

P-04-490 Antiretroviral Medication in Cardiff – Correspondence from the Petitioner to the Committee, 18.06.14.

Joerg Thieme

Petition: P-04-490

Thank you for your detailed agenda and the response of the health minister dated 12th June 2014. I wish to respond in detail:

- 1. Finally it came to light that the definite answer about waste reduction of HIV medication is unknown.**
2. The Minister mentions "national guidance on prescribing durations" but fails to mention that specifically for HIV patients the interval seen by a consultant or a nurse is 6 months. The European standard on stable patients is going towards yearly interval!
3. If a patient with HIV is not even seen by a doctor or nurse monthly how can be a monthly prescription interval be justified?
4. The Minister is arguing that prescribing policy meets patient's needs and that he was reassured by "his officials" that this is the case. The Minister has not even consulted one single HIV patient, has not even seen the HIV clinic himself. So I would ask whether his "officials" are reliable. Even I was not able to talk to the Minister in person, instead he sent his "official" to me, not having a clue what's going on. I feel betrayed.
5. The fact is that HIV is rising and that Cardiff as the capital needs urgent changes to the way it treats HIV. That is a fact that was supported by the patient advocacy team.
6. Bluntly the current prescription of a monthly interval for HIV medication is totally out of touch with reality. I am still not willing to come back to Cardiff for treatment. Instead I rather go to London where it is easier and hassle free.
7. I can only reiterate what I said before. Some people in the gynaecology department suggested a monthly prescription of HIV medication

without consulting one single HIV patient and that is sheer a disgrace! Patient representatives might have been consulted in this but they do not have a clue about the demands on HIV and the patients who have to walk through a waiting area every single month. Feeling stigmatised and guilty when passing through waiting patients just to pick up the monthly medications for the sake of it (without seeing a health care profession). I feel ashamed of this as it reminds me of treatment 20 years ago but has nothing, absolutely nothing to do with the world we live in 2014. Cardiff needs to adapt, it needs dignity for patients, it needs patients included in this process. Certainly it needs decisions not by the gynaecology consultants but by consultants who treat HIV!

8. I cannot stress enough that HIV is rising and there needs to be a change in this monthly prescription policy. My previous statement that not a single hospital in England is taking part in this monthly interval that was not even contested!
9. It might actually help if the Minister is speaking to HIV patients himself rather than relying on his "officials".