

## **Summary of ECD Global Alliance Internet Chat**

### **17 Oct 2015**

#### 7 Attendees

- Many of the chatters had been to the conference in Houston. Next year it will be in Paris (the one in France, and NOT the one in Texas! Don't get mixed up!!!). [editor's note: The event next year will be held on September 16, 2016. Hold that date!]
- Members mentioned some of the things that they had learned. One realized that she was "selling myself short" by staying with the local oncologist whom is very good, but has no 'team'. She realizes that she should be going to a center that treats ECD patients, and all of their issues.
- A member asked about calf pain. She thinks that she has "histiocytes having a party" in her calf. They "partied big time" in her left shoulder and left a big mess behind! She has lots of other joint issues, but they always resolve after a few days. Dr. Janku at MD Anderson (MDA) thought that maybe she should have Kineret added to the vemurafenib (V) that she is taking to help reduce the pain. Her arm/shoulder has been hurting for a couple of months now, and she is seeing an orthopedic oncologist at the University of Kentucky in the near future.
- Another member has some calf issues. Her husband puts Bio-freeze on them, and the next day they seem fine. She wonders whether it could be her Rheumatoid Arthritis (RA) acting up, when her leg or shoulder are sore. She was first put on Kineret by her RA doctor. She has had no problems with the Kineret. She was put on it long before the V drug. She had been on others too, but she did not like their side effects.
- The question of whether drugs are covered by insurance was raised. A member on Kineret has to have her prescription sent to the insurance company from the doctor treating her RA, or they won't cover the medicine. Another member said that since her attorney called the company, when they refused to cover a PET, she thinks they will "cover anything!"
- A member who is now taking a dose of 3 in the morning and 3 in the evening of V said that she felt that she "had energy" on most days. She gets up at 5:30 am and has noticed that this is when she can get most done. She has always been an early bird. Her husband does not know what to think since he doesn't go to bed until 2 am! She has been told by others that it looks like she has more energy on the V, and her color is better.
- A member told us about a new clinic session that he has started. It is a "Walking and Not Falling Down Course" at a local physiotherapy department. Most of the others at the session are at least 20 years older than him, but they are a good laugh!
- Someone returning home from Houston developed severe pain in her calf last Saturday before she left. But she didn't say anything because she wanted to fly home on the Sunday. Her doctor at home ordered a Doppler study on her calf to be sure that she didn't have a blood clot (she didn't!). But the pain is still there.
- The member with macular edema told us that it was still there. There had been a tiny bit of improvement. She is being seen again this week.

- Another member came home to a sick daughter. The daughter stayed home for 1½ days and then went to the doctor. It was diagnosed as a viral infection, and it could take two weeks to go away.
- Fertility was the next topic. A fairly newly diagnosed member has had sperm frozen “just in case”, and another said that she had spoken to a doctor about the “baby question” and he recommended that she should freeze her eggs.
- A member asked us to sympathize with her 22 year old son. He is returning to the family home in the US, and then flying to New Zealand and staying until March, working on a golf course. “Poor little fellow, how will he cope? It’s a hard life!”
- A member was out East for a Fall Fest, and having a few Captain Morgan (summarizer’s note; that’s a type of rum) and Cokes and picking pumpkins.
- Members who had been to Houston said that it had been “really nice” to meet others in the same boat. “All of a sudden everyone understands”.
- The members who see Dr. Diamond said that he was VERY good, that he had been at the conference, and recommended that a member who would be at Memorial Sloan Kettering (MSK) should start to see him. One said that Dr. D had met her husband who is, in her words, “an acquired taste”. Apparently most doctors don’t like him “because he is a pusher and wants to get the best care for me.” Dr. D said that it was a good thing that he was in her corner. It is always better to have two sets of eyes and ears when you go to your appointments.
- Transport and accommodation facilities at MSK were mentioned. Either JFK or LaGuardia can be used for flights. MSK does not have a hotel attached, according to one member. Hotels in New York are also pretty pricey.
- A member in the trial at MSK is going soon for blood work. On his last visit he was told that he may be coming off the trial soon.
- At the conference “everyone was positive” and those who responded to V were often well enough to go way down on the drug. The LOVE study was mentioned. It is researching how to safely lower, and hopefully stop, V in those who have responded.
- The final topic of the evening centered on various members of a family whose daughter has lost most of her sight due to ECD. She and her husband have a specially built bicycle. It has a recumbent seat on the front for her, so that she can pedal. He sits behind, does the gears and brakes, and pedals too (summarizer; who steers???). The bike gets them out and about quite a bit, and it’s a great conversation piece. It works well and it helps keep strength in her legs.