Thank you for the opportunity to respond to The Scottish Government letter dated 31st October 2008 (Revised)

It would appear that the letter dated 31st October is merely a copy of the letter dated 5th March 2008 from The Scottish Government, which leads me to believe not a lot of new research has gone into answering your letter of 15th May 2008. If I may take the letter from Scottish Government on a paragraph by paragraph basis:

Para 1...The agencies involved have responded to communication by McPherson family.

Para 2...Perhaps it would be helpful if the outcomes of the letter of 26th January 2008 were to be made public, thus allowing the position of each NHS Health Board to be transparent to the general public.

Para 3...Again perhaps the contents of the CMO/NHSQIS letter of 26th January 2008 were made public.

Para 4...Perhaps the Petition should be held open until the outcome of the follow-up exercise in November were known. This would show how much improvement there has been since the initial letter of 26th January 2008 compared to the initial responses received. At this time ,obviously, the information regarding the responses from each Health Board has not been shared with myself as the information has not been received from the Health Boards Indeed the follow up exercise has not been carried out-to my knowledge.

Para 5...Right from the very start, as a family,we have asked that the information leaflet should carry "official" badging i.e.NHS/NHSQIS/Scottish Government.

We have been advised that this direction would not be possible as it was not Government policy. The leaflet developed by Lifeblood had to have 15 versions produced before it was deemed suitable for the Scottish market and we have also been advised by many G.P. surgeries that due to the fact it was A.N.Other Charity leaflet it was deemed not relevant and disposed of rather than displayed!. This could be looked on as a waste of taxpayers money(We believe the amount donated to Lifeblood was in the region of £15000.)We are working with G.P.`s to produce an up to date leaflet and we have asked NHSQIS how to gain funding/badging to allow the leaflets to be more acceptable to G.P.`s and A & E Departments.

Para 6...This is a true reflection of Factor V Leiden,as far as we are aware.

Para 7...If the Scottish Government are content to FOLLOW the lead of the National Screening Committee rather than supply G.P.`s, Dentists and Surgeons with proactive information regarding bleeding times, risk of Thrombosis, clotting risks i.e. information which should reduce the deaths

attributed to Thrombosis (Approx 12000 per annum in Scotland alone) there is perhaps a need for further rethinking regarding this line of thought.

Para 8...Prior to Katie`s death we, as a family, knew nothing of Thrombophilia therefore we were ignorant of the fact we could be "at risk". Subsequent to Katie`s death, Steven, our son, was tested and was found to carry the Factor V Leiden genetic abnormality.

Para 9,10 & 11...It is true that SIGN are reviewing Guideline 62 and that Gordon McPherson is a lay member of the Guideline Group.

We would request that the Petition (PE1056) is kept open until all matters raised above are concluded. We would also draw the Petition Committee to the Thrombosis Symposium held in the Scottish Parliament on September 11th 2008 and hosted my Margaret Curran MSP. The speakers on the day were all leaders in the field of Thrombosis (please find attached a copy of the report from the Symposium).

The Scottish Government has stated that those "at risk" should be tested. One would ask the question How do you know if you are at risk until you are tested? If family history is not available (Adopted persons)?In the case of Katie we, as a family, had no knowledge of any family history...prior to Katie dying of a P.E.

Yours Sincerely

Gordon, Jane and Steven McPherson

REPORT

'FACING THE CHALLENGE'

A Half Day Conference on Prioritising Thrombosis Best Practice in Scotland
Thursday 11th September 2008,
Scottish Parliament, Edinburgh

INTRODUCTION

On 11th September in the Scottish Parliament, Margaret Curran MSP, Shadow Health Minister, hosted a half day conference on thrombosis in Scotland, a condition that is estimated to kill over 3,000 Scots a year. The aim of the event was to educate medical professionals, Parliamentarians and key Scottish stakeholders about the issue of thrombosis and the need to ensure the continued development and uptake of best practice protocols and guidelines in Scotland.

New guidelines on the prevention and management of VTE will be put out for consultation in 2009 by the Scottish Intercollegiate Guidelines Network (SIGN). Ahead of their publication, Margaret Curran MSP and a number of cross party colleagues in the Scottish Parliament felt it would be appropriate for the gatekeepers of Scottish Health Boards to come together and hear what shape these guidelines are likely to take, so that they can prepare the ground for their implementation at a grass roots level and ensure any concerns they might have are raised as early as possible.

A host of expert speakers educated attendees on the risks these VTE guidelines are designed to combat, informed delegates on the current safeguards and discussed the barriers that may hinder implementation when the final SIGN guidelines are published in July 2010.

Notable attendees included the Conservative Health Spokesperson, Nanette Milne MSP, the current Chair of SIGN and member of the SMC, Dr Keith Brown, and Dr Jason Leitch, National Clinical Lead for Patient Safety and Improvement at the Scottish Executive Health Department.

Gordon McPherson followed Margaret Curran MSP in opening the debate, outlining the campaign his family have run since the tragic death of his daughter in 2003 from a misdiagnosed DVT, noting the need for heightened awareness about the condition amongst the general public and medical professionals.

Following a lively discussion the attendees undertook a lively debate, surrounding the need to effectively implement current guidelines. This included a focus on audit, staff responsibility, education of both healthcare professionals and the general public, together with the need for a better understanding of the cost of VTE, covering treatment, fatalities, and the often overlooked issue of morbidity and post thrombotic syndrome to the health service.

PRESENTATIONS

Presentations were made by Professor Gordon Lowe, Professor of Vascular Medicine, University of Glasgow and former Chairman of SIGN; Dr David Steel, Chief

Executive, NHS Quality Improvement Scotland; Professor Mike Greaves, Head of School of Medicine, University of Aberdeen and Professor Isobel Walker, Consultant Haematologist, Glasgow Royal Infirmary.

Professor Gordon Lowe Presentation

'THE PROBLEM'

Professor Gordon Lowe, Professor of Vascular Medicine, University of Glasgow

- Gordon Lowe welcomed the debate in Parliament as public awareness of DVT in Scotland needs to be improved. Next to heart attacks and stroke, DVT is the most common cause of death and disability from cardiovascular disease.

- 1 in 1000 people will have an asymptomatic DVT while 3000 Scots will die of pulmonary embolism, many after recent hospitalisation. DVT kills five times the number of patients than hospital acquired infection which has relatively high awareness.

- Prof Lowe outlined the medical and lifestyle risk factors of DVT and explained how these can be multiplied by a factor of 10 following major surgery, especially in the leg, hip, spine, pelvis, abdomen and patients suffering from cancer. This increase in risk is also the same for patients who have suffered a major medical illness, due to an increase in the blood clotting mechanism and increased immobility (being bed bound). He noted that 3 out of 4 patients dying of PE in hospital were not 'surgical'.

- Many deaths are preventable with prophylaxis, such as heparin or compression stockings but must be weighed up against an increase risk in bleeding in some patients.

- Guidelines produced in 1992 by the Thromboembolic Risk Factors Group (THRIFT) in 1992 stated all patients admitted to hospital should be risk assessed for DVT, with preventative measures prescribed to those most at risk.

David Steel presentation.ppt

CURRENT SAFEGUARDS

Dr David Steel OBE, Chief Executive, NHS Quality Improvement Scotland

- David Steele outlined the purpose of NHS Quality Improvement Scotland, commonly referred to as the 'watchdog of the health service' in Scotland which exists to provide advice and guidance, including standards; support for implementation and improvement; and assessment, measurement and reporting. In addition NHS QIS has central responsibility for patient safety and clinical governance and is involved with the Scottish Patient Safety Programme.

- A report by the Scotish Public Service Ombudsman in May 2006 found that consideration should be given to the need for Scotland-wide guidance on the management of suspected DVT and a patient information leaflet, integrated into any such guidance.

- A stocktake of guidance and audit relating to DVT prevention and treatment in NHS Scotland commissioned by NHS QIS from the TREATS Research Group found variations in the existence of written, up-to-date protocols and policies for the prevention and management of DVT existed, together with variation in the availability and quality of patient information materials.

- The CMO and Chair of NHS QIS issued an open letter in early 2008 which asked all NHS Boards to address the requirement for written policies on the prevention and management of DVT (based on SIGN 36 and SIGN 62) and to ensure that consistent and accessible patient information is available.

- All Boards have reviewed or are reviewing their policies and procedures in line with SIGN guidelines and all Boards have reviewed their patient information leaflets. Many boards have established multi-disciplinary groups to ensure a common approach.

- Dr Steele indicated that the most powerful mechanism of ensuring lasting clincial improvements is sharing best practice and undertaking Peer Review. To ensure Health Boards continue this approach they will be surveyed again in November 2008.

- Dr Steel explained that at the same time the SIGN guidelines into DVT are being reviewed, with a national meeting scheduled for 2009 with publication expected in 2010.

Mike Greaves Presentation.ppt

BEST PRACTICE – HOW WE HAVE HELPED

Professor Mike Greaves, Department of Medicine and Therapeutics, University of Aberdeen

- Prof Greaves agreed that implementation is where the focus is needed and clinicians should be encouraged to follow protocols where it is clear that evidence proves this will have a positive impact on patients.

- The updated SIGN guideline on 'the prophylaxis of venous thromboembolism and antithrombotic therapy' is an update which is hoped to improve the existing guideline, which is pretty effective its current form.

- Prof Greaves outlined that preventative treatment such as low molecular heparin was not necessarily the silver bullet, as it did reduce mortality from DVT, however it was proven to reduce mortality from Pulmonary Embolism by 60%.

- It is important to continuously assess the patient as individual circumstances can change through the patients' stay in hospital.

- He welcomed the review of SIGN guidance as all guidance should be continually updated. He said key to the success of the review so far was Roberta James, Programme Manager at SIGN, having been able to bring together the disparate groups of medics in this area.

Isobel Walker Presentation

FACING THE CHALLENGE – BARRIERS FACED, FUNDING, EDUCATION & AWARENESS

Professor Isobel Walker, Consultant Haematologist, Glasgow Royal Infirmary

- Professor Walker said that the key issues that needed tackling were raising awareness of DVT and improving clinical practice.
- The risk of dying from venous thromboembolism is often underestimated by the public and by the medical profession.
- The statistics are alarming with pulmonary embolism in hospitalised patients causing 25,000 - 32,000 deaths each year.
- There is no single solution to this problem, rather a multifaceted approach is needed which looks at local protocols; local access to educational materials; local patient information; and audit.
- In implementing guidelines, translating knowledge into guidelines is very important, with detailed descriptions of the particular steps for delivering care or treatment to a patient designed at local level to implement national standards or using the best available evidence.
- Education for healthcare staff is also important and should be made relevant through local meetings and local handbooks and use of electronic intranet resources.
- Patient specific reminders should be utilised with reminder systems regarding appropriate investigations, medications; linking patient-specific information at the time of clinical encounter with underlying sets of rules based on high quality medical evidence for example algorithms for diagnosis of DVT or PE.
- Patient information should be simple and understandable but should NOT replace information delivered face to face by informed staff.
- Funding is integral to the issue. In the long term the additional cost of prevention and treatment of venous thrombosis – may be negative. In the short term funding will be needed for additional staff to develop services and to support Thrombosis Committees, to facilitate education and audit and to provide for some minor diagnostic equipment.

DISCUSSION

Implementation

- Dr Jason Leitch, National Clinical Lead for Patient Safety, explained that success of patient safety initiatives was a combination of buy-in from executive leaders coupled with local implementation by frontline staff. He said that DVT prophylaxis was one of the indications in the Scottish Patient Safety Campaign.

- The work in Westminster with the Chief Medical Officer's Expert Working Group added a useful dimension, in particular the structures that could help in implementing good local practice such as thrombosis committees.

- Mike Greaves felt that there should be a team of dedicated nurses in every hospital responsible for ensuring the review of all eligible patients every day, although he did admit that this would be expensive.

- Dr Angus Cameron, Medical Director of NHS Dumfries and Galloway did not believe that the resources could be justified and argued that the doctor should be responsible for this.

- Dr Cameron added unless a system is in place, risk assessment will not work. You need to inspire staff to risk assess in the first place.

- Dr Lishel Horn, Consultant Haematologist at the Royal Infirmary of Edinburgh proposed the implementation of a mechanism to identify VTE champions to lead the implementation of recommended best practice.

- Professor Isobel Walker felt this would be unsuccessful since there would be areas such as orthopaedics would be uncomfortable.

- Gordon Lowe advocated the anticipatory measure of assessing high risk groups of the population once a year so that when the patient is admitted, it will already be in their patient notes that appropriate therapy should be considered.

Audit and Reporting

- Margaret Curran MSP asked whether health boards undertake local audits and publish individual hospital statistics for the incidence of VTE and the uptake of risk assessment.

- Dr Steel said local audits are undertaken by some hospitals but it would be difficult to undertake a comprehensive survey in which Boards could be named or shamed and felt that this should be done within the privacy of the hospital. In Dr Steel's experience, Boards find it threatening when audited in this way by NHS QIS.

- Professor Gordon Lowe argued that there needed to be improvements to the way in which incidents of VTE were reported given that the patient was most likely to suffer a DVT five days after being discharged. He suggested that a system of direct feedback whereby the healthcare professional who readmits a patient with a DVT, should write to the clinician in charge of their care to inform them. He felt that this could be easily implemented and would improve healthcare professionals' awareness of the prevalence of hospital acquired DVT. He also argued that the personal element of this approach would have increased resonance with clinicians. Isobel Walker argued that this was not to do with individual care but a management issue.

- Dr Angus Cameron supported Professor Lowe's comments arguing that the same should also be implemented for patients who suffer a PE as he felt that Clinical Governance Committees and Executives are unaware of the scale of the condition.

- Dr Cameron said a 'stick' is needed to ensure that hospitals and staff follow SIGN guidelines. He often refers to a case heard by the local Sheriff (Coroner), in which the Sheriff referred to SIGN guidance that was not followed in the case of a patient that died under the care of a Health Board and the legal implications this could have. It is the legal profession that is making healthcare professionals 'sit up and listen' in some instances.

- Margaret Curran proposed the introduction of a statistical method for recording this data but Jason Leitch felt that any kind of audit needs an aim in order for it to influence clinicians, as currently the adverse incident reporting system only captures about 5% of instances.

- Jason Leith argued that "front line data for front line staff works". He suggested that an audit in which clinicians reviewed their case notes for mentions of 'DVT' and 'PE' which could then be fed back upwards to the board and front line staff to improve care would be more effective. He advocated the use of a trigger tool.

Patient Education

- Professor Chris Ludlam, Consultant Haematologist at the Royal Infirmary of Edinburgh pointed out that the patients have the greatest interest in their care. To this end patients should be made aware of the risk factors associated with VTE before coming into hospital for elective surgery.

- Professor Lowe explained that the last SIGN guideline had a draft letter for hospitals to send to patients before they were admitted for elective surgery which would empower the patient to ask for a VTE risk assessment on admission. He suggested that Gordon McPherson should feed this into the current review of the guidelines.

- However, Stacey Freeman, a DVT nurse specialist at Clyde Royal Hospital did not feel that this provided a solution for her patients, most of whom were non-elective admissions. She felt that the emphasis should be on staff education.

Cost of VTE

- Dr Keith Brown, Chair of SIGN, explained that SIGN will be undertaking a cost effectiveness assessment alongside the guidelines, which could provide powerful evidence for uptake.

- Gordon McPherson explained that just five injections of low molecular weight heparin at a cost of £1 per an injection could have saved Katie's life.

Morbidity

- Ken McLay, Medical Lead for the Acute Sector at NHS Grampian raised the point that the high degree of morbidity in patients who have suffered a DVT is underestimated and under appreciated both clinically and in terms of costs.

AGENDA FOR ACTION

The Parliamentarians present agreed an agenda to take the campaign forward:

- **NHS Quality Improvement Scotland to undertake a follow up 'stock-take' of Health Board VTE protocols in Scotland in November 2008**

- **Margaret Curran MSP agreed to raise a parliamentary debate surrounding this and to table a number of parliamentary questions around the cost of the condition, how to mandate risk assessment and how to better audit existing protocols.**

- **On the advice of Gordon Lowe, former Chairman of SIGN, SIGN will look at developing a VTE pre-admission letter / self assessment to be sent to patients in advance of elective admission**

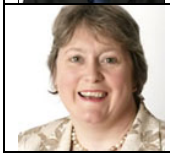
- **The MSPs present agreed to examine how they could best run a public awareness campaign**

- **NHS QIS will look at current patient information leaflets and see how they may be able to officially brand these as Scottish Health Executive Department literature to encourage medical professionals to distribute these, as charity leaflets are often thrown away by surgeries and clinics.**

- **Trish Godman MSP will contact all MSPs asking them to audit GP surgeries in their own constituencies to ascertain whether the Lifeblood patient information leaflet, produced in association with the Scottish Health Executive Department, was being used and will raise a parliamentary debate on the outcome if necessary.**

APPENDIX 1 - ATTENDEES

Parliamentarians

	Trish Godman MSP Labour, Renfrewshire West
	Annabel Goldie MSP Conservative, West of Scotland
	James Kelly MSP Labour, Glasgow Ruthergien
	Tricia Marwick MSP SNP, Fife Central
	Jamie McGrigor MSP Conservative, Highlands and Islands
	Dr Nanette Milne MSP Conservative, North East Scotland
	John Park MSP Labour, Mid Scotland and Fife
	Margaret Smith MSP Lib Dem, Edinburgh West

Stakeholders

Name	Position	Organisation
Dr Keith Brown	Chair	SIGN
Dr Angus Cameron	Medical Director	NHS Dumfries and Galloway
Lorna Campbell	DVT Nurse Specialist	NHS Greater Glasgow and Clyde
Lorraine Deegan	DVT Nurse Specialist	Royal Alexandra Hospital
Stacey Freeman	DVT Nurse Specialist	Royal Alexandra Hospital
Linda Gray		Friend of the McPherson Family
Prof. Mike Greaves	Head of School of Medicine	University of Aberdeen
Dr Lishel Horn	Consultant Haematologist	Royal Infirmary of Edinburgh
Dr Roberta James	Programme Manager	SIGN
Elinor Jayne	Parliamentary and Media Officer	Royal College of Nursing
Dr Jason Leitch	National Clinical Lead for Patient Safety	Scottish Executive Health Department
Prof. Gordon Lowe	Professor of Vascular Medicine	University of Glasgow
Ken McLay	Medical lead for the Acute Sector	NHS Grampian
Gordon McPherson		Father of Katie McPherson
Jane McPherson		Mother of Katie McPherson
Janette Owens	Acting Director of Nursing	NHS Fife
Pat Smith	DVT Nurse Specialist	NHS Greater Glasgow and Clyde
Dr David Steel	Chief Executive	NHS QIS
Dr Charles Swainson	Medical Director	NHS Lothian
Dr Jean Turner	Chief Executive	Scotland Patients Association
Prof. Isobel Walker	Consultant Haematologist	Glasgow Royal Infirmary
Margaret Watt	Chairperson	Scotland Patients Association