

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

### **09 Jan 16**

15 Attendees

- A new member, an ECD spouse, left a message on the Chat days before it began. They are from Libyan and his wife was diagnosed with ECD in the Fall of 2013 by a Tunisian physician. In fact, it was the radiologist who suggested that it could be ECD. They traveled to Germany in the Spring of 2014, where the diagnosis was confirmed. She was given an injection of interferon 180 mg once a week.

In the last three months the pain started to spread in the bones of chest and shoulders. It is an ordeal. The pain is unbearable. She had sleepless nights crying because of her tormenting pains. She became dependent on painkillers (Tramadol) since 2013, because of the pains in her legs. Now the painkillers seem to have a very limited effect. Her chest aches even when lying in bed. Can I do anything for her ordeal? I need something to reduce her pain until I can make the arrangements to take her back to Germany to make further medical checks and to find out whether she needs an extra medication. Here in Libya we have lots of difficulties. Medical services are worsening every day because of lack of state and security. Getting a traveling visa to a western country is extremely difficult. I took her to a local hospital and took some time to explain her case to the physician, who simply told me that he has nothing to do, except suggesting some painkillers. This might explain why I can't offer my wife, such a taken-for-granted thing, a visit to the relevant physician.

Summarizer's comment: At the moment, there is a civil war in Libya with a number of factions fighting for control. Medical care has been badly affected. Medicin Sans Frontieres, the international charity health group has been trying to help. There is a great shortage of medicines, too. (Editor's comment: We are reaching out to this family to see if anything can be done to help them.)

- A member's wife left a message saying that he wasn't very well and would not be on the Chat.
- A member came on who had been taken ill during the ECDGA conference earlier this year. She has been fine since then. She leaves this week for the National Institutes of Health (NIH). Her "year is up" and she feels almost as good as she felt before ECD. She doesn't come on the Chat very often because her fingers and brain don't work well

together (Summarizer; I always blame ECD for that!). Her memory is not as good as it was, but the doctors keep saying that it is due to aging. Although the lesion in her brain is gone for now, there is still scar tissue.

- A new member, from Michigan, joined the Chat. He has been on Kineret for 4 weeks, since his initial diagnosis and "feeling good". Dr. Diamond has just confirmed that he is BRAF+. He has ECD in the bones and the abdomen. Also Dr. D said that they had "spotted a touch of it" in his heart that nobody else had picked up. Dr. D wants to see how he responds to Kineret for a few months before he starts trying the anti-BRAF drugs. Also the trial of vemurafenib (V) is now closed, so they are not taking new patients.

If he "goes with" V, his insurance would have to cover it, and he hasn't yet tried to see if they will pay. He was told that it was well worth checking. For one member his insurance didn't cover it, but as of January he is on his wife's insurance company (Empire NYSHIP) and this covers the drug 100%.

- The member whose sister has ECD told us that she was doing well and she has been sent the link to the Chat to use if she would like to.
- A member is having problems with his kidney. He has had a kidney transplant, and it appears that the ECD is affecting it. He hopes that if he gets on V, it will save the kidney. "I can't lose this one, too."

He is not on any medication yet. Things are difficult because he lives in Toronto where V is not a standard/licensed treatment. It is hoped that Canadian insurance would want to avoid the loss of another kidney. He has a CT scan of the abdomen due in the next week, and this should give a good idea of how the kidney looks.

He had originally thought he had a urinary tract infection, but the urine test came back negative. He has a constant urge to urinate. A member, who has been having V treatment himself, said that V would slow the ECD down, and that he may not need a very high dose. The members thought even 1-2 V a day can stabilize things and turn things around over time.

- A number of members were chatting about who sees Dr. Diamond. They all agreed that he was very nice.

One member got onto the V trial with Dr. D in early 2014. He has moved and now sees Dr. Kurzrock at the University of California in San Diego (UCSD), for maintenance.

He was on a dose of 6 V/day for many months during the trial, but is now down to 2/day. He considers himself to be in remission now.

Another member was on 6 V for six months and now she has gone down to 4

because of shoulder/joint issues. She hopes to get down to 2 in April when she has had all the scans that are lined up.

- The member, who had to stop ECD treatment while she had chemo for lymphoma, has recently had a PET scan. It was good, and she continues to use Kineret, which helped the most in the past.
- A member had chills, fever, double vision, and headaches and this landed him in Memorial Sloan Kettering Cancer Center's Urgent Care for a day. He was diagnosed as having sinusitis and was prescribed an antibiotic and steroid.
- A member reported that V had "definitely" taken her leg pain away, and helped her lung lesion and cerebellar lesions. She is now working on stamina and balance, although her hip does hurt sometimes.
- A woman, whose husband has recently climbed aboard the ECD "merry-go-round" came on. It was just her, because her husband was not feeling great, having come down with a cold, but he got his PET scan done that week, and so hopefully they will get some answers from that. And they hope that there will be some more blood tests. They are Canadian, and the insurance arrangements are not fully sorted out. This member also has some bladder problems. He saw his urologist last week and was told that an overactive bladder is an issue, also there is some kidney scarring, but they are still working. It was suggested that taking prostate tea might help, and also that he should stay away from caffeine products, so drink de-caffeinated tea as well. He has been advised to train his bladder and been given a diary to track his bladder activity for a few days, how often he goes and how much is passed. He was also given a pill to take, which was supposed to help. However, he is now starting to have a strange reaction to the pill at the normal dosage, and it usually affects his balance.
- Others then discussed their bladder habits. One said that he tends to go to the bathroom 2-3 times overnight, but he has a perfectly normal bladder habit during the day. He thinks that the need to get up at night is just because he is getting older.  
One described sometimes having the urge that she needs to get to the bathroom immediately. A member who has diabetes insipidus takes a nasal spray at night, so she can stay in bed.  
One told us that he used to go to the bathroom a lot during the night before V treatment.  
The new member told us that his primary physician had put him on Flomax a few years before ECD reared its ugly head. This took care of his problem with urine flow, but he still goes every hour or so, and still gets a bad urge to go.

- Members discussed whether they would be going to Paris for the conference later this year. Some are, some would like to, and some aren't able to. It has been suggested that a Skype session be looked into to connect with those who aren't actually there, so that they may feel part of the sessions.
- The Canadian patients thought that it would be a good idea to get their respective physicians in contact. They are going to exchange details.
- The LOVE study was discussed. This is Dr. Haroche's study, located in France, to see the long term effects on those who have used V for a while and then stopped. A member knows someone who stopped for 2 months but had to restart due to a flare-up.
- The topic of testosterone (T) was brought up by one of the male patients. The discussion was started by a member who asked whether a low T was a part of ECD, or was he just getting old. T was low for some of the others as well. Someone asked, whether there was any hope for getting the testosterone level back up. He was told that you can get hormone shots, also a cream and gel, although one member said that his primary had taken him off the gel after he had a few strokes.
- And finally, in reply to the message from Libya, he was told that on Facebook there is an ECD community with members from Europe and this includes a few doctors in France & England who know more than most about ECD.