

P-04-460 Lives not Airports – Correspondence from the petitioner to the Chair, 02.10.2013

LIVES NOT AIRPORTS Petition
A response to your letter dated 26th June 2013

Members of the Petitions Committee in December 2009 a 29 year old woman was given a stark reminder of how fragile life can be when diagnosed with a large brain tumour. From that moment to this a myriad of red tape, governmental bodies and procedures have precluded the use of a proven highly specialized drug that has a real possibility to increase the quality and substantially prolong her life. Our petition /campaign is not about this particular case, more it is designed to eliminate uncertainty, fear and above all deliver required treatments to those who desperately need them.

Why is this happening? many patients I have spoken with over the last few years have asked...The answer is simple “money”. The AWMSG has the remit to look at and make recommendations as to the distribution of rare drugs that have no recommendation from NICE. This said as in the case of Kaldeco the Welsh Government has and can overturn negative recommendations. If you were to be cynical the Kaldeco affair could be seen as a highly popular government intervention that avoided a massive public backlash.

I will not go over our petitions aims as they are well known to you I will only suggest that it has to be the right of any patient in Wales to be sure that their clinicians’ recommendations will be acted on when they have clearly stated there are no alternative treatments. All licensed treatments must be available to people without the need for endless paperwork and twists and turns. If this is seen as an open ended money drain it is worth looking at the costs of not treating patients. Twenty four hours hospital care is very expensive and in many cases is the end result of not delivering the right treatment.

Sometimes in politics the right decision is hard to make but as I have found in the stories of many frightened, vulnerable and desperate patients, this state of affairs does not belong and has no place in our society. Rapid action is needed now as a day to some can be a lifetime to others.

On a more personal note I find it very difficult to watch my 33 year old wife slowly deteriorate and lose hope. If as may be the case, if not rapidly treated, she loses her fight my reactions will be even swifter and highly public as we do not want this situation continuing for other patients and their families.

I hope you will keep me informed as to the next steps and invite me to give evidence at the earliest opportunity.

I thank you all for your hard work and consideration.

Jeremy Derl-Davis