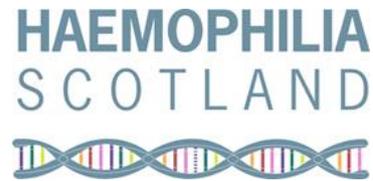


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The Rt Hon Nicola Sturgeon MSP
Bute House
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firstminister@gov.scot

16 September 2020

Re: Haemophilia and the Infected Blood Inquiry


Dear First Minister,

I write five years on from your personal, much appreciated undertaking to give all those affected by the infected blood disaster the support they deserve (FMQs 26/03/15). They include those, in particular, with bleeding disorders. I wish to draw your attention to a number of pressing issues now facing us and seek your stamp of support once again in tackling those problems.

Funding of Haemophilia Scotland.

Since Scottish Government's announcement also on 26th March 2015 of much needed financial support for Haemophilia Scotland, and our partner charity the Scottish Infected Blood Forum (SIBF), we have faced steady cutbacks in that Scottish Government backing from £100k pa to now £25k for one year only with much stricter constraints on how we deploy that funding in support of those with bleeding disorders.

We are grateful for the work of the officials managing our grant for their efforts to make the terms as appropriate as possible. We also recognise that those constraints are largely standardised requirements set as a result of legal and financial policies, we are left with little room for flexibility in our ability to try and meet the needs of those who are most vulnerable and anxious while the UK Inquiry proceeds amid the Covid crisis.

Having been already faced with severe limitations exerted by other funding sources, we face such a reduction in our income that we could no longer provide the services that the bleeding disorders community in Scotland have come to expect from us. This is in stark contrast to, for example, the Irish Haemophilia Society (IHS). They have benefited from full government funding ever since the Lindsey Inquiry, allowing them to have support staffing at least four times that in Scotland.



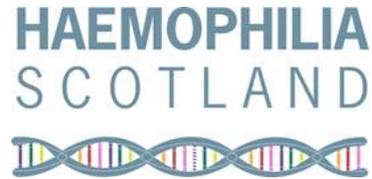
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I urge you to please draw the attention of relevant Ministerial colleagues to the commitment you personally have consistently made to support those with bleeding disorders. Our volunteers have devoted thousands of hours to support the bleeding disorders community but find themselves potentially with less professional support if the funding constraints we face are further tightened.

UK Inquiry into Infected Blood and recent Cabinet Office involvement.

We very much acknowledge that this Inquiry was announced by former PM Theresa May on the spur of the moment without consultation with devolved governments. Nevertheless, it does afford the opportunity to finally get to the bottom of much of the strategic decision making that was made prior to devolution and was not addressed during the Penrose Inquiry. It has wider Terms of Reference and has engaged those affected much more than was the case under Lord Penrose.

I personally have already given oral evidence and publicly acknowledged the positive action taken by Scottish Government and its willingness to engage with us and the mutual benefit brought about of working together to meet the needs of those with bleeding disorders and their families. That co-operation has until now involved working with both Ministers and officials. In anticipation of the findings of the current Inquiry, we urge Scottish Government to press for their own retention of funding decisions. We very much see the benefit of working with Government within Scotland rather than in London - building on former Cabinet Secretary for Health and Wellbeing, Shona Robison's platform that, in Scotland, support schemes that should be accountable in meeting the needs of those affected.

I raise this because we are now very much in the dark about the nature of the discussions that UK Government's Paymaster General, the Rt Hon Penny Mordaunt MP, states she has been having with devolved governments (in correspondence 19/08/20).

Clearly these behind the scenes exchanges between respective Governments on matters that potentially deeply affect our community give rise for serious concern. Unlike the work done in Scotland during the Infected Blood Financial Review (2015) and the Clinical Review of the Impacts of Hepatitis C (2018), it appears matters are now being deliberated by officials only, with the Cabinet Office Minister going on record that a framework for compensation that involves the UK Treasury is being considered. The secrecy surrounding these exchanges is simply unacceptable.

We trust that Scottish Government will not agree to any related decisions being made without early wider consultation and urge you to write to the Prime Minister accordingly. I am thus also copying this letter to both Kate Forbes MSP and Joe Fitzpatrick MSP. We are anxious that any new funding provisions, if they are signalled by the Treasury, are administered by Scottish Government, and include consideration of funding for the support charities SIBF and ourselves, Haemophilia Scotland.

Memorial / Tribute to those affected by infected blood disaster.

You may recall your attendance at our memorial event on 2 March 2016 led by Richard Holloway and our launching of a proposed permanent memorial as a tribute to those so grievously affected by the infected blood disaster in Scotland. It was an idea that Shona Robison when Cabinet Secretary for Health and Wellbeing, fully gave her support to.



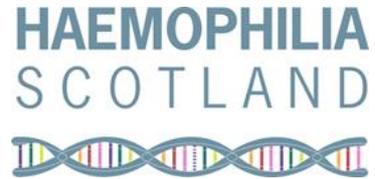
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Since then we have raised over £30,000 toward erection of such a permanent tribute. Its location remains to be determined but we have been having some positive discussions with Scottish Parliament officials about what possibilities might exist within the vicinity of the Parliament, given the distinctive role it has played over the last twenty years in addressing the infected blood disaster in Scotland. As I understand it, officials and the Corporate Body are reviewing their policy on artworks and memorials around the Parliament.

I fully recognise that the Parliamentary authorities have the ultimate decision on any possible outcome. However, an expression of support from you as First Minister of the principle of erecting such a tribute, wheresoever it is located, would be a tremendous boost to securing the outstanding funding required and securing a suitable location.

As ever, we are very willing to work positively with Government to resolve these thorny matters. Until now, we have been consciously avoiding troubling you. Scottish Government and its agencies have performed some great work on haemophilia, particularly in funding new treatments, a psychological service, a managed clinical network and well-run infected blood support scheme.

We are however, now at a pivotal moment where a personal expression of support for those in Scotland with bleeding disorders is required to spark a new impetus to meet their evolving needs. I have confidence you will re-iterate your commitment to support those much-needed services.

With best wishes,

Yours sincerely,



Bill Wright

Chair, Haemophilia Scotland.

CC Joe Fitzpatrick, Kate Forbes, Sir Brian Langstaff.

scottish.ministers@gov.scot

contact@infectedbloodinquiry.org.uk



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