

Rt Hon Theresa May MP
Prime Minister
10 Downing Street
London. SW1A 2AA

12 July 2017

Dear Prime Minister,

I am writing to you on behalf of Haemophilia Scotland to welcome your announcement of a Public Inquiry into the contaminated blood disaster.

Haemophilia Scotland is the Scottish charity for individuals and families affected by inherited bleeding disorders. We were a Core Participant in the Penrose Inquiry and are anxious that your inquiry doesn't duplicate the efforts or mistakes of that process. Most of our affected members were infected in Scotland but we also have members where were infected in other parts of the UK or rely on the financial support schemes out-with Scotland.

We were surprised to learn from the Scottish Government that neither you nor your ministers made any contact with them prior to announcing a UK-wide inquiry. As I'm sure you know, section 27 of the Inquiries Act means that a statutory UK-wide inquiry can't be established without the involvement of the health ministers in the devolved governments. Should we infer from your decision not to consult them that a statutory inquiry has been ruled out? If so, how can that be reconciled with your intention to "work with the victims and their families to decide what form this inquiry should take?" Are you intending to formally consult on this decision? What future involvement do you intend for the devolved governments and charities operating in the devolved nations such as ourselves and Haemophilia Wales?

Your announcement raises a lot of questions about how your Inquiry will be conducted.

- a. What will the process for producing terms of reference be? Will those affected in Scotland have input into those terms of reference?
- b. Will you ensure that the Inquiry has the power to compel witnesses and evidence?
- c. How will the Chair be selected and how will those affected by the disaster be involved in that process?
- d. If your Inquiry is going to be a UK-wide inquiry it should be accessible to those affected throughout the UK. Will you undertake to hold oral hearings out-with London, including all nations of the UK? All venues used for public hearings must be wheelchair accessible. Will the public procedures of the Inquiry be streamed live on the internet so those in remote areas or suffering with poor health or mobility are able to follow them?
- e. The Penrose Inquiry only allowed a very small number of affected people to give oral evidence. We believe this was a mistake and that every affected individual who wishes to should have right to be heard. Will you give all affected people that right and give them access to legal advice before doing it to prevent them prejudicing any future case they may have?

In our view, the Penrose Inquiry did a reasonable job of cataloguing the events of the disaster as they related to Scotland. However, it was extremely weak on analysis of those events and comparing them to current practice. It failed to establish where lessons can be learnt to improve public safety and the lives of those affected. Therefore, it is imperative that your inquiry is better focused on reaching conclusions which are of practical benefit. As I'm sure you realise, for your Inquiry to be truly UK-wide it must cover elements of the disaster distinct from those examined by the Penrose Inquiry. If your terms of reference duplicate those of the Penrose Inquiry you will succeed in providing our friends in the rest of the UK with access to an equivalent process but fail to provide much additional benefit for affected people in Scotland.

The following areas were either not covered by the Penrose Inquiry or not covered sufficiently. They are areas where a UK inquiry might contribute to providing justice for those affected in Scotland.

1. Liability.

A statutory inquiry is not normally competent to establish legal liability. Until now those affected have been in a Kafkaesque situation of being told that full compensation can't be paid because liability hasn't been established while being denied any opportunity to establish liability.

2. Criminality.

Much of the recent political pressure for a public inquiry has revolved around accusations of criminality. These must be explicitly investigated by the inquiry if it is to avoid being branded a whitewash. The Inquiry must have a duty to refer suspected criminality to the police and/or prosecution services.

3. Accountability and decision making.

The Inquiry should resolve the issue who was, and is, ultimately responsible for the safety of blood products in the UK. The process of clinical trials, licensing, importation, inspection, public health, and political oversight failed to protect people with bleeding disorders. Decision making process also appear to have been at fault, relying too much on consensus and not taking sufficient account of the costs of inaction. The Inquiry should make specific recommendations to address these failings.

4. Learning lessons and CJD.

Successive UK Governments have claimed that all relevant lessons have been learnt. The terms of reference for any UK-Inquiry must details what changes in practice have been made in response to the disaster. We believe no analysis of changes in practice can be conducted without considering how the risk to people with bleeding disorders from CJD has been handled.

5. Consent, Communications, and Risk.

It was evident from the Penrose Inquiry that people with bleeding disorders were tested without their consent and were involved in clinical research without their knowledge. People were not automatically told of their infected status and when they were eventually informed it was without the appropriate support. People were not made aware of the risks and were not offered choices to help them mitigate those risks. Any new Inquiry must examine the medical ethics of consent in research and make clear recommendations about how results and risks are communicated to patients.

6. Full disclosure of pathogens.

People with bleeding disorders have been exposed to a wide variety of blood borne pathogens as well as non-pathogenic viruses and prions. Your Inquiry should produce a list of all of these agents as well as a narrative explaining which are currently believed to be pathogenic and what diseases or conditions they are associated with. This section of the Inquiry report should also detail what is known about how these agents interact and make recommendations where further research is required.

7. Conspiracy to conceal.

The persistent accusations that there has been a concerted effort to conceal the disaster and thwart the attempts of those seeking justice should be investigated. This should include,

- a. Former Ministers being denied access to their papers.
- b. Individuals reporting gaps in their medical records which related to the relevant period. There should be a consensual and systematic examination of medical records to establish if there is any constant pattern of gaps.
- c. The inadvertent destruction of documents by junior civil servants. The Inquiry should specifically examine whether a department where this is possible is competent to maintain its own archive and whether documents related to disputed issues like this should be held out-with the departments who are implicated.

8. Documentation

There should also be a commitment that following the Inquiry all relevant documents will be preserved, archived, and published online. They should be held in more than one place to protect them from further inadvertent destruction.

9. Financial Support

The Inquiry should look at the financial support available to affected people. Should full compensation be paid and if so by who? What impact have changes to benefits entitlements had on those affected? Should the current levels of financial support across the UK be improved? Should financial support be available to bereaved parents and children? Are the financial losses suffered by widows sufficiently recognised? Should those who are eligible for support be able to choose if it is provided as ongoing payments or as a lump sum?

The Penrose Inquiry cost £12,123,754 and seven years. It is vital that the time and money spent on your Inquiry does not prevent you taking practical steps to improve the financial and practical support available to those affected. You must make it clear that the Inquiry is not a valid reason for inactivity in the support of those affected until it reports. Notwithstanding the importance of the search for truth and justice the immediate needs of affected people must be addressed as a matter of urgency. If the Inquiry is turning into a long running gravy train for lawyers and judges while some affected people continue to live in abject poverty, it will already have failed. This would be an outcome we believe you would wish to avoid.

Yours sincerely,



Bill Wright
Chair, Haemophilia Scotland

CC'd

Nicola Sturgeon MSP, First Minister, The Scottish Government
Shona Robison MSP, Cabinet Secretary for Health and Sport, The Scottish Government
Liz Carrol, CEO, The Haemophilia Society
Lynne Kelly, Chair, Haemophilia Wales