, to highlight the great programs and services your organization already provides. One of the most exciting aspects of these communities is an on-demand translation tool that can be used to translate to and from five different languages, to further break down barriers of international communication. To date 39 communities have been launched.

If you have any questions please don't hesitate to contact me at afreitas@rarediseases"

- A new member came on, for the first time, who is a caregiver for someone with ECD. This member asked whether anyone had any experience with an ECD patient, with Alzheimer's-like symptoms of dementia. The member has not seen anything in the literature about this, but has DEFINITELY seen it in the loved one. The patient forgets where ordinary things are, and when to take his meds. He has strange routines, that he must stick to or else he wigs out. He loses sense of time & location, and acts in socially inappropriate ways. He was diagnosed in early 2009. Sometimes the member suspects, that his mental limitations, are due to exorbitant use of his pain medicines, but then, sometimes he uses none, and his mind is still as messed up. He is in his middle 50s.
- Another member, whose father has ECD, said that he was in a similar situation. There had been short term memory issues, and also loss of sense of time and location. Prior to the diagnosis of ECD in late 2012, his son had wondered about dementia, because his father was so confused. It turned out to be due to the ECD. The member believes that such issues are relatively common, if the lesions have affected the central nervous system.

His father is better this week. His pneumonia has cleared, and he has been discharged from re-hab. His steroid dose has been increased, and he is doing very well. He will be restarting his interferon this week. He, initially, had been unresponsive, but he has gradually improved. He was in rehab for 3 weeks, and "it's great to see him home".

- Another member, whose son has ECD, said that he, also, has short time memory problems. He has recently had problems with a broken tooth, after eating a Milk Dud! NIH advised pulling the root of the tooth as it is sitting on a nerve.

- A member, who had been diagnosed only a month ago, at UC Davis, told us of her difficulties with therapy. She is so sick of pain medicines. When the effects of the painkilling patch wear off, she is reminded, again, of the pain, and steroids "are no fun". She is on her second phase of chemo, and "it's been hard on my body, like a roller coaster". The white blood count keeps dropping too low. The member wonders how long it takes to make the ECD diagnosis, since she had had a blood transfusion in 2000, and blood samples were taken then. The member had felt a lot better when she was on interferon. She is going to Maryland on May 11 and looking forward to it.
- A member, whose son has ECD, told us that he had just returned from his second trip to NIH. They had many helpful hints. He is doing much better since receiving B-12 shots, and wearing a testosterone patch.

NIH said they could see a slight improvement in the patient's kidneys, and the lesions on his heart have disappeared. He is taking Gleevec, which often has horrible side effects, but so far he has had none of these. He will be 48 in April. The NIH told him that using an exercise bike was not enough, and that he should join a gym, and, also, lose some weight.

- A member has just got back from Tennessee. He has done with chemotherapy, for now, and feels a little better for it, although he is still having back spasms.
- The European members came on late. Daylight Saving Time hadn't started in Europe, although it has in the States. One member is having such problems with balance that they can hardly go anywhere their own. They are going to try some intensive physical therapy after Easter. The plan is to go to the therapist, every day for 3 weeks, for 1.5 hours, and apply for a 3 week rehabilitation stay.
- Another member goes for physical therapy, for his balance, and it has really helped. And another member said that their balance was bad, also.
- A member told us his story of his recent "Close Encounter" with a car, while out on his disability scooter, aka "The Harley". Although, it was all very exciting, he, fortunately, had no injuries at all, but the poor old Harley is pretty bent! He was just crossing the road, taking a prescription for a new medicine, up to the pharmacy, when a car pulled out of a side road, and hit the Harley amidships. Ambulance, paramedic, and a cop turned up. The cop said, it was the other guy's fault, so the member should be able to make the Harley better, with the insurance money! The ambulance crew loaded the member and the Harley into their truck, and brought them home! Both an ambulance and paramedic car turning up at the house, certainly made the neighbours look!
- This member is thinking of getting a combined exercise bike and cross trainer, or a recumbent exercise bike. The goal is to get fitter, and maybe even lose some more weight! Others recommended recumbent bikes. Low impact exercise and stronger leg muscles should help with balance.
- Another member told us that she was not able to exercise at the gym anymore, and was using a spinning bike at home and small weights. It had become too difficult to walk around at the gym.
- We were told that a member had joined a gym last year, but really, there were too many days when any meaningful exercise wasn't possible. Physiotherapy can also help with balance, and this member had had sessions last year, with water therapy, as well, for strengthening. But this didn't help very much, as she is very limited in the amount of exercise she can really do.

- A member, who has been having difficulties getting Social Security, was asked how things were going. An appeal was submitted a while ago, but there has been no word back. Fortunately, she got renewed through the State of Arizona retirement system long term disability.

This member is going to NIH in the week of April 22, after having had to reschedule several times, but it looks like it is really going to happen this time.