Summary of ECD Global Alliance Internet Chat
7 Jan 17

7 Attendees

- A new chatter started things off. She has Erdheim-Chester disease (ECD), but was diagnosed with Rosai Dorfman disease (RDD) at first. This is another really rare histiocytosis! On top of this, she also has sarcoidosis and lupus, which are not rare, but both autoimmune. She is on the COBI trial at Memorial Sloan Kettering Cancer Center (MSKCC). The Cobi is a MEK inhibitor (cobimetineb) pill given in cycles for 21 days, followed by 7 days of rest without the pill. She is on her 7th cycle.

  ECD was eventually diagnosed in June 2016. She has bone involvement in three places, one of which needed a bone graft. Before the trial, she had "a whole laundry list" of symptoms. Now, it is mostly bone pain, and in general feeling very tired, and overall not well. The treatment on the Cobi trial is working and her eyes have been okay. She has itching all the time, and this affects the skin around her eyes. She had to take a treatment break because her heart function was lower, but the doctors are now thinking that this was caused by something other than the medicine.

  Before she was diagnosed with ECD, she was getting treatments for RDD (10 months of chemo in total) at a local hospital. Now, she is still followed by a local oncologist, but Dr. Diamond drives all the care. "I love him," she writes.

  The last two years have been tough. She has had to use a crutches, wheelchair, walker, and cane. But she has been mobile for the last eight months. She lives in upstate New York (NY) and attends MSKCC.

- A French member who was diagnosed in July 2016 has ECD in the legs, lungs, and pains in the fingers. He has been on Kineret for four months. He mentioned that he has to use the Google translate service on the Chat, as his English is not quite good enough. As far as the ECD goes, he feels that he is not too bad when compared with others, but does find that he drops a lot of things. He added that we all have restrictions and he is lucky enough to be able to move around on his own. He does not need to be helped although there are certain positions that he "can no longer do."

- A member told us that she had had a cortisone injection in her left shoulder on the previous day. This was not needed because of a rotator cuff issue, but because of a cyst which had been found on an MRI done in December 2016. She has "typical 60 year old arthralgia and tendonitis" with a little labral tear, but the doctor felt that her terrible pain was from a cyst. This is the second cortisone shot in that shoulder. She has had two in the other shoulder as well, and the second one worked. She also had shots in her hands last Spring, and had surgery on one hand in early December. She started on Dabrafenib (D) 7 days ago, since the Vemurafenib (V) that she had been on was "killing my joints". More information about these medicines at http://erdheim-chester.org/treatments/.

  She had been unable to go on the COBI trial because she lives too far from NYC. She said that her local oncologist seems to have lost interest. Dr. Diamond is driving the ECD treatment, but she has many local specialists who seem only to talk to her, not to each other.

- There was discussion about what time to take your pills, how soon that you should eat or drink after or before taking them, and how long to wait between doses. The instructions being given vary between V and D.
- A member who also has changed from V to D goes for scans in late January, and will meet with Dr. Diamond. Dr. Diamond is looking to reduce the D dose, since he has been on the max dose for 6 months. He has little in the way of side-effects, just "a lot of hair gone on arms and legs".
- The French member said that he is due to go to the hospital in Paris in October for further test on his bowels. He had a colonoscopy in December, and you need to have a further examination to see if there is any transformation into cancer.
- The wife of a member said that they will be seeing more doctors in the next few weeks. He is still mainly the same (low in mood), although he has been a bit better because he is being looked after by his mother, and he has some good things to look forward to. She still thinks that his pills need reviewing.
- A new member said that he was "doing good" with his last PET scan showing "remarkable improvements". He sees Dr. Go at Mayo, and he has now been dropped from a V dose of four in the morning and four in the evening to 2+2 for maintenance. He doesn't go back for 6 months. As far as side effects go, hair loss is an issue. He did have a full head of hair, but it has thinned out. He also got several keratoacanthomas, a nasty rough skin tumor that will grow and grow ("looks like a wart to me") and originates from hair follicles. He was told they were common with V, and he had them removed.
- A message was left on the Chat site by a member, Khaki. He asked, "Anyone out there have ECD and Diabetes type II? If so please get in touch: mink77@aol.com Thanks."