PE1448/E

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The Scottish Government

David Stewart MSP Convener Public Petitions Committee T3.40 The Scottish Parliament Edinburgh EH99 1SP



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Dear David

CONSIDERATION OF PETITION PE1448: IMPROVING AWARENESS OF THE CANCER RISKS IN ORGAN TRANSPLANTATION.

Thank you for your clerk's letter of 14 December seeking the views of the Scottish Government and the Scottish Transplant Group (STG) on improving awareness of the cancer risks in organ transplantation.

You will be aware that the remit of the STG is to give advice and make recommendations to the Scottish Government on matters relating to organ and tissue donation and transplantation and to oversee the implementation in Scotland of the recommendations from the first report of the UK Organ Donation Taskforce. In response to an item of ministerial correspondence regarding Petition PE1448, I asked that the matter be discussed at the December 2012 meeting of the STG. My officials have provided feedback on that discussion which is included in this response. Please, therefore, consider this letter to be a response from both the Scottish Government, and the STG.

Firstly however, I would like to state how sad I was to learn of the premature death from skin cancer of the petitioner's partner in summer 2012, following a successful kidney transplant in 2004. Transplantation has huge advantages over other treatments for organ failure. It does carry risks but it also saves a great many lives which would otherwise be lost.

There are three transplant units in Scotland. The transplant unit at the Royal Infirmary of Edinburgh which undertakes liver, kidney, pancreas and islet cell transplants; the kidney transplant unit at the Western Infirmary in Glasgow; and the heart transplant unit at the Golden Jubilee National Hospital in Clydebank. All 3 units are represented on the STG by a consultant transplant surgeon and a consultant transplant physician.







My officials have advised me that when this matter was discussed at the December meeting of the STG, representatives of all Scottish transplant units confirmed that:

- the risks and benefits of transplants, including the side-effects of essential immunosuppressive drug therapy are always discussed with patients before any operation takes place;
- information on the importance of good skin care and protecting skin from exposure to the sun is included in written patient information provided to all patients on admission and discharge from hospital;
- patients are encouraged to undertake skin surveillance regularly and to report any suspicious lesions immediately to their GP or to the transplant team;
- all those involved in the follow-up care of patients post-transplant are aware of the risks and recognise the importance of ensuring patients are referred for specialised dermatological care as required;
- transplant units have developed links with dermatology staff with an interest in the dermatological management of transplant patients post-operatively.

Two of the three patient representatives on the Scottish Transplant Group were present at the meeting and both confirmed that prior to their transplant operations the risks had been fully explained to them. They had also been provided with written advice on admission and discharge. The third patient representative was not present but has subsequently confirmed that the risks of skin cancer were clearly explained to him at the time of his transplant and that he has been reminded of the importance of being careful in the sun at a subsequent follow up clinic.

I'm assured that the STG gave serious consideration to this issue. The Group is aware that the quantity of information given to patients and their families when being assessed for a transplant is great, and the setting in which it is received can be very stressful. Transplant units therefore ensure that information relating to the risks and benefits of transplants, including the side-effects of immuno-suppressant therapy, are repeated in written literature as well as being discussed in person. In terms of further actions, the Chair asked the patient representatives to review the written patient information provided at each transplant centre to ensure that it is accurate and up to date, and to report back to the Group with their findings at the next meeting in March 2013.

There is clearly a separate issue about awareness across the wider NHS of the potential long term health effects following transplantation. We would expect that those professionals closely involved in transplantation would be aware of the potential risks but that is not necessarily the case for other clinicians. Given how relatively rare transplantation actually is in Scotland – with only 346 transplants taking place last year – many clinicians will never come across a transplant recipient throughout their professional career. It can therefore be difficult to ensure all professionals are aware of the risks and that knowledge is up to date. I will ask the STG to give consideration to what more, if anything, can be done on this issue.

MICHAEL MATHESON





