

## P-04-460 Lives not Airports

Petition wording:

We call upon the National Assembly for Wales to urge the Welsh Government to consider the following.

Procedures currently in place that decide case by case the delivery of specialised medicines to patients through the Welsh Health Special Services Committee (WHSSC) are fundamentally flawed, damaging and extremely distressing to patients. New protocols and procedures are now required as a **matter of urgency...The Welsh Government must review** the whole procedure of allocating specialised medicines to patients. The system needs to be made far simpler to navigate. Doctors must have more say in the decision making **process as they are the best judge of a 'patients' needs. Alternative ways to** fund medicines, such as negotiating with manufacturers more realistic pricing structures and the possibility of individual short term free trials should be looked at.

Supporting Information:

Further details of the problems we see and our proposals are as follows...

1. When the WHSSC assess a requested drug the recommendations from the All Wales Medicines Strategy Group (AWMSG) should be no more than 18 months old. This is due to the fact those that are years old do not have a reliable bench mark. Reliable data for all medicines improve day by day as case studies multiply. The WHSSC should have the right to request an up to date review from the AWMSG and this should be carried out as a matter of urgency.
2. When the WHSSC declines a request for a medicine an appeals process is then initiated in which the patient, doctors or an advocate can be present but none are allowed to speak. This must not continue therefore the WHSSC should by law be required to hear the case with the full participation of the patient, doctors or advocate.
3. In many cases patients are extremely ill, alone and vulnerable. It should be a priority to make sure such patients have an advocate to help them through the procedures in place for the funding of medicines. Doctors have large case loads so are unable to give extra time to patients.
4. A review of the actual costs of specialized medicines that have been refused and the subsequent hospital admissions, alternative treatment costs should be carried out. This would be beneficial to determine the true costs of specialized medicines to the tax payers.

5. The WHSSC should have the power to grant a medicine if the medical teams have concluded that all other treatments have failed and that the said medicine in their opinion has a chance to benefit the patient.

6. The WHSSC should be given the option to at least give a patient a trial run with a drug to ascertain if a positive result could be expected.

Petition raised by: Jeremy Derl-Davis

Date petition first considered by Committee: 19 March 2013

Number of signatures: 51