IN THE MATTER OF THE INFECTED BLOOD INQUIRY

ON BEHALF OF THE CORE PARTICIPANTS
REPRESENTED BY MILNERS SOLICITORS

OPENING SUBMISSIONS FOR THE PURPOSES OF THE PROCEDURAL HEARINGS 24-26 SEPTEMBER 2018

Introduction

1. The person who knows that the blood products they supply contain a high risk of infecting another person with a disease such as Hep B/C or HIV commits the offence of inflicting GBH if the person supplied does not immediately die. If the supplied person dies as a consequence it is murder. Those who are part of the supply chain when either supporting or assuring such a supply with the requisite knowledge of what they are doing are guilty of conspiracy to murder. It is clear that those who were responsible for the criminal infection of people through the supply of contaminated blood should be prosecuted. Those people who wiped out thousands of haemophiliacs and other people should be made to pay for their crimes.

2. In the United States, this scandal has been labelled 'the haemophilia holocaust'. In the UK over 4,500 haemophiliacs were given HIV and Hepatitis C by treatments provided on the NHS, of which approximately half have since died and thousands more human lives have been destroyed. The haemophiliacs infected and killed, died horribly, their lives made a sheer misery, their families broken and all too often also infected. The evidence discovered by campaigners suggests that state bodies, including the NHS,

actively pursued human observation, testing and experimentation that was unthinkable in the wake of the development of the Nuremberg Code.

3. With Alan Barker and instructed by Milner's Solicitors I appear on behalf of four Core Participants and a witness from the infected and affected haemophilia community. Through these opening submissions we shall set out our representations as to how this Inquiry should proceed in order to operate most effectively and to support the participation of infected and affected persons, and achieve the objectives of the Inquiry. Following this preliminary hearing we will provide a copy of our speaking notes, we will also draft and file written submissions based and building on our oral submissions and provide comments on the proposed expert panel.

4. The Core Participants we are privileged to represent have over decades campaigned for the protection and rights of infected haemophiliacs and all gave evidence to the Archer Inquiry. They have devoted their time and in the absence of any public funding have invested significant financial resources to ensure that their fight was not forgotten:

    a. Peter Mossman, a haemophiliac infected with HCV in 1985 who having previously been an active member of the Haemophilia Society North West, jointly formed The Manor House Group in 1994 and who has since played an important role in lobbying parliament and protesting on behalf of infected haemophiliacs. Having left the Manor House Group, he today continues his campaign work despite significant health problems.

    b. Colette Wintle, a woman with haemophilia infected with hepatitis C in Scotland in 1976, hepatitis B in Kent in 1982 and again with hepatitis C at the Royal Free Hospital in London in 1985. Colette lost a career in nursing due to hepatitis B infection but also subsequently lost a career in the airlinee due to the sole fact she was haemophiliac. Colette was also exposed to vCJD in 1993, a fact that was shockingly withheld from her until 2004. Since 1994 she has actively researched and campaigned for justice.

c. Colette's husband Steven Wintle, has campaigned with her and one occasion wore a necklace of blood bags around his neck outside the Ministry of Health. He also simultaneously fulfils the role of her primary carer whilst working to provide for them both and their daughter.

d. Carol Grayson, the sister in law of Stephen a haemophiliac who died of HIV/HCV in 1986 and the widow of her haemophiliac husband Peter Longstaff who was also co-infected with HIV and hepatitis B and C and exposed to vCJD. Peter passed away in 2005. Following the death of her husband, Carol researched and wrote an acclaimed dissertation on contaminated blood in 2006, That dissertation critiqued the findings of the now discredited Government Report 'Self Sufficiency in Blood Products in England and Wales from 1973 to 1991' published by the Department of Health in 2006. Her research revealed previously unpublished documents that had been allegedly destroyed or lost, which exposed glaring omissions and inaccuracies, whilst pointing towards a government led cover up.

e. But let me not forget Matthew Johnson, a haemophiliac and a witness who was infected with Hepatitis C and exposed to vCJD.

5. For all four of our Core Participants and Mr Johnson and undoubtedly all of those infected and affected by contaminated blood products, the gravity of this long overdue Public Inquiry cannot be underestimated.

6. By 1991 the Minister for Health Virginia Bottomley had recognised what she termed the Special Status of Haemophiliacs. This was because she appreciated that a haemophilia sufferer in the 1970's and 1980's already faced a battle against a lifelong condition that adversely affected their health. It also affected schooling, employment, insurance, travel and mortgage prospects amongst other restrictions. If they survived the fight against the condition then these issues have been grossly exacerbated by infected blood. The recognition of the 'special status of haemophiliacs' was also because haemophiliacs had often been infected with multiple viruses and multiple members of their families have been infected and killed. The factor concentrates provided to haemophiliacs carried such a high risk of infection that even if you were lucky enough to avoid infection once, twice, or more times, eventually with blood sometimes carrying a 50 – 70% chance of transmitting a disease you were going to be infected.

7. The fact that only about half of haemophiliacs who were exposed to infected blood are alive today speaks for itself. Over recent days we have been reminded of the words of Lord Winston who in reference to the disastrous treatment of haemophiliacs correctly asserted that this was "the worst medical treatment disaster in the history of the NHS".

8. So this inquiry is dealing with a double disaster of whole blood cases and what appears to be the targeting of the haemophilic community. BUT both cases must be fully investigated by the Inquiry. Sometimes the two groups will require different considerations, different experts and different evidence.

9. We also suggest that always addressing the two groups together without careful thought will confuse the public's understanding of the issues. The different facts which apply to each group already confuses the media with

many stories having been published with incorrect or misleading facts. This is a disservice to both cases. The education and understanding of the public of the issues and medical conditions are fundamentally important, particularly considering the unjust stigmatisation and discrimination of the haemophiliac community in the past.

10. Therefore we ask that **where it is possible** and where there are separate questions to be addressed that haemophilia and whole blood issues are separated. We submit that dealing with this inquiry and these groups in this way may also provide some assistance to the respective members of the groups in allowing them to believe that their issues are understood, and this may also allow a better ability for people to lives and work and focus their attention on the parts of the inquiry for which they have the most concern.

The need to investigate 1950 onwards – Paragraph 1 TORs

11. We say this must be done in a proportionate and careful way. The Terms of Reference have provided a solid foundation for the Inquiry to begin what will be a sizeable task. However, noting that paragraph I of the ToR states that the Inquiry will "examine the circumstances in which men, women and children treated by the NHS in the UK were given infected blood and infected blood products in particular since 1970" we suggest that the if the Inquiry is to properly investigate what happened and why, the questions of precisely **who** knew **what** and **when** need to be answered. We believe that failing to adequately investigate what was known prior to 1970 would be a mistake.

12. What we suggest is required is a settled foundation or platform of what was known and what warnings there had been prior to 1970 about the danger of collecting blood from contaminated sources.

13. It was recognised in the 1930s that a virus from a blood donor could be transmitted to a recipient of blood or blood products. The potential problem of Hepatitis B began to be appreciated only shortly before World War II ended. During the Korean War of 1950-53 a plasma program that had been developed by the United States was discontinued because of the "alarming" percentage of hepatitis in service personnel who had received plasma infusions, especially where the plasma had been prepared from large pools.

14. Outbreaks of hepatitis in haemophiliacs in the US from first exposure to factor concentrates are known to have occurred in the early 1960’s. Importantly in 1966, the eminent American professor of surgery J. Garrott Allen published his findings in the peer-reviewed medical journal of surgical science and practice the ‘Annals of Surgery’ where he said that the most practical method of reducing the hazard of hepatitis B from blood is to **stop** using blood from prison and also ‘Skid Row’ donors.

15. We therefore feel it is essential that the Inquiry covers the period **prior** to the introduction of factor concentrates to the UK in 1973 so as to properly establish what was known in relation the dangers of Hepatitis A and B and the risk of pooling plasma and when it became known. We suggest that considering what we know had been identified by the end of the Korean War that 1950 would be the most appropriate start date from which to determine what was already understood by 1970 onwards. The most effective and economical way for this to be done will be for the Inquiry to provide a timeline or chronology of relevant dates and facts.

Timeline or chronology

16. There have already been timelines produced by campaigners which can assist. A detailed chronology showing the correspondence, the published research materials and warnings, the various media reports and

investigations and correspondence, charted against the known activities of the companies producing and pooling the infected plasma and against the various medical and political pronouncements will provide this Inquiry with a backbone of facts from which to draw its conclusions and make recommendations as to change.

17. Of course this timeline can only be populated, filled in, by the Inquiry who will act as the gatekeeper for references to be included and we will need to develop a system to differentiate hard facts and points from more debatable references. We can discuss with our document handlers, Relativity, the question of whether the documents held by this inquiry can be hyperlinked to the timeline but in any event each reference must be accompanied by the Inquiry reference.

18. We suggest that the use of a living and growing timeline will help the inquiry to come to a conclusion as to **who** knew **what** and **when**, and who was at fault and where criminal actions have been identified this Inquiry must not hesitate where it is appropriate to refer the matter to the DPP.

Extent of known infection – Paragraph 3 TORs

19. We welcome paragraph 3 of the TORs and the commitment to examine what other diseases people may have been exposed to. It must be highlighted that haemophiliacs have been infected with HIV, the full range of hepatitis viruses, parvovirus and exposed to vCJD. The Inquiry must utilise the latest expert research and analysis to establish what else infected blood has exposed the victims to and what medically can be done to help them.

20. We invite the Inquiry to specifically establish the number of haemophiliacs who have been exposed to vCJD, examine how this compares proportionately with instances of exposure in those receiving whole blood

transfusions and whether there is any malign reason why exposure amongst haemophiliacs was proportionately greater.

21. Sadly it seems to us that we have not yet seen the full crisis of vCJD.

Consent – Paragraph 6 TORs

22. The Inquiry will of course examine the issue of consent. The Nuremberg Code deals with consent to human experimentation:

> "1. **The voluntary consent of the human subject is absolutely essential**.
>
> This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved, as to enable him to make an understanding and enlightened decision."

23. The Hippocratic Oath for Doctors taken or at least in theory held dear by Doctors states "I will utterly reject harm and mischief".

24. The least any patient should expect before undergoing any treatment, let alone experimental treatment, is to feel safe in the knowledge that they have been allowed to make an informed decision to undergo that treatment with the full knowledge of the potential risks and consequences of that treatment. The last thing any human being should become is an unwitting guinea pig or lab rat, but that is precisely what happened to haemophiliacs.

25. The fact that haemophiliacs were targeted and used as unwitting test subjects was communicated in a letter discovered and preserved by Carol Grayson dated the 11th of January 1982 to all Haemophilia Centre Directors from the

Oxford Haemophilia Centre: The relevant passage will be shown on the screen by Henry upstairs and reads:

> "Although initial production batches may have been tested for infectivity by injecting them into chimpanzees it is unlikely that the manufacturers will be able to guarantee this form of quality control for all future batches. It is therefore very important to find out by studies in human beings to what extent the infectivity of the various concentrates has been reduced. The most clear cut way of doing this is by administering those concentrates to patients requiring treatment who have not been previously exposed to large pool concentrates. Those patients are few in number but a study along those lines is being carried out at Oxford to determine the infectivity of factor VIII concentrates produced by the Plasma Fractionation Laboratory, Oxford and Blood Products Laboratory, Elstree. This study shows that it is possible to demonstrate infectivity using quite small numbers of previously untreated patients."

This is truly, awfully shocking.

26. We now know that there was non-consensual testing of blood and organs of haemophiliacs; withholding of test results from patients who had been infected or exposed to disease who were being tested without their knowledge; there was destruction and withholding of medical records that evidenced what each individual had been tested and treated for; and the inaccurate recording of statistics including deaths of haemophiliacs exposed to infected blood.

27. Documents have been uncovered that provide evidence that government ministers gave their approval to the surveillance of haemophiliacs who had been infected with Hepatitis C and HIV. There are identifiable conflicts of

interest, particularly for doctors and the NHS, with decision makers believed to have been on the payroll of pharmaceutical companies who were providing the NHS with infected blood products and funding research. All whilst maximising profit from the exploitation of haemophiliacs. This warrants specific interrogation and investigation. Any who benefited financially must be exposed.

28. The clear, repeated and unacceptable breaches of the Nuremberg Code and the Hippocratic Oath must be fully investigated and those responsible identified and brought to justice.

Practical considerations

Commemoration

29. Yesterday we witnessed an incredibly moving commemoration. So many people have died and so many people's lives have been lost. For the survivors, their lives have been devastated and entirely consumed. Chair you stated yesterday that you want to put people at the heart of the Inquiry and that in order to do so during the first x3 months and final period of the Inquiry you will hear from the infected and affected. The Inquiry needs to hear from those who have been so infected and affected and needs to hear the evidence that they can provide about events, which are central to the understanding of the facts that are crucial to the core of this Inquiry.

30. Other Inquiries have allowed CPs to present what were called pen portraits or as I prefer, personal commemorations of people's lives and deaths. Within this Inquiry under the Terms of Reference at paragraph 4 (p.3 ToR onwards) this Inquiry is committed to considering the impact of infection from blood or blood products on people who were affected and on partners, children, parents, families, carers and others close to them. As Ms. Richards QC said yesterday the Inquiry is to consider "all of the impact on people's lives".

31. This aspect of the Inquiry is very important and the need to commemorate the lives lost has an important impact on this Inquiry's determination to ensure that (i). This never happens again (ii). There can be an accurate assessment of the extent and amount of financial support and compensation that should be considered in the future.

32. So, we need to address the question of how this can best be done when Sir as you pointed out, there is also a sad need to complete this Inquiry in a timely fashion. We ask that real latitude is given to those giving evidence concerning the impact on their lives and the lives of those who have been lost in order to properly present their evidence in this regard. In order to achieve this goal we suggest that there will be a need to discuss the impact section of the evidence with CTI and STI and the need potentially to provide a presentation that may well require photos, films or documents to be shown on a screen. This will ensure that this is dealt with properly and with dignity.

Establishing a Documents Protocol

33. Paragraph 9(a) of the TORs recognises that there is a real and identifiable issue as to the extent to which there have been wilful attempts to conceal the truth of what was known and what has happened. We say that there was a systematic attempt to destroy evidence, avoid the truth and thereby abdicate responsibility for the actions of the state and its representatives. We know that documents that ought to have been kept and stored in the National Archives have been destroyed or have gone missing. We know from the experience of Carol Grayson that she provided documents to the Government to plug the gaps in the archives that were said to be irretrievably lost and that since then that the documents she provided have since been held out to be 'newly discovered'.

34. There will no doubt be other infected and affected persons who hold documents or copies of documents that have been destroyed or lost according to official records. Due to the distrust of the Government and public bodies such as the NHS, there is understandably a deep sense of suspicion as to what will befall documents that are released to the Inquiry and this may give genuine cause to question whether to release those vital documents at all. This must be avoided, particularly if an accurate timeline is to be established so we know who knew what and when.

35. We therefore call on the Inquiry to establish a documents protocol to ensure that original documents are not lost and that in the spirit of openness and to fulfil the duty of candour for this Inquiry, there is a record made on copied documents and a referencing facility provided to ensure we know exactly who has produced each document to the Inquiry and when. We will of course provide more detailed points in our written submission setting out our proposals.

CP support

36. We also request that every effort be made to ensure the needs of the infected and affected families are put first in this Inquiry. Thought must be given through discussions with CPs to the provision of support and childcare at inquiry hearing days. Accessibility issues must be addressed, not only at the chosen venue for hearings but also through the provision of IT equipment and continuing IT support to enable those that can’t attend in person due to their health and who cannot otherwise afford such equipment are able to observe the Inquiry hearings. We also need to recognise that when it comes to the provision of evidence, video-link facilities may well be required.

Interim recommendations – Para 11 of TORs

37. We welcome the specific scope for the Inquiry to make interim recommendations set out at paragraph 11 of the TORs. We say it is entirely appropriate for the Inquiry to make interim recommendations as soon as it possibly can, particularly considering the financial plight of infected and affected haemophiliacs and the fact that many have died waiting for this Inquiry. The advantage of an Inquiry that will inevitably take some time is that the life span of the inquiry can be used to both make recommendations and the Inquiry can follow through those recommendations in to action.

Compensation and the current support payments schemes

38. We ask that the Chair reaches out to the Government and requests that they undertake through the DWP, not to carry out any further re-assessments of the **England Infected Blood Support Scheme** (EIBSS) payments for the duration of this Inquiry. In due course we will seek a recommendation of benefits pass-porting for haemophiliacs in line with the recommendations made by the Archer Inquiry, but there can be no good reason why the infected and affected should have to suffer the ignominy of having to jump through unnecessary procedural hoops to receive basic entitlements in what the final Report of the Archer Inquiry labelled "*an undeserved affront to their dignity*" (Archer Report p.93).

39. We suggest that the Inquiry reviews as part of its possible interim recommendations the disparity in support payments made across the UK and the inadequacy in particular of support in England for widows and widowers. Acknowledgment should be made that, after their loved ones were infected by the actions or inactions of the Government, many gave up their careers or could only enjoy limited careers because of the need to care for their infected partners.

40. As to current support payments and their assessments, there is a complete departure (in England through EIBSS at least) from the principle at Para 3, Pg13 of the 1991 Settlement leading to the MacFarlane Trust. That payments under that scheme (and therefore its successor, EIBSS) should be excluded from consideration in the assessment of social security or statutory benefits.

41. We also need to resolve the current and gross unfairness of ongoing payments across the English and Scottish borders and across the sea to Ireland. We suggest that the factors which have led to these payment inequalities be the subject of a timetable for written submissions, responses and a dedicated period set aside to hear representations to resolve these issues sooner rather than later and dealt with by interim recommendations.

42. Given the urgency of the situation facing the infected and affected members of the haemophiliac community, we also seek a recommendation for the payment of compensation. We remind you the important statements made in the final report of the Archer Inquiry with regards to the duty of government:

> “The very purpose of government is to protect its citizens, so far as possible, from life’s vicissitudes, and to afford them the best achievable quality of life…
>
> Where poverty is widespread, even though not universal, among a limited and readily defined category of citizens, and particularly where it is attributable to a specific misfortune, we believe that they are entitled to look to the government for redress...” (Archer Report p.93)

43. The Government has an immediate duty to step up, to protect its citizens and to provide the financial recompense that infected and affected members of both groups deserve.

Conclusion

44. This Inquiry cannot turn the clock back for the victims but it must establish the truth behind this terrible atrocity.

45. The medical profession must wake up to what has happened and people must be treated with respect. Once this inquiry is complete there must be an apology from the state, which acknowledges all that has happened. Everyone needs to find some measure of peace from the knowledge at least, belatedly, the State through this Inquiry has thoroughly investigated this tragedy and made recommendations to ensure that nothing of the like ever happens again.

46. Now this Inquiry has started over these two days with a real display of determination and goodwill - “positive waves”. Working with Peter, Collette, Steven and Carol we will all strive to support and where required Sir, push the Inquiry in the pursuit of its mandatory objectives.

47. Finally, let us not forget that after Archer and Penrose, this for our CPs and for many others is the third Inquiry into this disaster. That means, we suggest, we must work together to make this the last.

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The Chambers of Michael Mansfield QC

Instructed by:
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