

18 February 2013

PE1448/petitioner's consolidated response

Public Petitions Committee
Scottish Parliament
EDINBURGH
EH99 1SP

Dear Sirs,

Re. Petition PE 1448 –

Calling on the Scottish Parliament to urge the Scottish Government to raise awareness of the links between organ transplantation and cancer by providing appropriate guidance and education to medical professionals, patients, their families and carers; to improve health warning and patient information on the cancer risks associated with the long term use of immuno-suppressant medications and to introduce regular dermatological clinics for these patients to improve on early skin cancer screening and detection levels.

Note: - amended following receipt of late response to Committee from NHS Lothian dated 13th February 2013.

I am in receipt of the responses received to date from the various organisations and NHS Scotland Health Boards written to by the Public Petitions Committee following consideration of my petition and evidence at the Parliament on Tuesday 11th December 2012.

The following is my consolidated response to the above, to be submitted to the Petitions Committee no later than 8th February 2012, for their further consideration on 18th February 2012.

My initial action must be to convey my extreme disappointment at the poor response received from the various Health Boards in respect of this petition.

The Committee wrote to all 14 regional NHS Boards in Scotland following the initial consideration on the 11th of December 2012 and, at time of writing this letter, there have been only 6 responses received.

I am dismayed by the lack of importance attached to the issues raised in the petition by the 8 Boards who elected not to respond to the Committee and feel that this reflects my own first-hand experience that there is a great deal of ignorance within the medical profession in Scotland in respect of the matters raised in the petition.

Particularly disappointing is the lack of response from NHS Lanarkshire - the Authority that treated the petitioner's deceased partner – particularly as the author has been advised by a GP in the region that a dermatology clinic has now been established for transplant patients at Monklands hospital since Sharon Argue's death.

As I am required to keep this response to 3 pages I will not labour the point however I would hope the Committee would agree with me in saying that the lack of response from the Boards is a completely unacceptable situation given the seriousness of the subject under consideration?

Of the 6 responses from NHS Boards that were received, I note that all confirm transplant patients within the respective areas receive advice on the high risks of skin cancer associated with transplantation and long-term immuno-suppressant therapy. I also note that dermatological screening clinics are offered to patients within these areas. Should the conclusion be drawn that the 8 Boards that failed to respond do not offer the same levels of patient care?

While I welcome this information I must however record my disappointment that not one of the responses received addresses the issue raised in the petition of the inadequacy of the patient information provided with immuno-suppressant medication. I feel this also indicates an unacceptable lack of awareness within the NHS as to how potentially harmful these medications can be for people requiring to take them over long periods.

I would also wish to highlight particular disappointment with the response received from the BMA Scotland. I find it astonishing to note that the British Medical Association can write that “the risks of long-term use of immunosuppressants and the lack of awareness of this...is not something the BMA has a policy on.” Further, the response goes on to offer the equally unenlightening opinion that “It also seems sensible to ensure that medical practitioners treating patients post-transplant are aware of any evidence of a link and are able to take steps...to increase the chance of early diagnosis”.

What I want to see – and what I hope the Committee will support me in campaigning for - is a definitive code of practice introduced and implemented throughout the entire country that DOES ensure ALL medical practitioners are made aware of the risks of immunosuppression - and not just for transplant patients - and that “taking steps to increase the chance of early diagnosis” is something that becomes a CRITICAL and CLEARLY DEFINED element of care in post-transplant AND ALL OTHER immuno-suppressed patients, not something that is left to chance, depending on a patient's postcode and on which hospital/G.P. they attend for their treatment.

On this note, I welcome the response from NHSBT who state in their reply that although development and implementation of clinical guidelines is not within their statutory responsibility, they are nevertheless “very keen” and “well placed” to work with professional and statutory bodies to help develop and publicise such guidance. This response is very encouraging, as is that from NHS Dumfries and Galloway, who have made provision for patients to be seen by a Dermatologist within a matter of days should any concerning skin malignancies or lesion be discovered/develop between routine consultations.

I also welcome the response from NHS Lothian and it appears that there are systems in place in certain regions to address the high risk the transplant community faces from skin cancer. However, I must temper this by stating to the Committee that it is my suspicion that what is stated as a matter of policy may not reflect what happens in practice. Shortly after I launched our campaign I had a discussion via Facebook with a woman who contacted me to discuss the case of her friend, a transplant patient being treated in Edinburgh. She advised me that she had spoken to her friend about Sharon Argue's story and her friend had informed her that prior to her own transplant she had indeed been aware of the risks she was at of developing skin cancer however she also added that she had never once seen a dermatologist nor had a skin inspection since her operation several years prior. Further, she added that she had no idea what sort of things she should be looking for on her own skin. I can provide this evidence to the Committee if requested.

To conclude I would respectfully call upon the Committee to continue to support the aims of Petition PE 1448 as I believe the above demonstrates the situation in many areas of Scotland is far from adequate for organ recipients and other immuno-suppressed patients.

I would also welcome the opportunity to provide further evidence on these matters to the Committee, should they (the Committee) feel this would be beneficial.

Yours faithfully

Grant Thomson
Petitioner (PE 1448)