

Summary of ECD Global Alliance Internet Chat

12 Mar 2016

8 Attendees

- A Canadian member said that he was still trying to get hold of the medications that he needs. His doctor is going to contact Roche directly. He had heard from one of the husbands in the US, that Roche is supplying them for free under "compassionate" grounds until their insurance comes around.
- Approval is taking so long for the drug, and this is "ridiculous for something that's working so well". For cancer there is no problem in getting approval, but ECD has been "another story". If you are able to get the medicines under "compassionate" grounds then probably they will be free. If the drug is approved, people will be required to pay their co-pay portion.
- A member has returned to Norway after a holiday in Florida with her folks. Every morning, she "walked, used the exercise room, swam, and then shopping!" She did get a little tanned, but this must have been from walking about. She didn't do any sunbathing.
She has been on a dose of just 1 in the morning and 1 in the evening of vemurafenib (V) for quite a while, and now has bloodwork every 6 months or so. She hasn't had a PET scan in 1 ½ years, but has an MRI of her brain, pituitary, and spine along with her 6 month check-up. There is no radiation involved in an MRI scan.
- It was asked whether there was a standard monitoring scheme used during maintenance. During the clinical trial, a lot of scans are done. A member wants to reduce the number of scans so that he can "rest a bit and also catch up on paying my previous bills!" He has a lot of bills to pay, including those from the clinical trial and more from UCSD.
- A member in Canada gets mostly CT scans and is not a fan of this because of the radiation involved.
- The differences in the systems of finance for health services in the US and Norway were mentioned. The US patients have to pay a lot, but the Europeans pay a lot in general taxes.
- A member has just had a PET scan. He has been using interferon as his treatment for some years, and the plan is for him to continue on that treatment.
- A member came on briefly, saying that she has been off the trial medication since January. She is feeling some return of symptoms, and goes back to NIH in April.
- A member came on who was in San Francisco airport waiting to catch another flight on her return to Kentucky from New Zealand. With the time differences, she lost a day on the way out, and had gained a day coming back! And her "body has no idea what time it is".
- After the Chat Room had emptied a member came on whose husband has just started V therapy. He continues to do well, improving daily. He is still walking with a walker, but his balance is much better, and he stands sometimes not holding the walker. Tests have shown that he has achieved improvements in balance, gait, and swallowing, and he is now able to use his right hand and arm, which he couldn't do before.