Summary of ECD Global Alliance Internet Chat
13 Sep 2014

9 Attendees

- Members mentioned that the meeting in Bethesda was approaching rapidly. They were looking forward to meeting in person. The Chat covered most of the world today, from the United States, Norway, Turkey, Saudi Arabia, and Canada.

- There were 2 “first-timers” on the Chat. A woman from Florida had been originally diagnosed with Rosai-Dorfman Disease in 2012. This is another very rare histiocytic disorder (probably rarer than ECD!!). She was treated with cladiribine (2CDA) in 2012 and clofarabine for what they thought was RDD. It lowered her CD4 and immune system, but she thinks that the drugs stabilized the disease. She did not receive treatment for a year and her disease remained stable, but it has now been 'acting up'. A further biopsy made the disease look more like ECD. She has just started Anakinra injections daily. The disease is in her orbits, long bones, and left kidney. The NIH thought that she had RDD and did not accept her into the ECD program. Now, she is going to Sloan-Kettering. Her biopsy tissue favored ECD, but tested negative for BRAF, so she could not join their study either. It was them that recommended Anakinra (Kineret). The disease is affecting her vision, especially her left eye. She is also taking steroids because she has macular oedema. She will be getting an injection of Avastin next week. She asked whether other members have had similar problems, and also, whether they were on or have had similar treatments. Most have had the same symptoms and problems.

- One is currently on 2CDA (cladiribine) and has had 2 treatments so far. He had a kidney transplant in February, and lives in Canada. He had been diagnosed with retro-peritoneal fibrosis 4 years ago, and this was recently changed to a diagnosis of ECD (in May).

- A member told us that he goes to the Dayton Veterans Hospital, and gets good care there. He has ECD around his lungs, heart, aorta, and in the long bones of his arms and legs.

- A member told us about her kidney problems. She has had a nephrostomy for 11 years (a passage-way from the center of the kidney, to the surface of the abdomen or back, to allow urine to drain freely from the kidney).

- A member said that he has a small diseased area in his kidney. This shows on CT, but not on MRI. He is treated by Dr. Estrada Veras, whom works with an oncologist to control his medications. A spot has also shown up on the top of his skull.

- The other new chatter said that she was from Saudi Arabia, and that her mother in law has ECD tissue around her lungs. Initially, the doctors said that she had breast cancer, and she received one cycle of cytarabine. Then she was diagnosed with ECD. She plans to go to Sloan-Kettering to get treated.

- A member from Turkey spoke about his situation. One of his friends is ill, and he is trying to help his friend. A firm diagnosis of ECD has not been made yet, but one of the doctors has said that it could be ECD. BRAF testing is going to be done. They have visited Ataturk University, and are going to go to the Rheumatology department at İstanbul Cerrahpaşa.

- Finally, a question was raised as to whether there was a list of all who chat, and where they are from. There is no list as this would be breaking the "confidentiality" of the Chatroom. The number of Chatters, and the members who come on, vary each week (although there are a fair few "regulars"). The numbers who come to Chat also change as the seasons pass. The time of day of the Chat also changes according to where in the world you are. For those in the US it is Saturday afternoon. In the UK it is Saturday Evening, and in Australia it is VERY EARLY in the morning!