Summary of ECD Global Alliance Internet Chat
09 Aug 2014

9 Attendees

- A message had been left for a member who came on the Chat site during the week. She asked for help, and was advised to contact Kathy Brewer at support@erdheim-chester.org, who will send a lot of information.

- A new Chatter came on for her first time. She has been having Anakinra shots for a month. She can't feel any difference in her condition as of yet. Her back and leg pain seem to be getting worse, and sometimes her back hurts so bad that she has to just lay straight out on her bed to get relief. "It has become a chore just to get a shower and vacuum my house." Any kind of upper body movements is very painful. Her doctor is thinking of doing an MRI of her head to see if there is any visible neurological involvement. She has a pace maker and stents. The pacemaker is MRI comparable, but she is not sure about the stents.

- The wife of a patient came on and told us that her husband has had his medication changed from Interferon to Neoral/Sandimmune 100mg twice a day. This is also known as cyclosporin- an immune suppressant used particularly in kidney transplant patients. She asked whether anyone else takes this medication.

- The member who uses the Dragon Dictate Speech Recognition program welcomed all us "cheddars". The PC must have a problem with picking up the "T" sound.

- The first topic of discussion was, as usual, the weather! There was a storm in Norway, keeping one member from going out! The UK had a BIG storm on the previous day. Today, though, it was fine. The UK summer has been so good that a lot of the farmers have got all of their harvesting done already! Ohio weather has been great for the past few days.

- Another new Chatter came on. She is from Arizona (where it's hot- surprise, surprise!), and her husband has ECD and he had asked her to join us. He was out with their 6 year old twin boys. He has been BRAF tested 3 times and is negative (so no Vemurafenib). He is waiting (on insurance appeals) to start Kineret. She had been on the caregivers chat earlier that day. She has registered, and made room arrangements for Bethesda. She and her husband would like to be there. Last year they were in "the dance of ECD diagnosis" at the time of the San Diego conference. He has major bone pain that is being mildly managed by pain medicines, and Kineret is their hope at the moment. Testing has been going on for the last 11 months. He does not have all of the most classic pathology and imaging, but he has bone pain, hormone issues, and "hairy kidneys". In the past year, they have worked with Dr. Colby, Scheel and Diamond. Bethesda "could be like a reunion."

- A member who is using Kineret and Methotrexate has recently had a PET CT which showed much improvement.

- The doctor who treats a member in the UK will be attending the Bethesda conference. He is collecting quite a number of ECD patients.

- Members said that it was “great to see the awareness developing”. The woman whose husband has ECD said that she was “always educating every medical professional” that she comes across. She then said “Poor people, they want to talk about the weather”!

- The dates of diagnosis were discussed. Two of the Chatters had been diagnosed in 2005, and one in 2011. They also gave details of their journey on “the ECD dance”. One had only had to go to two places to find out about ECD, the VA hospital in Dayton and Ohio State University Hospital in Columbus. He has been on interferon since then. Another now has his care organized by a doctor less than a half hour cab ride away!

- For one member, Dr. Diamond at MSK in NYC, has been a great resource. The member’s local docotr had reached out to him, and he has been a guide for treatment. They traveled to NYC because they have had good success with getting tissue for a biopsy. The doctors wanted a clearer picture of pathology. They went to John Hopkins for Dr. Scheel, because he is a nephrologist, and the member has “hairy kidneys”. They have also traveled to Memorial Sloan Kettering in NYC, but their primary doctor is only 8 minutes away. Having easily accessible medical care is “very nice”. She jokes that they will need to go to Paris or Milan next. In fact, the member did make it to Milan, “at least a tiny piece of his fibrosis did”. The member will be going to the NIH but a date hasn’t been set yet. Members suggested that they should both go. “Dr. Estrada, he would encourage you to go and be with your husband at the NIH.” The member’s wife said that she can help answer some of the questions about her husband’s medical history.

- A member had an MRI the day before the Chat because she felt that she was getting worse again. Luckily, everything appeared the same.

- After the Chat had finished a member came on and apologized for missing the Chat. She has been getting ready to leave for the NIH. She has still been having back pains. Therapy has been helping her shoulder with improved flexibility, but she is still having sharp pains.