15 April 2013

PE1448/petitioner's consolidated response(2)

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.

I am in receipt of the additional responses received to date from the various organisations and NHS Scotland Health Boards written to again by the Public Petitions Committee following further consideration of my petition at the Parliament on Tuesday 19th February 2013.

The following is my consolidated response to the above, and although I appreciate this response may be submitted too late in order to be considered by the Committee at its next sitting on 16th April 2013, I would request that it nevertheless be recorded and held on record in relation to this petition. I would also respectfully request that this late response does reflect negatively on my continued commitment to the petition.

Since the previous sitting of the committee regarding PE 1448 there have been a further six responses received from the organisations originally contacted by the Committee. Five of these have been from NHS Boards that did not respond to the initial enquiry in late 2012, with the remaining response coming from the Scottish Government's Scottish Transplant Group (STG). The STG did respond initially to the Committee's first enquiry and this second response was issued following further consideration of the petition's aims at the STG's meeting held on 20th March 2013.

Of the 5 responses received from NHS Boards, that issued by NHS Grampian was the most positive in its' content.

The responses from NHS Borders, Forth Valley, Orkney and Shetland are disappointing. NHS Borders has provided a single paragraph advising that transplants are not carried out within the region and that, basically, the matter is someone else's concern. NHS Forth

Valley have also stressed that transplants are not carried out within the region and have then quoted part of the Greater Glasgow and Clyde response that was made to the Committee following the first enquiry in December 2012.

NHS Shetland responded merely to advise the Committee that they are declining to comment on the matter. I note their response was not even provided on an NHS letterhead!

NHS Orkney has likewise provided a cursory single paragraph response (again on a non-identifiable letterhead) that pretty much states that organ transplantation and follow-up patient care is someone else's problem.

Rather depressingly, I am not surprised by this detached attitude as it is exactly what our family has encountered from NHS Lanarkshire and is, I believe, the primary reason why patients such as the petitioner's late partner, are 'slipping through the net' and who's lives are being cut short through what is a basic ignorance of the issues surrounding their medical problems within certain NHS regions in the country. I would caveat the above and say that while I am not surprised, I am most certainly appalled by this state of affairs.

I feel more strongly than ever that this situation is totally unacceptable and must be resolved most urgently.

I believe the information provided in the detailed responses from the STG, NHS Grampian and those responses received previously from NHS Lothian & Borders and NHS Greater Glasgow & Clyde should have been the level of response received from ALL NHS Boards. The fact that it is not – indeed, 3 Boards have yet to respond at all to the Committee, one of which is NHS Lanarkshire – shows that a nationwide direction is required in this matter in order to rectify what is a seriously worrying situation.

I commend the STG and the NHS Boards that responded with proactive responses to this petition and I note that both the STG and NHS Lothian tacitly recognise in their responses that certain NHS Authorities are not 'up to scratch' in terms of how transplant patients are informed and monitored pre- and post- operation. The STG have said they intend to write to all Transplant units to reinforce the seriousness of the issues raised in the petition and while this is a positive move on the part of the STG I can't help but feel it will still fall on deaf ears in some parts of the NHS.

As such I would respectfully call upon the Committee to continue to support the aims of Petition PE 1448 as I believe stronger measures are required in order to make sure the message 'gets across'. I believe there should be a clearly defined nationwide policy that is set by the STG, NHS Lothian and Borders and NHS Greater Glasgow and Clyde (the two transplant centres in Scotland). I believe there should be a standard nationwide policy for transplantation information and post-operation follow-up care and monitoring that *ALL NHS BOARDS* are required *BY STATUTE* to implement and I would like to thank the Committee for its continued support over the previous few months in helping address the current unsatisfactory state of affairs.

I would like to close this response with an apology in advance for being unable to attend the next sitting of the Committee on 16th April 2013 as unavoidable work commitments prevent me from attending in person however I would like to stress that this in no way reflects a lack of commitment on my part to continuing to push for positive change in respect of this petition.

Yours faithfully

Grant Thomson
Petitioner (PE 1448)