

Summary Of ECDGlobalAlliance Internet Chat on 16 Nov 2013

8 Attendees

- Before the Chat started, Kathy left the following sad message.

“I am very sad to report that Bryan H, known as Jiggs in the chats, passed away peacefully on November 11th with his wife at his side. He was unable to attend chats recently due to dialysis treatment schedules. Please join me in sending our heartfelt sympathies to his wife and family. Bryan was a man of devout faith and will be missed.”
- A member told us that her husband had started interferon on the previous day with a shot to the stomach fat. There had been no reaction yet. She asked about side effects. A member, who has had interferon, said that he didn't have any side-effects (but no effects on the ECD either!). He is now taking a once a week dose of methotrexate, and has been stable for a couple of years. She was told that many (most) patients that take interferon do have side-effects, usually extreme fatigue. One member has noticed a slight reaction.....some redness and itchiness around the injection site.
- One member has never taken interferon. He didn't want to have the thrice weekly shots. He just takes Gleevec (a tablet) at night. He has been stable for a couple of years, and has no side-effects. Another member had also tried Gleevec, but it caused worsening kidney failure, so he had to stop it after 2 weeks. Members taking Gleevec were advised to make sure that their creatinine level is monitored. Another member, who takes Gleevec, has actually had a slight improvement in his kidney function.
- A member on interferon was pretty sick the first time he took it. He vomited the whole of the next day and felt terrible. But now he is only tired on the day after he takes it. Another told us that she ached a little on the next day but Tylenol “took care of it”. She also took a nap “lots of days”.

- It was said that the pegylated interferon is better tolerated. It only needs to be given once a week (as opposed to 3 times a week for ordinary interferon) as it stays in the body for longer.
- Then members were asked about their symptoms. One has ataxia (that's doctor-speak for uncoordination) and double vision, but no bone pain. Scans have shown some wedge fractures in the lower spine on a scan. The member has had some bad backaches in the past. Another also had had no bone pain.
- A member has just had a further biopsy to test his BRAF status. This has been difficult in that he can't get about well, and has to depend on his bad leg.
- A member, who has recently started Vemurafenib, is getting "better every week". This week, she had an almost "normal" schedule, having been to lunch with her bell group (she plays hand-bells), gone out of town to a concert, went to play bridge (for the first time in eight months!), got a pedicure and shopped! She was able to do all of this, after spending almost seven months confined to the recliner.

She attends Sloan-Kettering, every month, for follow up. One month she has a complete work-up with PET scan, MRI, CT, dermatologist visit, ElectroCardioGraph, labwork and a doctor visit. On the next month she "just" has an ECG, lab work and doctor visit, and she is done in less than two hours. And then she is given a month's supply of pills (\$13,500 worth!). It has "worked miracles" for her!

- Members discussed the dates on which they were going to MSK, to see whether they would be able to meet up. A member, who is going in early December has already made hotel reservations. That time of year is "crazy" in NYC.
- A member, who may be entered into the trial if his BRAF test is positive, will have to figure out the traveling. He is on the West Coast, and the trial centre is on the East! Another member is "only" 5 hours away and a short flight! One member on the trial has had a social worker assigned to her case who helped her find foundations that had grants that would help with some of the travel costs. The grant, that one member is getting, is not income based. It is based on how often you have to go to NYC. A member who is going on the trial has his hotel and train travel covered.

There is a Marriott Courtyard attached to the clinic. You can go through an interior door, from one to the other, and not have to ever get out on the street. There is also Hope Lodge, which is like a Ronald McDonald house, where you can stay for free. But this is 20+ blocks away, so you have to use the shuttle for all transport. The clinic is at 150 East 3rd street, but Sloan Kettering is an inner city hospital, and they are located all over town. There is a shuttle, that you can ride for free, from one location to another. Most things are done at the clinic, but biopsies and PET scans are at the main hospital. There are no hotels near the main hospital, so you need to make sure that you are staying somewhere close to a hospital location, so that you can ride the shuttle, and not have to pay cabs.

One member is staying downtown at Holiday Inn. It was a cheaper rate and the member knows the area. She thinks that she will be able to take the subway up to the hospital. She prefers to stay where it isn't so touristy, especially at that time of year.

- A member, whose husband has ECD, was asked about her new work arrangements. Things are working out very well. She goes into work on only 6-7 days a month now. Now she can do a lot more "Supervising" of her husband! But he still gets away with not doing any cleaning, ironing, or having to cut the grass!
- PET scans were discussed. One member said that he had never had one. A member has had quite a few scans and said that "They inject a radioactive tracer dye, and then you have to keep pretty still for an hour, because the dye goes to active cells, and they don't want your muscles to light up when they do the scan."

You are in a recliner, and can take a book, and read, during that hour. After the wait they scan you (like a big CT scanner). Afterwards, you have to keep away from children, and pregnant women, for a day or two until you've peed out the radioactive stuff! That is in the UK. In the US a member is only advised to stay away from babies for 3 hours. We were also told that "you have to use the johns at the hospital that have the "Radioactive" Warning signs, the ones with the roaches with 2 heads, and the rats with extra tails! ☺

- We were told that a member from Australia had attended the San Diego conference, and then carried on around the world to the UK. He

had visited friends and relations, and also gone to Yorkshire, in the North of England (and rated Number 3 in the recent edition of The Lonely Planet's Guide to the Best Places in the World to visit!!) to be a guest in a UK member's house!

- Members said that it had been great to meet up with each other at the conference. One said that he didn't "feel as lonely" as he did before the meeting.