Dear Fergus

In response to your request for an update on the above Public Petition progress I am pleased to submit the following.

Initially as a family we asked 3 aspects of the Petition

1) Commonality of information available to the general public from each Health Board in Scotland.

In January 2008 Dr Harry Burns and Sir Graeme Teasdale jointly issued a letter to all Health Boards advising that all Health Boards issue exactly the same information worded identically to the general public. In fact the letter of 26th January (coincidentally the 5th anniversary of Katie's death) laid out the wording to be used. I enclose as an attachment the up to date situation as at today's date. Unfortunately I have not received a response from NHSWESTERNISLES. As you will note in the attachment appended The Health Directorate advise that an electronic copy of the hardcopy leaflet distributed to all GP surgeries in Scotland has now been sent to all GP surgeries. The concern is that the general public have not been advised of the leaflets existence therefore the question has to be asked, if the public are not advised of its existence how are the to know to ask for a copy? I believe there now has to be a poster produced to advise the public to ask for a copy of the electronic leaflet! Would it not have been easier to have kept the original paper copies sent in the first place rather than waste time and taxpayers money by destroying the original leaflet through lack of knowledge by the Practice Managers? A case in point for our wish to raise awareness in both the Public and Medical Professionals! I also have to raise the point that if Health Boards are not willing to abide by the instructions of the C.M.O. and Chair of NHSQIS then who will they listen to?

2) Commonality of information used by Health Boards in the Assessment and treatment of suspected DVT

SIGN are updating SIGN 62 and 35 Guidelines and the resultant new guideline should be available October 2010. The problem just now is ensuring there is commonality of Assessment and treatment of suspected DVT in the interim period until the updated guideline is published and that the medical profession do not hold off this working to the same guidelines until then. SIGN have also advised that they have employed an Implementation Officer to ensure that Guidelines are indeed implemented within each Health Board.

3) Screening for Hereditary Thrombophilia.

Thrombophilia is the Genetic "fingerprint" which shows if someone has an increased susceptibility to being at risk to a DVT. The problem we have is that if a person tests positive it does not necessarily mean that the person will develop a DVT/Thrombosis. What it does show is that the person tested is now AWARE. If this awareness is recorded in medical files it would then mean that the Doctors are aware. There is now evidence being raised, in medical papers, of the recommendation to screen girls at 12-14 years of age for Thrombophilia. What I feel needs to be carried out is a process of education to advise that Thrombophilia actually exists!

An argument can be made and substantiated by figures from House of Commons reports that by Doctors being more aware, there is a case for savings primarily with lives but also financially. If a Doctor is aware the can advise the patient on changing lifestyle rather than dispensing medication.

I know this petition has been open for some time now but would request it is held open at least until SIGN publish their update to Guidelines 35 and 62. There is also the aspect that having looked at figures released by WHO, European Parliament, House of Commons and Holyrood they show that the UK has an average of 14% of all deaths being attributed to Thrombosis compared to Scotland which shows an average of 22% of all deaths are attributed to Thrombosis. Scotland has the second worse % in Europe, just behind Georgia. WHY?

I would ask that pressure continues to be brought to bear regarding our petition to allow for change in the mindset and procedures adopted by ,primarily ,the medical profession. Until there is a realization that unless awareness is raised we will continue to "accept" 12000 deaths per annum whereas with a little effort we could significantly reduce this total without a significant financial input.

Regards Gordon McPherson ----Original Message-----From: Gordon McPherson

Sent: Thursday, April 30, 2009 9:27 AM

To: 'foirequest'

Cc: Will.Scott@scotland.gsi.gov.uk; Godman T (Trish), MSP; Goldie A (Annabel), MSP; 'Carolyn

Churchill'; Harry.Burns@scotland.gsi.gov.uk; Cochrane FD (Fergus)

Subject: RE: Patient Information Leaflet DVT

Good Morning

Thank you for your information regarding the Information leaflet for DVT.I am perturbed that NHSWESTERN ISLES seem to be working to a different set of Guidelines than the other 13 Health Boards making up NHSSCOTLAND.

As far as I was informed ALL Health Boards were to work to the instructions given within the letter of 26th January 2008 from Dr Harry Burns C.M.O. and Sir Graeme Teasdale Chair of NHSQIS. To compound my fears Mr Will Scott of Healthcare Policy and Planning Directorate in a letter to Public Petitions Committee stated "The NHS QIS report in December 2008 showed that all but one Board had suitable leaflets in place, and since then the remaining Board has produced its leaflets" The suitability of the leaflets was based on the fact that ALL Health Boards worded the leaflets IDENTICALLY to ensure that ALL 14 Health Boards give out the same information and there could be no ambiguitity regarding patient information

Another paragraph from Mr Scotts letter dated 16th April 2009, some 10 days prior to your letter dated 29th April stated "NHS QIS has also been able to verify that Boards` leaflets are in line with the text recommended by C.M.O. and the Chairman of NHS QIS, and has provided Mr McPherson with copies"

Can you please explain this?

I have copied in Dr Burns as I am sure he must also be wondering how 1 department can say one thing and supply proof of its authenticity whilst another totally contradicts the information. One of the requests we as a family put to the Public Petition Committee was that we wanted commonality of information throughout ALL Health Boards regarding Patient Information in the hopes that if common information was avaliable then this would cut down the possibility of another family suffering as we have, due to the unneccessary death of our daughter Katie.

There must be commonality of information throughout ALL 14 Health Boards not 13 and 1 goes its own way.

I look forward to your response, hopefully a little more timeous than 4 months after this letter as was the case the last time I wrote to NHSWESTERNISLES.

Regards

Gordon McPherson

Bòrd SSN nan Eilean Siar Western Isles NHS Board

Public Health & Health Strategy Division

37 South Beach Stornoway Western Isles HS1 2BB Telephone 01851 702997 Fax 01851 704405 www.wihb.org.uk



Private & Confidential Mr Gordon MacPherson Creagowrie 65 Middlepenny Road Langbank PA14 6XF Date: 28th April 2009 Your Ref: FOI Req 111/91

Enquiries to: Tina Macritchie Extension: 3031 Direct Line: 01851 708031

E-mail: Tina.Macritchie@wihb.scot.nhs.uk

Dear Mr MacPherson

Freedom of Information Request

Thank you for your freedom of information enquiry regarding NHS Westerns patient information leaflet on Deep Vain Thromboysis (DVT) which was send to you on 22nd December 2008 and can be found via the Western Isles Health Information Project which is available online at www.wihb.scot.nhs.uk/HI/home.htm.

In response to your subsequest freedom of information request dated 22nd December 2008 asking why NHS Western Isles leaflets do not reflect the information given in the joint letter from CMO and the chair of NHS QIS dated 26th January 2008. The patient information provided from Intouch With Health which is used via the HI projected is always up to date and fully accredited. The Director of Patient Safety & Performance Assessment, NHS QIS was also contacted and cofirmed that the leaflet in use in NHS Western Isles is compliant with the guidelines.

Please accept our apologies for the delay in responding and if you require any further assistance please do not hesitate to contact me.

Yours sincerely

Eddý Yates

Information Governance Manager

Oifisean Bòrd na Slàinte

37 Mol a Deas, Steòrnabhagh, Eileanan Siar, HS1 2BB

Cathraiche: Ceannard an Gnìomh: I.A. MacAoidh G. MacSheumais Headquarters

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