

Summary of ECD Global Alliance Internet Chat on 29 Mar2014

7 Attendees

Because the change to DST happens on different days in different countries, members have been having some difficulties sorting out the Chat time.

- A new member came on, a 63 year old man from Texas, who was diagnosed with ECD 2 years ago. He had a pericardial effusion (fluid around the heart) which was treated by having a "window" cut in the pericardium (the bag of connective tissue that the heart is in) to allow the fluid out, and take the pressure of the heart. He then had a bone scan which showed some areas of increased uptake. He has a pacemaker fitted and the doctors think that he also has diabetes insipidus. He is still working, as a trumpet player in an Orchestra! He is in the V trial and sees Dr Janku at MD Anderson. He had been found to have a tumor on his heart. His case was discussed at the monthly "tumor board" meeting'. This is a meeting of cardiologists from the 7 hospitals at Tx Medical Center. They discuss each other's more challenging cases. It was suggested that he should go to MD Anderson to see Dr. Kurzrock., an expert in ECD, and so he did. Dr. Kurzrock has now moved to the West coast, and his care was taken over by Dr Janku. He is now part of their clinical study of Vemurafenib. His latest MRI showed the tumor getting smaller. He had some side effects initially which meant that he had to stop taking V, but then restarted at a lower dose, 720mg twice daily. He said that he is "doing much better now". He has been on the treatment for 3 months. When all of this started he gained 30 lbs in 2 days! Dr Janku says that this is "normal" in ECD. The member is waiting for the day when he loses some weight! The other member on the Chat had gained a lot of weight, too. He had thought that this was due to all the steroids that he had had to take, and a lack of exercise!
- Symptoms were discussed. There was also some "trumpet talk" since the other member who was on the Chat, at that time, has been "attempting" to play the trumpet for 12 years!
- A member has ordered a recumbent exercise bike, so that he can exercise in safety.
- A member came who has also been on V for a few months. She is doing well, although her dose needed to be reduced, due to side effects. Her PET scan shows a lot of improvement in the long bones.

- A member came on and told us that the disease is spreading, according to a bone scan, although she has been on interferon for 9 months.
- Members discussed their plans for the ECD patient-family gathering later this year. Members, who had gone last year, thoroughly recommended us to attend.
- A member, who lives in Texas came on. She, and the trumpet man both go to the same hospital and both see Dr Janku. These two members will try to get together.