

## Summary Of ECD Global Alliance Internet Chat 10 August 2013

### 11 Attendees

- Before the Chat started, a member came on and said that they would not be at the Chat. She is taking advantage of the nice weather, and has been busy trying to fit outdoor activities, and family time, into her work schedule. She has a funeral to go to so will not be able to be on the Chat. She told us that she has been on kineret (having previously been on interferon) for just over a week now, and has also switched gabapentin to lyrica. Her “simple aches” seem to have gone away completely, but the major pains are still a problem. Hopefully, in time, this medication change will help. Her doctor has been in touch with Dr Estrada-Veras, deciding what new medication she should try, and making sure that it is helping.
- A new member came on who is the wife of a man in Belgium, who has been diagnosed with ECD. The Global Alliance is becoming even more “Global”!
- A member came on who has not been able to be on recent chats. He has had to cope with family sickness, and a funeral after his mom had died. Also his computer needed repairing.
- A member told us that she was in New York at Sloane Kettering. Her doctor is very enthusiastic about vemurafenib ( a new BRAF inhibitor drug), which she is about to start. He said that one patient had had good results in just two days! She has also agreed to some additional tests, for research purposes. She has an MRI booked. She has rented a scooter, because her leg/foot edema has got bad in the past two weeks. The scooter has been a “lifesaver”, but she is a little nervous crossing major streets on it! A member, who has a disability scooter of his own, said that it was very important to be VISIBLE on these machines! He said that he had been knocked off his scooter by a car!! At least the Policeman had said that it was the other guy's fault!
- Mark Mcelwee volunteered his e-mail address ([mark.mcelwee@yahoo.com](mailto:mark.mcelwee@yahoo.com)) to the newcomers, for their use should they want to get in touch. He then gave an outline of his daughter's history and treatment.
- The new Belgian member told us that interferon treatment will start in early September. She was told that, interferon has been shown to stop the progression of ECD in a large number of patients. But the down side is that, many patients feel poorly (extreme fatigue) when taking interferon, but not all. Of those who feel badly, most begin to feel better after being on the treatment for some number of months.
- A member is seeing Dr. Paul Scheel Jr., at John Hopkins. Dr. Scheel is part of the ECD-GA network of doctors. He stays up with the latest treatments for ECD. The member does not know what the doctor's plans are. He doesn't, yet know the

results of the BRAF test. At the moment, he is on 40 mg of Prednisone a day, but this was started because the doctors thought that he had retroperitoneal fibrosis. He will get his treatment plan in the next week.

If he is BRAF positive, there is a trial open at Sloane-Kettering in NYC that is accepting ECD patients. Kathy is planning to visit with the Sloane-Kettering docs on the 27th of this month.

- For one member there has been some confusion about the BRAF test. The doctors can't make up their minds whether to send a sample to the NIH, or to do the test in Norway, where the member lives. Since this member has been to the NIH twice, it was suggested that she should check with Dr. Estrada-Veras, as to whether the test has been already done at the NIH. The trial of vemurafenib is open in Europe as well. This member has also recently started taking fampridine, with the aim of improving her mobility. It is working a little, but she has had so much to do at work, that there has not been time for very much exercising. BUT she is leaving for the Greek islands, on vacation, next week! Hopefully, she will have a wonderful time, having time for some rest (and time for some exercise!).
- Some members said that they had been “control freaks” in earlier life, and were finding it hard to cope with all the uncertainties that ECD throws at you. They have questions like;
  - How will this affect my life?
  - Will I live long enough to see my kids grow up?
  - Will I continue to be able to work?
- Difficulties with mood control were mentioned. One person with ECD had a new kitten and this really did help her along. Another giant help has been her psychologist, who started seeing her years ago. It was once a week then. Now he sees her every few months.
- Another member, who has had ECD for 30+ years, was fully independent and functional, until the past five months. She has had to adjust to new symptoms, and ailments, along the way, but has been determined not to let ECD win.
- A member told us that there were 3 things that he thinks of often;
  - #1 the incredible kindness of strangers, whether it's a fundraiser or just holding a door
  - #2 no matter how ill Kit (his daughter) was (and he almost lost her twice), there's always someone who is worse off. This doesn't make you better, but it does offer perspective
  - #3 he wonders “why us?”, but he realizes that sometimes what happens to us, is a reminder to others that they shouldn't waste the good times. Life is too short even if you are in great health, so make the most of the life we have.
- A final comment on this subject was the advice to “Take it one day at a time. One hour if you need to!”

- A member has been given the go-ahead, by Medicare, to start taking Kineret. Her husband has a further 5 more chemotherapy treatments for his cancer before he has further surgery.
- A member told us that he shares the chat summaries with the doctors that are involved in his daughter's care. He was encouraged to see if they would be interested in going to San Diego, for the ECD conference. It looks like all the major ECD researchers involved will be there, and it would be nice to have some of the treating doctors present as well.
- A member asked about registration details for San Diego. We were encouraged to sign up as soon as possible. The registration fee will go up, to \$60 per person, on Sept. 1. There will be an email coming out, about this, in the next few days. However, you can sign up the week before, if you find out, at the last minute, that you can make it. If anyone wants to attend the Patient Gathering, in San Diego on Nov 1-2, but has questions or concerns, please feel free to email Kathy at [support@erdheim-chester.org](mailto:support@erdheim-chester.org). This should be a good opportunity for those who are able to make it.
- There was a member from Spain who shared information in Spanish. All Spanish speaking members of the ECD Global Alliance are invited to join the chat sessions. Without another Spanish speaking patient, all communication is made via [www.google.com/translate](http://www.google.com/translate).

This patient shared that he was initially on interferon, but stopped treatment. He is now returned to taking the pegylated form of interferon once a week, but is experiencing extreme tiredness and fatigue. He plans to ask his doctor about the BRAF mutation when he returns for a visit in 3 months. Anyone wanting more information about the BRAF mutation and the vemurafenib trial is welcomed to contact Kathy at [support@erdheim-chester.org](mailto:support@erdheim-chester.org).