



**THE
HAEMOPHILIA
SOCIETY**

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Prime Minister
10 Downing Street
London
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Re: Contaminated Blood and Blood Products Inquiry

06 October 2016

Dear Prime Minister,

I am writing to you on behalf of our members who are victims of both Hepatitis C and HIV infections arising out of receipt of contaminated blood products.

As you are undoubtedly aware, over 4,500 persons were infected with Hepatitis C virus as a result of their treatment with contaminated blood products.

Of these, 1,243 persons were directly infected with HIV arising out of receipt of contaminated blood products. In addition many partners/spouses of such persons were also infected with HIV and Hepatitis C.

It is noted that your Government estimates that in total over 30,000 persons were exposed to contaminated blood and blood products in the United Kingdom. Although, the majority have never been identified in numerous look-back exercises.

Accordingly the circumstances surrounding the manufacture and distribution of blood and blood products has resulted in one of the major health catastrophes in the United Kingdom's history.

Although belatedly, this Government has agreed to establish a full inquiry in to how contaminated blood transfusions and blood products infected many UK citizens with Hepatitis C and HIV infections. That particular development is still very much welcomed.

It is noted that you are on record as indicating that the infection of thousands of people and many haemophiliacs was *"an appalling tragedy which should simply never have happened"*.

For all people affected by bleeding disorders

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Also, it is noted that you indicated in a subsequent statement to the announcement of the inquiry, that *“the victims and their families who have suffered so much pain and hardship deserve answers as to how this could possibly have happened”*. In addition you have indicated in your statement that *“they have been denied those answers for too long and I want to put that right”*.

Considering the seriousness of the issues of public concern that require to be investigated it is of the utmost importance that the Terms of Reference for this Inquiry are comprehensive and all encompassing. Also considering the delay that has occurred in relation to the establishment of this inquiry process it is of the fundamental importance that *“this appalling tragedy”* is properly and comprehensively investigated in an effective and efficient manner.

The Haemophilia Society wish to have an input in relation to the drafting and finalisation of the Terms of Reference for such an Inquiry. Also, we believe that we can contribute in a constructive and effective manner to achieve focused and comprehensive Terms of Reference thereby ensuring that all relevant issues are so investigated. The Haemophilia Society has met with certain of its members who have voiced serious concerns and indeed anger that the Department of Health is so involved in the formulation of the Terms of Reference as the sponsoring body for this Inquiry.

There is a clear conflict of interest in the Department of Health being so involved or involved at all in the drafting of Terms of Reference for the inquiry that will inevitably focus upon its own remit. In short, the Department of Health has the capacity to influence the extent of the Inquiry that will occur in to its own actions or inactions.

It is patently wrong for the Department of Health to be placed in such an invidious position where it could be contended that it is conflicted in relation to this particular role as the sponsoring body. Accordingly, we would respectfully suggest that it is incumbent upon you as Prime Minister to rectify this issue as a matter of priority otherwise public confidence in an Inquiry to be established could be damaged by such a failure.

We confirm that we have not engaged in the consultation process in relation to the Inquiry (closing date the 18th October 2017) on the basis of this potential conflict. Yet we have delivered correspondence setting out our said concerns in a similar manner to the content of this letter to the Department of Health itself.

We confirm that the issues that require to be addressed at this juncture are as follows:

1. Department of Health

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The Department of Health cannot be the sponsoring body for this Inquiry. Nor can the Department of Health oversee any consultation process or fund the Inquiry in any way. Their role should be limited to providing evidence as a party who is inevitably involved in the circumstances surrounding the NHS treatment of patients with contaminated blood and blood products.

This issue must be addressed before the Government addresses any other issue and indeed prior to the conclusion of submissions on the Terms of Reference as otherwise the inquiry could be severely damaged prior to its commencement.

The consultation process on the inquiry should continue post the transfer of responsibility from the Department of Health. This will allow the substantial number of our members who have not responded with substantive information on the remit to do so.

For the avoidance of any doubt, our members want an inquiry to be established as early as is feasible yet, subject to the caveat that it must be effective and efficient so as to achieve its objectives.

2. A statutory inquiry under the 2005 Inquiries Act.

A contaminated blood inquiry must be capable of compelling both the attendance of witnesses and delivery of documentation. The 2005 Inquiries Act would appear to be the most appropriate and proper investigation method to achieve the objective which both our members and the public expect.

Our members require an inquiry established with appropriate statutory powers to be able to compel the attendance of witnesses and delivery of documentation. It would appear that the 2005 Act provides the necessary basis for such an objective although certain legal frailties may exist with this legislation.

We and our members would like to see the chair of such an inquiry supported by a panel to assist the most effective progression of the inquiry.

3. Consultation process re Terms of Reference, method of participation and other associated matters.

The Government, it is contended, should not advance the establishment of an inquiry without achieving the confirmation from persons affected that their issues are capable of being properly investigated under the proposed terms of reference. That scenario inevitably involves a consultation process where the affected community should be invited to make submissions and engage, for the purposes of ensuring that the drafting

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and subsequent approval of comprehensive terms of reference deliver both an effective and efficient inquiry process.

There are a vast range of issues that would require to be addressed as part of that consultation process which are inappropriate to canvass in the content of this letter. What needs to be established is the basic concept of consultation prior to finalisation of the terms of reference and the establishment of an inquiry.

In addition, we welcome the observations made by the Co-Chairs of the All-Party Parliamentary Group on Haemophilia and Contaminated Blood and we endorse those particular observations as providing an additional set of issues that require to be considered in the context of any consultation process to be established.

In addition, our members are anxious that the Terms of Reference are finalised as a matter of priority yet, that desire is a qualified desire to the extent that it is essential that a comprehensive and effective inquiry process is established. Consequently, it is preferable to expend time on achieving appropriate Terms of Reference than to allow inadequate Terms of Reference be approved which would result in further delay and inappropriate expenditure.

Accordingly, I wish to confirm that The Haemophilia Society will participate in any process in a constructive, effective and fair manner to achieve a comprehensive set of Terms of Reference subject to those discussions not involving the Department of Health as the sponsoring body.

We await hearing from you as to how you intend to address this difficult situation or impasse that now exists in terms of the progress of the Terms of Reference by way of a consultation process.

Yours sincerely,

A handwritten signature in black ink that reads "Liz Carroll". The signature is written in a cursive style with a large initial "L".

Liz Carroll
Chief Executive

[The Haemophilia Society](http://www.haemophilia.org.uk)

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