Summary of ECD Global Alliance Internet Chat
24 Oct 2015

7 Attendees

- A member told us that he has been doing pretty well except for just recently. He only got out of the hospital last Tuesday, having spent a week there. He had been "filling up with fluid", and this had made it very difficult to breathe. He had stopped vemurafenib (V) for two weeks to see if that would help reduce his side effects, but it didn't. The doctor put him back on a dose of 2 in the morning and 2 in the evening this time. He is still having trouble with his hands. Another member asked whether he had tried ice or cold compresses on them. He had not used ice, but had tried some heat treatment. The other member then said that he would not use heat himself, because V generates a lot of heat on the skin surface, especially on the hands and feet. The cold treatment really takes this away. He used a cold compress or sometimes just put them into iced water for a few minutes. This treatment "was a must" for him when he was on 4-6 pills a day!
  He used to carry an ice chest to all his son's summer baseball games last year, so that he could quickly chill down the heat on his hands and feet. "Then everything was fine!"
  However, he thinks that things may be more difficult for the member who has been having symptoms for some time. And he said that the heat will come back as soon as the V is restarted. The best thing to do is to take the heat away, before it can damage nerve or tissue.

- A member, who has been on the V trial at MD Anderson for the last 2 years, told us that he was doing well. He is now taking 2+2. He is still seeing slight improvements. At first, he had a lot of the usual side effects. Reducing dosage helped with that tremendously. He still has hand and foot syndrome. He will try the cold treatment. So far, he has only used warm water soaking. His doctors gave me some Hydrocodone (a painkiller). This seems to help, but he will definitely try cold compresses.
  He asked what experiences people have had of stopping V for a short while. One said that, regarding side-effects, there should be an improvement in a couple of days, but some people have relapses within 2 months. Their symptoms begin to come back. It is going to be up to the member and his doctor whether he stops ("mostly up to the doc!"). He is on the clinical trial with a reduced dose. Dr. Janku says that they are allowed to go down to 2+2, and he thinks that if the member stops V, and then starts to have symptoms again, he can restart the V. The member thinks that he will try a reduction for a short while, maybe a month or so. It seems that most ECD patients do not need such high doses of V, and most have had their doses reduced. The high dose was the clinical trial protocol, and so the doctors had to "stick with it". He was asked to keep us posted on his progress as this will be exactly the kind of information that everyone would like to find out.

- A member who has been through the dose reduction process, said that even 2+2 is a high dose for maintenance. He and another member has found that 1+1 is good enough. He wonders whether even 1 a day might be enough, as you are trying to maintain a BRAF zero blood level, and you don't need much V to do that. He has virtually no side effects right now. He just tries "not to be in the sun too much". When he was on a high V dose, his head was always "feeling funny", and he felt like his brain was functioning slower. After he had come off everything, the "funny feeling" was gone and he could think/react much faster.

- BRAF+ patients can use either a blood or urine test to monitor BRAF levels. The blood test is about $500 (so that, even if insurance doesn't cover it, it is affordable), the urine test is close to

$2000. You can do a test every 3-4 months and it will tell you that you are having a relapse before you see symptoms. That way, you can resume the drug before the problems start.

The BIG question is whether, just like with other cancers, if you are off a drug for a while and then resume it, it will again be effective for the same disease? The answer is often “no”, for cancers. But for ECD, it seems to be “yes”; “but there could be exceptions”.

- A member said that she was “out on the town” last night with her walking sticks. A doorman asked whether she had injured herself. When she told him that she was sick, he apologized.

- Exercise was talked about. One member said that exercise is very important for him to feel better, and another has started exercising before work and this really helps. Yet another had been doing some light walking, and working in his wood shop. But he hasn't felt like doing anything for the last couple months. He was on oxygen (part- time) for about a year, and has needed this more often.

- A member said that he is due to be admitted to hospital soon to have some kidney stones removed, so he might be missing for a week or two!

- And after the Chat had finished a member came on to tell us that she is going to go to Memorial Sloan Kettering (MSK) to see Dr. Diamond. She realized, after coming home from the conference, that she has been "selling myself short" by staying with private doctors.