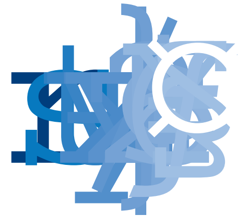

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Fergus D Cochrane Esq
Clerk to the Committee
Public Petitions Committee
TG.01
The Scottish Parliament
Edinburgh
EH99 1SP

Your ref: Petition PE1056
5 March 2008

Dear Fergus,

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

I'm replying to your letter of 30 January to Roy Sturrock in which you asked for an update from the Scottish Government on this Petition. I note that you have also asked for views from NHS Quality Improvement Scotland and the National Screening Committee.

The Committee is of course aware that the Scottish Public Services Ombudsman's report of her investigation into the complaint brought by the McPherson family 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 my letter to you of 8 November, I advised that the Chief Medical Officer and the Chairman of NHS QIS had 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. That letter, a copy of which is attached, issued on 26 January, and NHS Boards are required to provide a response to NHS Quality Improvement Scotland, by Friday 28 March 2008 on the action they have taken. The fact that replies should go to the Chief Executive of NHS QIS is intended to highlight for Boards the seriousness of the issue. As the Committee will see, the letter also attached patient information leaflets which are intended to be used as standard across Scotland. These emphasise the McPhersons' main concern, that there is no definitive test for DVT. The McPherson family were given the opportunity to comment on both the content of the letter and the accompanying leaflets before these were issued and indicated that they were satisfied with them.

The Committee will also be aware that 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.

The content of the leaflet has been finalised, again with direct input from the McPherson family. The leaflet is in the process of being printed, and we have made arrangements for its distribution to general practices across Scotland.

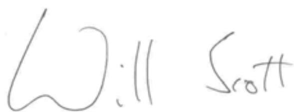
You also asked me to address the complaint set out in the McPhersons' email of 19 February to the Health Directorates, that the leaflet is not being issued in the name of the Scottish Government. We have explained to the McPhersons that it is not appropriate for the Scottish Government to produce information leaflets on specific clinical conditions such as DVT, since that is the responsibility of SIGN. Production of the leaflet by a third sector organisation through Government funding and with direct involvement of stakeholders seems consistent with the approach set out in the Better Health, Better Care Action Plan. In our view, *Lifeblood* is well placed to develop this leaflet, given it standing as the leading thrombosis charity in the UK. The letter from CMO and the Chair of NHS QIS indicates endorsement of the leaflet.

It is of course for SIGN and NHS Quality Improvement Scotland to deal with the point about the timescale for the process of revising the Guideline. Our concern has been to put in place measures to cover the interm period until the revised SIGN Guideline is in place.

On the issue of neonatal screening for Factor V Leiden, there is nothing further I can add to the comments in my letter of 8 November 2007.

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**

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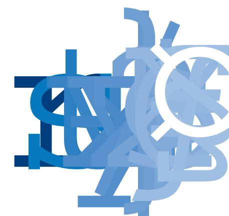

Chief Executives, NHS Boards
Medical Directors, NHS Boards

Copy to: Chairs, NHS Boards
Directors of Nursing, NHS Boards
Consultants in A&E Medicine
General Practitioners
Scottish Public Services Ombudsman

**Further enquiries:**
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26 January 2008

Dear Colleague,

**Management of Deep Vein Thrombosis (DVT)**

As you may be aware, the Scottish Public Services Ombudsman (SPSO) investigated a complaint by Gordon McPherson against NHS Lothian following the death of his daughter Katie from deep vein thrombosis (DVT). The Ombudsman's report raised two general concerns, one of which was the apparent lack of an integrated care pathway for those patients in Scotland who present at facilities operated by different NHS Boards. Work to address that recommendation is in hand. This letter is concerned with the other general point, which was 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 the implementation of this recommendation, the Scottish Government Health Directorates asked NHS Quality Improvement Scotland to commission a stock-take of guidance and audit relating to Venous Thromboembolism (VTE) prevention and treatment in NHSScotland. This was undertaken on NHS QIS's behalf by the Thrombosis: risk and economic assessment of thrombophilia screening (TREATS) Research Group. A copy of the Group's report is attached.

As you will see, the report reveals variations in the existence of written, up-to-date protocols and policies for the prevention and management of deep vein thrombosis in the four relevant specialties across NHSScotland. In obstetrics and gynaecology, all Boards reported that they had protocols or policies, but some of these had been developed up to 10 years

previously. In the three other relevant specialties - medicine, orthopaedics and general surgery - the existence of protocols and polices varied across NHSScotland. This is unacceptable, given the existence for many years of evidence-based advice on the prevention of DVT.

The stock-take also reveals variation in the availability of patient information materials, and this is of particular concern given the specific recommendation on this point in the Ombudsman's report. NHS Boards should therefore address the requirement for written policies for prevention and management of DVT as a matter of urgency, based on SIGN Guideline 36 on the Management of VTE and Guideline 62 on Prophylaxis of VTE. A response on the action taken by NHS Boards should be sent to Dr David Steel, Chief Executive, NHS Quality Improvement Scotland, Elliott House, Edinburgh EH7 5EA by **Friday 28 March 2008**.

NHS Boards also need to ensure that consistent and accessible patient information is available. From the survey of leaflets undertaken as part of the stock-take, those used at Glasgow Royal Infirmary for patients attending with a suspected DVT were considered to represent the best starting point. These have now been adapted to make sure they are as easily comprehensible as possible, and a copy of the revised leaflets is also attached to this letter. Allowance clearly needs to be made for local variations such as contact details and the existence or otherwise of a local DVT service. In the interests of consistency, however, **all NHS Boards are expected to use the text of the leaflets attached instead of the local leaflets they may have been using up until now**. (Boards are however free to design the leaflets to suit their "house style".) These leaflets give proper emphasis to the fact that there is no definitive test for DVT. The consistent use of these leaflets across NHSScotland will also contribute to addressing the Ombudsman's other main concern about the need for integrated care pathways across NHS Boards.

The Scottish Government has also commissioned Lifeblood, the thrombosis charity, to develop a general information leaflet on DVT, which should be finalised in the near future. We will expect GPs, local DVT services and A&E departments to make people aware of this leaflet and to display it so that it is available to the general public.

In the longer term, NHS QIS will address the recommendation for the development of clinical standards. SIGN is currently developing a revised Guideline on the investigation and management in both primary and secondary care of VTE dealing with the diagnosis and treatment of patients with suspected (symptomatic) DVT or pulmonary embolism. The Guideline will cover pregnant women and adolescents but exclude children. The Guideline development group will, amongst other issues, address the evidence on clinical predictors for VTE, including family history, and the optimal time within which people should return for further investigation should their symptoms fail to resolve. Publication of the revised Guideline is expected during 2009.

Yours faithfully,

***Dr Harry Burns*** ***Sir Graham Teasdale***

Dr Harry Burns
Chief Medical Officer

Sir Graham Teasdale
Chairman, NHS QIS

# Emergency Department Leaflet

## *Discharge advice for patients following attendance with a possible clot in the leg (Deep Venous Thrombosis ~ DVT)*

You have been assessed today (date: ___ / ___ / ___) for a possible blood clot in your leg(s) using a clinical examination and blood test. The results suggest that you are very unlikely to have such a clot.

### *Why is my leg sore or swollen then?*

You may have been given a specific explanation for this. However, if there is no other obvious cause, the most common explanation is a muscle injury which should go away over the next week.

### *Can I still have a clot?*

The blood test and clinical examination system we use can never completely exclude a clot. The chance of us failing to detect a clot has however been estimated to be very low, (typically less than 1 in 200 for people like yourself who have a sore leg).

### *Why didn't I get blood thinning drugs?*

This treatment is not without risks, such as bleeding. Although these risks are uncommon, they mean we should use the drugs only when there is a clear benefit to outweigh these risks.

### *Why did I not get any other tests (e.g. an ultrasound scan)?*

We feel this is unnecessary because your chance of having a clot is so low.

However, since we can never fully exclude the possibility of a clot (DVT), and in the interests of your own health, **you are advised to return to the A&E Department for further assessment** (and possibly an ultrasound scan) **in certain circumstances – see below.**

***What should I look out for?***

- Increased pain or swelling in the leg
- Sudden onset of breathlessness that is unusual for you
- Chest and/or back pains that are unusual for you
- Coughing or spitting up blood
- Any episode of collapse
- Fast heart rate, racing pulse or palpitations
- If there is absolutely no improvement in your symptoms, with the treatment given, within the next few days

If you have unusual chest or back pain, coughing or spitting up blood, or an episode of recent collapse, call 999 immediately and ***advise the operator that you have recently been tested for DVT***.

# Outpatient DVT Service

## *Discharge advice for patients attending hospital with suspected Deep Vein Thrombosis (DVT)*

***Discharge advice for patients attending with suspected Deep Vein Thrombosis (DVT) but negative ultrasound.***

The scan (ultrasound) investigation carried out on __ /__ /__ has not shown any evidence of a clot (also known as a Deep Vein Thrombosis or DVT) in the blood vessels in your leg. However, this test is unable to exclude a clot completely. Although the probability of a clot is very low, you should be aware that it is important to check that your symptoms are not getting any worse.

***What should I do if I have these symptoms?***

- Seek urgent medical advice, either from your GP, or from NHS24 or your nearest Accident & Emergency department.

***What should I look out for?***

- Increased pain or swelling in the leg
- Sudden onset of breathlessness that is unusual for you
- Chest or back pain that is unusual for you
- Coughing or spitting up blood
- Any episode of collapse

***In the case of unusual chest or back pain, coughing or spitting up blood, or episode of recent collapse, call 999 immediately and advise the operator that you have recently been tested for DVT.***

### *Is there anything else I should do?*

- If any further tests have been organised for you it is important that you attend for them.
- If you have been prescribed any medicine you should take it regularly and finish the course.
- If you have been given a diagnosis of muscle injury and your symptoms have shown no improvement within a few days, seek further medical advice, either from your GP or Accident and Emergency.

*If you are unclear about any of the above instructions, please contact the DVT service:*

[*Include contact details here*]