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Fergus D Cochrane Esq  
Clerk to the Committee  
Public Petitions Committee  
TG.01  
The Scottish Parliament  
Edinburgh  
EH99 1SP

Your ref: Petition PE1056  
8 November 2007

Dear Fergus,

**CONSIDERATION OF PETITION PE1056 (DEEP VEIN THROMBOSIS)**

I'm replying to your letter of 3 October to Roy Sturrock in which you asked for the Scottish Government's views on this Petition. I note that you have also asked for views from NHS Quality Improvement Scotland, the Scottish Intercollegiate Guidelines Network, LifeBlood, and the National Screening Committee.

The Scottish Public Services Ombudsman's report of her investigation into the complaint brought by the McPherson family against NHS Lothian following the death of Katie McPherson from deep vein thrombosis (DVT) recommended that consideration should be given to the need for Scotland-wide guidance on the management of DVT, and that a patient information leaflet should be integrated into any such guidance.

In order to take forward that recommendation, the Scottish Government commissioned NHS Quality Improvement Scotland (NHS QIS) to carry out a stock take of all guidance and audit material relating to Venous Thromboembolism Prevention and Treatment in NHSScotland. The report of the stocktake, which has been shared with the McPherson family, showed variations in the existence of written, up to date protocols and policies for the prevention and management of deep vein thrombosis (DVT) within NHSScotland.

The Chief Medical Officer and the Chairman of NHS QIS have therefore agreed to write jointly to NHS Boards requiring them, as a matter of urgency, to address the need for written policies for the prevention and management of DVT, based on the relevant SIGN Guidelines. Boards will also be asked to provide NHS QIS with a response within 2 months of the date of the letter, setting out the action they will be taking to implement the measures detailed in it.

The NHS QIS stock-take also showed variation in the availability of patient information materials. From the survey of leaflets undertaken as part of the stock-take, those used at Glasgow Royal Infirmary for patients attending either the hospital's A&E department or its outpatient DVT service with a suspected DVT were considered to represent the best starting point. These are being adapted to make sure that they are as easily comprehensible as possible and a copy of the revised leaflets will be sent to NHS Boards with the letter from the CMO and the chair of NHS QIS. Allowances clearly need to be made for local variations to take account of contact details and the existence or otherwise of local DVT services, but in the interests of consistency, all NHS Boards will be expected to use these leaflets instead of local leaflets.

We will want to make sure that the revised leaflets give the emphasis which the McPherson family is looking for to the fact that there is no definitive test for DVT, and to the need to consider family history in reaching a diagnosis.

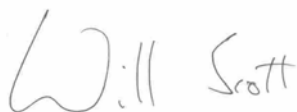
The McPherson family will be given an opportunity to comment on both the letter and the accompanying leaflets before these are sent to CMO and the chair of NHS QIS for signature.

The Scottish Government has also provided *Lifeblood the Thrombosis Charity* with funding to assist them with the development of a more general patient information leaflet on DVT. The aim of the leaflet is to promote awareness of thrombosis and to increase understanding of its causes, effects and the treatment available. I understand that a draft of the leaflet is expected to be ready by the end of the year. Our funding was conditional on Lifeblood involving the McPherson family in the process, and the charity has assured us that this condition has been met.

We understand that the issue of neonatal screening for Factor V Leiden has not been discussed by the National Screening Committee for the specific reason that the defect does not cause problems in babies and children, and there is considerable uncertainty about the implications of a positive test. It is not considered good practice to carry out genetic tests on children unless this is deemed to be of immediate value to the child. Where late onset disorders are concerned, geneticists (and ethicists) consider that the child has the right to decide for themselves whether or not they want such a test, when the time is appropriate. We have had a meeting with the McPherson family to explain the position to them.

I hope the information in this letter is of assistance to the Committee in its further consideration of the Petition. Its terms have been cleared with the Minister for Public Health.

Yours sincerely,



**W S SCOTT**