

### Petition

We call upon the National Assembly for Wales to urge the Welsh Government to act in regards to the very limited supply of antiretroviral HIV medications. Recent changes by the Cardiff University Hospital means that every single patient receiving antiretroviral medications has to come either to the hospital pharmacy with restricted opening times or opt for home delivery. Stable patients with good adherence are seen every 4-6 months for an appointment with the consultant yet distribution of medication is limited to a monthly supply only. The minister of health does not feel responsible and does not step in. Patients should receive a fair distribution of medication that is according to the guidance of the UK HIV association. Apparently the hospital wants to save costs and therefore hand out medication on a 28 days cycle. Patients on antiretroviral medication are normally stable. No consultant would prescribe medication for 6 months if there is a need to change the medication because of medical reasons. In those cases patients are seen more regularly anyway.

I cannot come to the pharmacy that's open 3 times a week from 8.30am-3pm and being forced to pick up my medication. Home delivery is not an option for me as I am not at home most days.

I have now transferred my care to London Chelsea Hospital and they are happy to prescribe medication on a 6 months interval. They have never heard of any guidelines stipulating a 28 days prescription cycle. I therefore strongly question the health minister's assumption of cost savings.



Joerg Thieme

6th February 2012

To whom it may concern,

I wish to make a formal complaint in regards to the amount of medication I am getting for antiretroviral therapy.

This month I was running out of medication and I received only 1 months worth of medication. My next appointment is in 5 weeks.

Furthermore I noticed that I am getting only 3 months worth of medication whereas my appointments are every 6 months. I am even considering having an appointment only once a year.

- I am stable and healthy
- I spare the hospital time and resources
- The current European and German guidelines tend to go towards once a year appointments and I would like to follow it

I am surprised that the hospital is facing financial difficulty as I was told. Apparently that's the reason for the once a month or every three months medication. I would much prefer a yearly subscription and a yearly attendance.

I would like to draw to your attention a FOI request (Ref FoI/12/38), there is about **£100.000** outstanding payments for foreign patients.

Nearly **£8.000.000** were spent on clinical negligence in 2011-2012. An enormous increase compared to the previous year.

1900 shifts were filled by agency nurses within the first 6 months of 2012. I estimate that the hospital has to pay about 3 times more compared to a nurse employed by the hospital. That would be roughly **£600.000** according to my estimated calculation.

There is a trend for increase in DNA, costing the hospital money that's not going to be recovered.

Considering the above points I am not happy with my treatment. I would like medication for a year and a once a year appointment. I am a Radiographer myself and in constant GP contact. I can manage my health as it's all good for many years.

Can you please investigate. I think if the hospital is more relaxed about appointments and medical prescription it would save costs and free space for more patients.

kind regards

Joerg Thieme

Hello Cathy

I understand you are supporting a action to keep HIV medication provided at current levels of six months for patients.

I hope you do not mind me mailing you but I have an issue that I fear needs addressing.

For nearly 5 years now I have been receiving HIV medication from the CRI after a diagnosis over 10 years ago. Over the last few years I have had no luck in finding a job in my area leading to me looking outside of Cardiff. currently I work abroad from 2 months up to 6 months at a time. (I have to return 6 monthly for my HIV levels to be checked at the CRI.

I have found going on medication very disturbing and in fact became very depressed shortly after starting the regime. However after a while it became easier and easier. I was visiting the clinic every six months which I found easier as it was every month when I first started medication and that was intimidating.

It was a great relief when the hospital said that I could have my meds every 6 months as I felt less stigmatised and also more comfortable. It also enabled me to look for work and finally find a post that means I will have to work abroad for considerable amount of time. as I do not work and live abroad permanently as the contracts can be 2 or even 5 months long it is impossible for me to get my medication and have a consistent care plan in another country and I do not want to be forced to out my status to people or employers that do not need to know. I feel like I am being made to beg for this medication, I have thought about stopping the medication all together but I have been advised that I will become ill if I stop.

Now I am told that I will have to get my medication every month from the CRI which means I have to suffer the stigma of visiting again and again. The medication service did send my medication to my home address once and my house mate opened my box of meds and as a result now is fully aware of my HIV status. I was not aware of this until I returned home to a quite angry flat mate who started to say I had no right to keep this info from her.

I found this so upsetting as it is nothing to do with the people I share a house with. it is becoming more and more stressful and I am feeling like I am being forced to leave my job after a long time in unemployment. This job has made me feel so much better about myself, and I think has helped me to come to terms at last with my status.

I hope I make my plight clear to you and hope you can present this as an argument for keeping the medication at the levels I have been used to.

regards