

Summary of ECD Global Alliance Internet Chat

25 Mar 2017

9 Attendees

- Two members mentioned weight gain and diabetes. One can't really exercise anymore, and one is a retired orchestra trumpet player. It was mentioned that playing a trumpet burns 130 calories an hour. Perhaps he should go back to work?
- Some people retain fluids because of ECD, so not all gains are "real weight" gains. If you have ever needed prednisolone (steroids) as part of your treatment for a good length of time, you will pile on the weight.
- Change of clock times was mentioned as the US had changed a week before Europe.
- A member is due to go back to Houston in late May. He takes a dose of two vemurafenib (V) in the morning and two at night. If he is still on the trial he won't be able to scale down the dose.
- One member is having problems with his bowels. Sometimes there is blood in the stool. He doesn't know if he will have to change treatment (he is on kineret). He has further examinations of his intestines scheduled for June, including a colonoscopy.
- Another member has ulcerative colitis (UC), as well as ECD. He said that he was fighting UC for many years before he went into remission 10 years ago.
- Another member said that he has been on methotrexate (MTX) for some years now and has been kept in remission, and has NO side effects! (This drug is, quite commonly, to keep rheumatoid arthritis under control.) It is an old drug, and much much cheaper than all the other stuff we use in ECD. It works by inhibiting folic acid metabolism (folic acid is one of the B vitamins), so that new cells cannot grow. It is taken just ONCE a week, and a folic acid supplement is taken on all the other days to "rescue" the other cells that need folic acid to survive. The plan is to kill the cells that are multiplying the fastest (the ECD ones!) and then help the others to cope.
- For those on V, insurance is more often covering the cost and it is possible it will cover dabrafenib (D), but still, it's not free. A member wants to be on something that, even if things change, or for some reasons he has to pay 100% out of pocket, it's still won't be too bad. The member on MTX, in remission, said that his doctors are going to keep him on it forever, and will only change if it stops working, or it starts to poison him! It can sometimes affect the liver badly. (OK so far!)
- A member has been accepted in a supportive housing environment, and will be moving there in April. They provide 24-7 care if needed, although you still retain your independence. It is wheelchair accessible, and meal prep and laundry are also provided. He is looking forward to having more independence to live. The family home is not that accessible. They have "been renovating our house" for the past 10 years; but the new place will provide more space for him to move around and be easier to do things in his own.