

14 June 2013

PE1448/petitioner's consolidated response(3)(amended)

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 response received from Professor John Forsythe – Lead Clinician for Organ Donation and Transplantation for the Scottish Government – and comment as follows: -

From a personal point of view, Professor Forsythe's response is rather depressing. The Professor writes that it is well known that immunosuppression, in general, raises the risk of certain types of cancer and that this has been studied by individual transplant centres and international registries.

From my own research carried out since Sharon Argue's death in July 2012 I too have found out that the issue of immunosuppression and malignancy is well known. However, what I have also found out – not only through the responses received from several NHS Boards in Scotland in the course of this Petition but also from harsh personal experience – is that there are large parts of the Health Service that are unaware of the extent of the immunosuppression/malignancy link.

I note that Professor Forsythe states that the three Scottish Transplant units and the unit in Newcastle that undertakes transplants on Scottish patients have all confirmed to him that they have implemented the recommendations set out in Professor Forsythe's previous letter to the Committee. This is well and good however there are two questions arising from this that I feel require further attention, namely: -

1. For how long have the measures detailed in Professor Forsythe's previous response been implemented by these centres? That is, have these measures been standard protocol

in these centres for a long period of time or have they been implemented recently as a result of the Professor's recent enquiries resulting from this petition?

My own thoughts are that the answer would be a. – that these measures have been long established at these centres. Which begs the question, what about the other NHS regions that, although not transplant centres, provide aftercare for transplant patients?

I am of course referring specifically to NHS Lanarkshire but this concern is by no means restricted to that sole authority as the quality – or lack of – in some of the responses made to the Committee by other Authorities/Boards leaves much to be desired.

The second question then leads on from the first, if the Scottish Transplant centres are so switched on about the matters raised in this petition then why is the dissemination of this information and knowledge to the other NHS Boards in Scotland seemingly a matter of chance?

Further, my family's own personal experience would also indicate a wider level of ignorance amongst medical professionals in general regarding the immunosuppression/malignancy risk. Sharon Argue was treated by three different Doctors in a ten-day period leading up to her hospital admission in July 2012 (two General Practitioners and a Consultant Nephrologist). Despite her obvious severe ill health, not one of these Doctors managed to link the fact that she had a cancerous tumour on her ear to her medical background. I believe part of the problem is the lack of information issued with the immunosuppressant medication itself and was one of the three points initially addressed in this petition although this has somewhat fallen off the radar as the main emphasis to date in the responses made by the various organisations approached by the Committee have focussed on purely transplantation and follow-up care.

I feel the time is now right to bring this matter back to the forefront of this campaign. The bottom line is that these medications are as toxic to health as many of the carcinogens found in tobacco yet it is not publicised enough. Any doctor will be able to tell their patients of the risks that smoking tobacco presents to their health yet how many GPs are aware of just how potentially dangerous Ciclosporine and similar medications are to human health? Statistics show that smokers are 50 times more likely than the general non-smoking population to contract lung cancer yet the risk to transplant patients of developing skin malignancies as a result of long term immunosuppression treatment is estimated by many trusted medical research sources to be even greater than this. Yet doctors in this country are prescribing these medications without this knowledge and understanding. This needs to be addressed urgently to make sure more lives are not lost. Firstly, a warning should be flagged on a patient's medical file that as a result of being prescribed these medications they are at severe high risk of developing skin malignancies. As such, GPs should be made aware that patients should be checked for any suspicious skin lesions regularly and that patients themselves should be constantly reminded to self-check for any warning signs.

Taking things further, I strongly hope that the Scottish Government and the Scottish medical community itself, can lobby the manufacturers of these medications in order to have them improve the health warnings and patient information provided with their products.

If these pharmaceutical companies do not comply in a spirit of co-operation and with the aim of betterment of public health then I would hope the Government would be motivated to enforce measures– as has been done over the years with tobacco companies – to force them to improve their patient literature.

I continue to feel strongly that the situation today is still not much different to twelve months ago and as such remains unacceptable and must be resolved most urgently.

I reiterate what was written in my previous consolidated response to the Committee - that the measures implemented by the Scottish Transplant centres in respect of patient education and follow-up care should be the benchmark level of care provided by ALL NHS Boards.

I would like to commend Professor Forsythe for his proactive responses to date to this petition and I would hope that both The Scottish Government and the Committee will recognise there remains much work to be done in this area and, as such, continue to support the aims of Petition PE 1448.

I would conclude by thanking the Committee for it's continued support with this Petition whilst also recording my continued disgust with NHS Lanarkshire for not having the decency to yet make a single response on this matter, despite repeated requests.

Yours faithfully

Grant Thomson
Petitioner (PE 1448)