Witness Name: Peter Wetherell
Statement No: WITN3912001
Exhibits: None
Dated: 09.04.21

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF PETER WETHERELL

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 30 November 2020.

I, Peter Wetherell, will say as follows: -

Section 1: Introduction

Q1: Please set out your name, address, date of birth and professional qualifications.

1. Peter Claude Wetherell, GRO-C. My date of birth is GRO-C 1950.

Q2: Please set out your employment history, including the positions you have held, the dates that you held these positions, the organisations in which you held these positions and your role and responsibilities in these positions. If it is more efficient, a CV could be annexed at this point.

2. I was a Civil Servant in the Department of Health and Social Security (subsequently Department for Social Security: Benefits Agency) from October 1971 to March 1997. I had various jobs appropriate to the executive grade, including trade union positions. From September 1997 to December 1998 I was key worker and housing assistant at Cambridge Housing Society. From May 1999 to date I have worked at Directions Plus (subsequently Disability Cambridgeshire) and have held the following roles; welfare rights caseworker, casework manager, Acting Chief Executive and Company Secretary and continue to do so.

Q3: Please set out your membership, past or present, of any committees, groups, associations, societies or working parties (not including those within the Haemophilia Society) relevant to the Inquiry's Terms of Reference, including the dates of your membership and the nature of your involvement.

3. I have not held or hold any membership relevant to the Inquiry's Terms of Reference.

Section 2: Previous Evidence

Q4: Please confirm whether you have provided any evidence or have been involved in any other inquiries, investigations, criminal or civil litigation in relation to human immunodeficiency virus ("HIV") and/or hepatitis B virus ("HBV") and/or hepatitis C virus ("HCV") infections and/or variant Creutzfeldt-Jakob disease ("vCJD") in blood and/or blood products. If you have, please provide details of your involvement and copies of any statements that you made.

4. I have not provided any evidence or been involved in any other inquiries or investigations as referred to in this question.

Section 3: Your Role and the Structure of the Haemophilia Society

Q5: The Inquiry is aware that you were the Local Chairman of the Cambridge branch of the Haemophilia Society in 1981, and an Executive Committee Member of the Society from 1983 to 1985. Please confirm and explain what your role and responsibilities were during your tenure and how your role and responsibilities changed over time (if at all).

5. I can confirm that I held these positions in the Haemophilia Society during the periods cited. I was also an active member of the Society with my wife from late 1978 following our son's diagnosis of Haemophilia B.

6. As Chairman of the Cambridge branch of the Society, my responsibilities included the chairing of regular meetings of the branch or group (including the Annual General Meeting) arranging fund raising activities and events in conjunction with the Secretary and monitoring the financial position with the Treasurer. Together with the Secretary I provided fellowship advice and support to families with newly diagnosed children within the area administered by the Haemophilia Centre at Addenbrooke's Hospital, Cambridge, subject to consent being obtained by the Centre Director. I attended Council meetings of the Haemophilia Society as often as required as a representative of the Cambridge Branch. I ceased to be Chair of the Cambridge Branch when I became a member of the Executive Committee in 1983. As a member of the Executive Committee my role was to join in delivering the policies of the Society as determined from time to time by the Council. This position did not change during my period of tenure.

Q6: When you joined the Haemophilia Society, what were the objectives and functions of the Society? If these changed over time, please detail when and why.

7. When I joined the Haemophilia Society the objectives of the Society were broadly to promote and protect the interests and well-being of haemophiliacs, their families and carers and the overriding objective was to seek improvements in care and treatment. To this end the objectives were to provide fellowship, raise funds to support local centres and the Haemophilia Society nationally, and to encourage research into improved and safer blood products.

Q7: Please describe how the organisation was structured, including the governance arrangements and the day to day management and running of the Society. If this changed over the period of your tenure, please set out those changes.

Q8: Please describe the relationship between the Board of Trustees, Council, Executive Committee and the day-to-day management of the Society.

8. As I recall, the structure of the Society and the relationship between its parts operated at three levels of organisation:

a) The local groups or branches had a relationship with their Haemophilia Centres and Centre Directors, reflecting the needs and requirements of members in their locality. The branches or groups appointed their own officers and committees and sent representatives to Haemophilia Society National Council meetings. Local groups raised funds and were generally self-supporting. They were empowered to submit motions to Council meetings and seek approval for the funding of local initiatives. Local groups maintained as and when contact with the Haemophilia Society through the Co-ordinator, David Watters based at the Trinity Street premises in London.

a) The Executive Committee which was elected by the Council of the Haemophilia Society at the AGM and included the Officers of the Committee: Chairman, Treasurer (the Trustees). The Executive Committee met monthly and was supported by the Co-ordinator (a paid member of the Trinity Street staff). The Executive Committee appointed from within its number Sub-Committees which dealt with specific issues of concern to Haemophilia Society members. The Officers of the Executive Committee maintained links with the Medical Advisory Panel.

b) The Council of the Haemophilia Society was the ruling body. It was convened by the Chairman of the Society to receive reports, listen to addresses by medical professionals and submit questions and generally oversee the governance of the Society. It determined the policy of the Society on key matters and bonded the Society together through the group representatives.

Q9: Please list all the different Haemophilia Society sub-committees, "task groups" and/or advisory bodies that you were involved in and describe the purpose, functions and responsibilities of each committee, "task group" and/or advisory body.

9. My primary interest was in strengthening the group structure. I felt that the structure of the Haemophilia Society was lacking; there did not appear to be a formal constitutional framework and I considered that there was cause to develop a formal means of liaison between Branches (often interchangeably referred to a 'Groups') and the Executive Committee in order to provide assistance to the Co-ordinator, as his workload was heavily increased by having to deal with enquiries from Branches. I also had concerns with regards to how often the Council meetings were held. Improvements as to the structure between the Executive Committee, the Council and the Branches was not however considered a priority at the time.

10. I was not involved in any of the sub-committees, 'task groups' or advisory bodies because I did not believe I had the requisite skills or qualifications. Further, I did not have the time to be involved in sub-committees due to work pressures I had at the time.

Q10: To the best of your knowledge, please list all the committees, "task groups" and/or advisory bodies that the Haemophilia Society's Executive Committee, Trustees and staff relied on for medical advice and opinions on the safety of blood products and/or the risks of transmission of HIV and hepatitis. Please include, where possible, details on the extent to which (if any) they were staffed by members of the Haemophilia Society, external advisors, pharmaceutical representatives and/or clinicians.

11. Other than the Medical Advisory Panel, to whom frequent reference was made during my time on the Executive Committee, I cannot recall all of the committees, 'task groups' and/or advisory bodies with which the Society was involved in the U.K. Sub-committee did also come and go.

12. To the best of my knowledge the Society at all levels relied upon the medical advice and opinions of the Director of the Blood Products Laboratory, Medical Advisory Panel and Centre Directors at all times in the matter of blood products, and/or the

transmission of hepatitis and HIV. They were trusted advisors and we were reliant on information provided to us given their expertise and qualifications. Haemophilia Society staff were not staff members of other relevant bodies as far as I am aware.

13. There was no register of outside interests that I was aware of but I feel certain that members of staff and members of the Haemophilia Society would have declared their involvement in any other relevant bodies.

3.1 The Medical Advisory Panel

Q11: To the best of your knowledge, please describe the purpose, function and responsibilities of the Medical Advisory Panel. If this changed over time, please set out this information according to applicable time frames.

14. To the best of my knowledge the purpose, function and responsibility of the Medical Advisory Panel was to provide advice in relation to the clinical aspects of managing and treating haemophilia. I do not recall any change during my time on the Executive Committee. I was however shocked to since learn that the Medical Advisory Panel did not sit as a Panel and in fact it was a loose arrangement where no minutes of meetings were made.

Q12: To what extent (if any) were the opinions of the members of the Society's Executive Committee informed by the Medical Advisory Panel? What other resources (if any) did committee-members rely on for opinions on the safety of blood products and/or the risks of infection from hepatitis and HIV?

15. I believe that the Executive Committee relied entirely upon 'our own' (in the words of the Revd. Tanner) Medical Advisory Panel in coming to collective decisions. We were dependant on their knowledge and experience.

Q13: How did the Haemophilia Society select members of the Medical Advisory Panel? What criteria were used, if any? How did membership change over time? You may be assisted by [PRSE0000956] which sets out the membership in the 1980s.

16. I do not recall that the Haemophilia Society appointed members of the Medical Advisory Panel, or had any influence in the selection process. The membership of the Medical Advisory Panel was listed in the Annual Report each year and was thereby formally noted by the Council of the Haemophilia Society when adopting the report at the A.G.M.

Q14: During your tenure at the Haemophilia Society:

a. How was advice sought from the Medical Advisory Panel?

b. Who decided when and about what matters advice would be sought?

c. Was advice sought from all members of the Medical Advisory Panel or only a selection of them? If a selection, how was that selection determined?

d. How were matters discussed by members of the Medical Advisory Panel?

e. Did some members of the Medical Advisory Panel have more influence than other members, and if so, who carried more influence than others?

f. How was advice communicated from the Medical Advisory Panel to the Society?

g. How was the Panel's advice recorded once it was received by the Society?

h. In relation to what issues relevant to the Inquiry's Terms of Reference, did the Society seek the advice of the Medical Advisory Panel and what was the advice provided by the Panel on those issues?

17. I cannot recall the precise arrangements that relate to questions 14 (a) to (h). I do not recall having sight of a protocol for the Society's communication and dealing with the Medical Advisory Panel but there was, I believe, a close relationship between the respective Chairs of the Haemophilia Society and the Medical Advisory Panel. I think communications may have been facilitated through the Co-ordinator, but not exclusively so.

Q15: As far you can recall, please describe:

a. The extent to which the Haemophilia Society relied on its own judgement when deciding whether or not to formulate policy on the basis of the Medical Advisory Panel's advice;

b. All examples, relevant to the Inquiry's Terms of Reference, of when the Society did not follow the Medical Advisory Panel's advice;

c. All examples, relevant to the Inquiry's Terms of Reference, of when other members of the Medical Advisory Panel disagreed with the advice of the Chair of the Panel;

d. All examples, relevant to the Inquiry's Terms of Reference, of when the Haemophilia Society did not follow the advice of the Chair of the Medical Advisory Panel.

18. In relation to questions 15 (a) to (d) I believe that the judgement of the Executive Committee was informed by the advice of the Medical Advisory Panel at all times. I am unfortunately unable to recall any examples in respect of points (b) to (d).

3.2 Blood Products Sub Committee

Q16: ***Please describe the purpose, function and responsibilities of the Blood Products Sub-Committee set up by the Haemophilia Society in the 1980s and the extent of your***

involvement with the group. [You may be assisted by HSOC0029476_038 and HSOC0029476 _039]

Q17: Who were the members of the Blood Products Sub-Committee and how were they selected to join the Sub-Committee? What criteria, if any, were used? How often did the Sub-Committee meet?

Q18: To what extent, if at all, did the Haemophilia Society rely on findings or conclusions from the Blood Products Sub-Committee to form its policies?

Q19: Did the Blood Products sub-Committee investigate the safety of commercial blood products? If so, from where was the information concerning the safety of these products sourced? Please provide as much detail as possible, specifying the investigations conducted by the Blood Products Sub-Committee and the resources they relied on.

a. Was the Medical Advisory Panel involved in any discussions about, or in the evaluation of, the information that was gathered and/or disseminated by the Sub-Committee in relation to the safety of commercial blood products?

b. Was the information that was reported to the Council of the Society disseminated? If so, please set out to whom it was provided.

Q20: Did the Blood Products Sub-Committee meet with pharmaceutical company representatives? If so, why? In your answer, please detail as much as possible any relationship (financial or otherwise) between the Blood Products Sub-Committee and specific pharmaceutical companies

19. In response to questions 16 to 20, Mr Ken Milne of the Executive Committee took lead responsibility for the work of the Blood Products Sub-Committee. I was not involved in the meetings that took place as I was not a member of the Blood Products Sub-Committee but the minutes of the Executive Committee reflect Mr Milne's progress reports as to his engagement with the parties. I think Mr John Prothero and Mr Howard Abrahams were involved from time to time in discussions about the BPL. I am unfortunately not able to recall the discussions and decisions that centred upon the matters raised in questions 16 – 20.

Section 4: Communication and Dissemination of Information by the Society

4.1 Knowledge of Risk and Decisions on Society's Policy

Q21: ***When you first joined the Haemophilia Society:***

a. What did you know and understand about the risks of the transmission of hepatitis from blood and blood products? What were the sources of your knowledge? How did your knowledge and understanding develop over time?

b. What did you know and understand about the risks of the transmission of HIV/AIDS from blood and blood products? What were the sources of your knowledge? How did your knowledge and understanding develop over time?

c. What did you know and understand about the seriousness of, and likely prognosis for those with, HIV/AIDS? What were the sources of your knowledge? How did your knowledge and understanding develop over time?

20. I had no knowledge of hepatitis transmission when I joined the Haemophilia Society in 1978, other than common knowledge at the time that intravenous recreational drug users were at risk because of needle sharing. I became aware that haemophiliacs were exposed to the risk of hepatitis infection, including Non A and Non B hepatitis, as a result of conversations with members of the Cambridge Group (Branch) in 1979. Through talking with the Secretary of the Group we became aware that Non A and Non B was regarded as being of no great significance and regarded as a mild infection which haemophiliacs were more liable to being exposed to as a consequence of treatment. The risk of hepatitis was however never disclosed to me or my wife by clinicians at that time through our involvement with haemophilia care in regards to our son's condition.

21. I became aware of HIV/AIDS transmission as a consequence of the publicity in the press and media in May 1983, arising from the incidence of transmission in the homosexual community and a reported case of an infected haemophiliac. Professor Bloom, Chairman of the Medical Advisory Panel, delivered a speech to the Council of the Haemophilia Society in the autumn of 1983 in which he played down the idea of risk to haemophiliacs, notwithstanding the publicity about 'killer blood.' I was not aware of the risks of transmission of HIV/AIDS before this date.

22. There was considerable unease about the emerging situation in 1983 but the Executive Committee and the Haemophilia Society Council felt that they had to be guided by the clinical judgements expressed through the Medical Advisory Panel's Chairman and the Centre Directors. It was felt that seemingly alarmist reporting of the press had to be challenged in an attempt to halt the fear, stigma and revulsion that haemophiliacs were starting to experience in their daily lives. Minute 83.124 of the meeting of 13th October 1983 refers [HSOC0029476_029].

23. In relation to the knowledge of risk, the Executive Committee had regard to the professional advice from the Medical Advisory Panel concerning the issue of supply of blood products and the clinical judgements of Centre Directors. I think risk was

regarded as rather an abstract concept at this time that had not been tested by sufficient factual evidence to inform the balance of probability. In regards to the seriousness of HIV/AIDS, I was aware that HIV/AIDS compromised immune systems, however at the time the most concerning issue was the social impact on haemophiliacs by being diagnosed with HIV/AIDS.

Q22: In the 1983 Annual Report, it was noted that "The Executive Committee published its policy as being that the benefits arising from the continued use of blood products far outweighed any risk involved with regard to AIDS" [HSOC0019506]. Please explain:

a. Who decided that this would be the Society's policy? Was it a unanimous decision of the Executive Committee? Did anyone disagree with the policy? If so, who disagreed and why?

b. What information did the Committee have available to them before making this decision? Who provided that information? When was it provided? Was the information in writing or was it conveyed to the Committee verbally?

c. Was any information provided to the Committee addressing any counter-arguments to the policy that was ultimately adopted?

d. Why was this policy decision made?

24. The policy statement in the 1983 Annual Report was based upon the Executive Committee's understanding of the consensus formed at the meeting of the Council of the Haemophilia Society held on 8th October 1983 following the speeches of Professor Bloom, Dr Rizza and Dr Aronstam - 'those present were unanimous in their appreciation.' Minute 83.26 refers [HSOC0019923_006]. The Council effectively endorsed retrospectively the urgent action taken in the name of the Executive Committee on 4th May 1983 when Revd. Tanner approved and issued the statement prepared by Professor Bloom [DHSC0001228].

25. I cannot recall that there were any counter-arguments or alternative evidence put forward. There was no mention of concern or resistance by the Haemophilia Centres reported to us officially or tabled to us as the Executive Committee.

Q23: Please consider the letter from Rev Alan J. Tanner dated 4 May 1983 [DHSC0001228]:

a. Please explain why the letter was sent out on that date?

b. Had the Haemophilia Society sought and/or obtained any advice in relation to AIDS before this date? If so please set out who that advice was sought from, what advice was obtained and what steps the Haemophilia Society took having received such advice.

c. Were the contents of the 4 May 1983 letter discussed and/or verified as accurate with any members of the Medical Advisory Panel, save for Professor Bloom? If so, please set out who it was discussed with and what their view was. If it was not, please explain why not.

d. This letter appears to have been discussed at the Executive Committee meeting on 12 May 1983 [HSOC0029476_024]:

i. Had the Executive Committee been told about the letter before it was sent out? If so, what was said, by whom and when?

ii. At the meeting, what were the Executive Committee told about the letter? What were you told about who provided the information in it?

26. As to the precise circumstances surrounding the communication of 4th May 1983 I am unable to recall how or by whom (other than Professor Bloom and the Revd. Tanner) the 'on the hoof' policy decision was made. I attended my first meeting of the Executive Committee on 12th May 1983 by which time the policy appeared to be de facto. There was no proposal to resile from the policy on the basis of alternative evidence or counter-arguments because that evidence did not appear to exist. I was guided by the senior members of the Executive Committee and the Co-ordinator's report of telephoned disquiet among the members about the implications for treatment and the emerging societal crisis. As far as I can recall minute 83.55 (b) [HSOC0029476_024] is an accurate summary of the agreed position at the time and it continued to be the policy of the Haemophilia Society throughout my two years on the Executive Committee.

27. I am not aware that any advice about AIDS had been sought before 4th May 1983.

28. The first time I became aware of AIDS was when the BBC Horizon programme, 'Killer in the Village' was broadcast on 25th April 1983.

29. I am not aware that members of the Medical Advisory Panel, other than Professor Bloom, were consulted about the content of the letter of 4th May 1983.

30. The Executive Committee as a whole had not been told about the letter before it was sent out, however it is possible that senior members of the Executive Committee may have been put in the picture before it had been sent out.

31. As far as I can recall, it was only Professor Bloom who had worded the statement incorporated in the Revd. Tanner's letter. I presume that his draft had been cleared by the Revd. Tanner, at the very least, since it went out in his name. We were told that

the letter had been issued in an attempt to forestall alarm and panic amongst the membership of the Haemophilia Society.

Q24: At the Executive Committee meeting on 12 May 1983 [HSOC0029476_024], it was also noted that "... it was agreed unanimously that until there is evidence to prove otherwise the Society's policy would be to encourage members to continue with their present treatment programmes, subject to the advice of their Centre Directors, and that full support would be given to self-sufficiency in blood products at the earliest possible date". Insofar as you have not addressed this matter already, please explain:

a. ***Who decided that this would be the Society's policy? Was it a unanimous decision of the Executive Committee? Did anyone disagree with the policy? If so, who disagreed and why?***

   What information did the Committee have available to them before making this decision? Who provided that information? When was it provided? Was the information in writing or was it conveyed to the Committee verbally?

   Was any information provided to the Committee addressing any counter-arguments to the policy that was ultimately adopted?

   Why was this policy decision made?

   What did the Society understand by achieving self-sufficiency? What actions was it envisaged that the Society would take in giving its full support?

32. I have nothing further to add in response to the above questions (a) – (e) other than to say that the need for self-sufficiency appeared to be imperative. Further, the need for self-sufficiency had been in the background since 1975 when Dr David Owen as Minister in the Department of Health and Social Security announced the programme to make the U.K self-sufficient in blood products.

Q25: In May 1983, the Haemophilia Society Bulletin 1983, included an article entitled, "'AIDS' and Haemophilia" [PRSE0004120, page 12]. The author interviews Dr Peter Kernoff, Director of the Haemophilia Centre at the Royal Free Hospital in London. Dr Kernoff claims that AIDS is an "unusual disease" and that he "expects it to remain a rare disease". He also claims that the link between AIDS and haemophilia is "very tenuous" and that the "idea that there's an epidemic of AIDS amongst haemophiliacs is ludicrous". He states that "the benefits [of treatment with concentrates] far outweigh the possible risks" and that he sees "no reason to make any change from current practice". To the best of your knowledge, how (if at all) did the Haemophilia Society verify the accuracy of the statements made by Dr Peter Kernoff in May 1983? Please set out precisely who within the Haemophilia Society verified the accuracy of the statements; who they spoke to and/or on what materials they relied; how that information was recorded; and who decided, and how the decision was taken, that this was proper information to include in the Bulletin.

Q26: In the minutes of the Executive Committee meeting on 8 October 1983 [HSOC0019923_006] it is recorded that Professor Bloom had given a presentation that morning on AIDS, including "the present situation in the United Kingdom".

Please set out, insofar as you can recall, what the presentation addressed and what information you understood from it. During the presentation, did any other attendees challenge and/or disagree with Professor Bloom's characterisation of the situation in the United Kingdom?

Q27: The Bulletin Edition 32, No. 1, 1984 published an article entitled "Blood Products" by Ken E Milne. In the article, Mr Milne states: "We have no evidence as yet [as] to whether AIDS may be acquired more readily from commercial Factor VIII than from the NHS product but, of course, if AIDS becomes established in the UK then NHS blood and plasma supplies are just as likely to transmit AIDS as commercial concentrates. All things considered, haemophiliacs have no reason to be worried about using commercial concentrates" [PRSE0000922]. To the best of your knowledge, how (if at all) did the Haemophilia Society verify the statements made by Mr Milne? Please set out precisely who within the Haemophilia Society verified the accuracy of the statements; who they spoke to and/or on what materials they relied; how that information was recorded; and who decided, and how the decision was taken, that this was proper information to include in the Bulletin.

33. In relation to questions 25 to 27; I cannot recall who verified the accuracy of the content of the May 1983 Bulletin. I presume the editor, Clive Knight, would have checked his sources.

34. I cannot recall the exact content of Professor Bloom's speech which was referred to in the Executive Committee meeting on 8 October 1983 but it was intended to reassure those present about AIDS transmission in the U.K. At the time I think there was a feeling that we were in a state of denial, damage had been done and we did not want to face it; it would also have meant many people having to abandon their treatment programmes. I think a couple of people walked out of the meeting (in response to the downplaying of the issue) but he was not challenged on any of the points he made.

35. I cannot recall who verified the accuracy of The Bulletin Edition 32, No 1. 1984. The editor, Clive Knight, marshalled the material for the Bulletin.

Q28: Subsequent minutes of meetings of the Executive Committee indicate that AIDS was mentioned but not discussed. What information was the Society receiving about AIDS at this time? From whom was it being obtained? Why did the Society consider that nothing further was required to be done? At what point in time, and why, did the Haemophilia Society decide that their advice to members needed to change?

Q29: In the 1984 Annual Report the "main responsibilities of the Executive Committee" were noted as keeping members informed and of emphasising their policy that "the benefits arising from the continued use of blood products far outweigh any risk involved with regard to AIDS" [HSOC0019505].

a. Who decided that this would remain the Society's policy? Was the decision kept under continuing active review or was it the case that the earlier decision was simply not re-visited? If

there was an active review of the decision, when was that decided? Was it a unanimous decision of the Executive Committee?
Did anyone disagree with the policy? If so, who disagreed and why?

b. What information did the Committee have available to them when maintaining the policy? Who provided that information? When was it provided? Was the information in writing or was it conveyed to the Committee verbally?

c. Was any information provided to the Committee addressing any counter-arguments to the policy that was ultimately adopted?

d. Why was this policy maintained in 1984?

Q30: In the minutes of the Executive Committee meeting on 16 September 1984, Ken Milne is recorded as providing a report from the Blood Products Sub-Committee [HSOC0019923_010]. It is noted that Mr Milne "expressed some concern about the apparent lack of screening of donors in the UK which in many cases is less stringent than that imposed by the major commercial companies in the United States". Was this a widely held view within the Society at that time? Are you aware of where Mr Milne obtained such information from? Was this information verified by the Society in any way? If so, by whom, when and how?

Q31: On 8 November 1984, "[i]n reply to a question from the Co-ordinator, the Executive Committee confirmed that there was no medical evidence available to show that UK products were in any way "safer" than imported ones, particularly from hepatitis or AIDS risk" [HSOC0029476_042]. How did the Haemophilia Society Executive Committee come to this conclusion? What were the sources that they relied on? How did this position develop over time?

36. In relation to questions 28 to 31 I cannot recall the position other than that I believe we continued to rely on the advice of the Medical Advisory Panel in the absence of any advice to the contrary. There appeared to be no reason to change the policy in 1984, particularly in light of developments in the heat treatment of concentrates as referenced in Haemofact No3 of May 1984 [PRSE0001094_0002] as this was thought to provide reassurance. Heat treatment of concentrates was introduced in the US in 1984 but there was a time lapse of a year until BPL started to heat treat blood products which I believe was due to financial reasons.

Q32: On 10 January 1985, the Executive Committee reported that it was "concerned that the introduction of heat-treated materials had been patchy [...] at least one Supra-Region had not yet introduced heat-treated materials" and that "there was wide disparity in the practice of individual centres". The Committee also expressed "concerns [...] that the reinforced leaflet for donors was not yet available while many Transfusion Regions had exhausted their supplies of the old leaflet. Many regions still had no warning notices for "at risk" donor groups" [HSOC0029476_044]. Please explain what happened in relation to these concerns and how, if at all, these concerns influenced the Haemophilia Society's policies on the safety of blood products and communications with members of the Haemophilia Society.

Q33: On 7 February 1985 and 14 March 1985, the Executive Committee expressed concerns about AIDS and blood product supplies [HSOC0029476_045 and HSOC0029476_046]. Please explain what happened in relation to these concerns and how, if at all, these concerns influenced the Haemophilia Society's policies on the safety of blood products and communications with members of the Haemophilia Society.

37. I cannot recall that we had reason to change our policy in light of these circumstances and as set out above, we referred to the Medical Advisory Panel for advice.

4.2 Communication to Members

Q34: Please identify the members of the Executive Committee and/or committees of the Haemophilia Society responsible for editing and selecting material for the Bulletin, Haemofact and other Haemophilia Society publications during your tenure.

38. Clive Knight was the editor of the Bulletin and Haemofact during my tenure. I am unable to provide any further information as to who was also involved in selecting material for the Bulletin, Haemofact and other Haemophilia Society publications whilst I was involved with the Haemophilia Society.

Q35: In his evidence to the Penrose Inquiry, Chris James, Chief Executive of the Haemophilia Society, stated that, "the activities of the Society in disseminating information to its members were often spearheaded by haemophilia doctors" [PRSE0000851, page 3]. Do you agree with this statement? If so, please provide details identifying doctors where possible and detailing their activities in disseminating information to the Society's members.

39. I agree with the statement made by Chris James to the Penrose Inquiry. The information in communications was clearly attributed to named practitioners or relied upon from approved and credible sources known to the editor and the Chairman. I am unable to provide any further details in identifying specific practitioners and their activities in disseminating information to the Society's members.

Q36: Did the Haemophilia Society receive direct inquiries from the public or members who required advice with regard to the safety of blood products? If so, how were these queries handled? Who would respond? What resources (if any) did the Haemophilia Society rely on to enable a response? Please set out specifically, to the best of your knowledge, what advice and/or information the Society had and from whom that had been provided.

40. I cannot recall inquiries being made by the public direct to the Haemophilia Society and inquiries by members would have been handled by the Co-ordinator at the Trinity

Street office. We continued to rely upon the advice of the Medical Advisory Panel and referred members to their Centre Directors for case specific advice.

Q37: To what extent, if any, did haemophilia centre directors and members of the Medical Advisory Panel assist in proposing and/or editing and/or selecting material for the Haemophilia Society's publications? If you have already answered this question in other sections of your response, please identify the paragraph number(s).

41. I cannot recall the precise relationship between the editor and the contributors in respect of the material chosen for publication. I do not believe that the Medical Advisory Panel exercised an editorial function. There was not a corresponding figure on the Medical Advisory Panel to Clive Knight (editor for the Haemophilia Society). He would have likely spoken with Revd. Tanner, Chairman of the Society who may have spoken with Professor Bloom. Most of the material included in the Haemofact series or Bulletins would have been word for word what medical practitioners had put together and Clive would edit in terms of presentation. He would not have interfered with the content when doing so.

Q38: To what extent, if any, did representatives of pharmaceutical companies assist in proposing and/or editing and/or selecting material for the Haemophilia Society's publications? If you have already answered this question in other sections of your response, please identify the paragraph number(s).

42. I am not aware that representatives of pharmaceutical companies had any involvement in the Society's publications.

Q39: How did the Haemophilia Society select or identify contributors and interview subjects for its publications? Specifically, in relation to its publications which gave medical and/or other opinions about the safety of blood products and the risk of infection, how were the contributors for such articles identified? What, if any, were the criteria for someone to be able to write an article for its publications?

43. I cannot recall the process under which the editor marshalled the material for the Society's publications. I believe Clive Knight as the editor may have consulted with the Chairman on topics that would have been of interest to members and who in the medical community may have been best placed to provide expert advice and information.

Q40: To what extent (if any) did the Haemophilia Society verify medical and scientific information and/or opinions provided by contributors to its publications? If verification took place, please describe the process by which this occurred.

44. I am unsure who the Society would have turned to, to provide verification other than members of the Medical Advisory Panel because they were deemed to be the experts in regards to medical and scientific information. Today, we have the internet, which allows for investigation of different sources of advice- for example from medical journals. At the relevant time there was no way that you could get anyone to put forward a counter-position.

45. Dr Peter Jones was an important person at that time, he had a progressive approach for treatment of haemophiliacs and improving prospects for their lives. The Cambridge Branch invited Dr Jones to speak to members of the Branch. His published book "Living with Haemophilia" was an important resource for us as we couldn't get information elsewhere, including from our Haemophilia Centre Director. He was the alternative voice, who opened up possibilities for future treatment.

Q41: Please identify the members and/or committees of the Haemophilia Society responsible for editing and selecting material for the Haemofact.

46. As far as I can recall, the editor, Clive Knight, and the Chairman, the Revd. Tanner consulted over Haemofact.

Q42: Please describe how the Haemofact was made available to healthcare professionals. What was the Haemophilia Society's knowledge of the extent of its reach amongst professionals who provided medical care and treatment to haemophiliacs?

47. I believe that the Haemofact was circulated to Haemophilia Centres with the understanding that it would be distributed throughout the Centres. I am unable to say to what extent it went beyond the leaflet rack and corridors of those Centres and its reach to healthcare professionals.

48. It is also worth noting here the influence of the Haemophilia Society at that time as we did not represent every haemophiliac and membership was a minority of haemophiliacs. The extent to which the Haemofact was an influential document with haemophiliacs is debatable and people with mild haemophilia might never have seen it if they did not have cause to attend Haemophilia Centres regularly.

Q43: In 1990 Professor Bloom prepared a report for the 1991 HIV Litigation [BPLL0001351_076]. At page 174, he notes that: "From May 1983 the Haemophilia Society circulated their members and Haemophilia Centres with a series of pamphlets on AIDS called 'Haemofact' which contained relevant information and advice. These pamphlets were produced by the Society but not with input from the Medical Advisory

Panel. I have no firm knowledge of the source of the factual information needed to prepare the pamphlets… ". Please comment on the accuracy of Professor Bloom's statement. To what extent (if any) did the Haemophilia Society rely on its medical advisors and/or the Medical Advisory Panel for the content of Haemofact? What other resources (if any) did the Haemophilia Society rely on?

49. I am astonished that Professor Bloom as Chair of the Medical Advisory Panel sought to distance himself and the Medical Advisory Panel from the Haemofact series in his report. I was always under the impression that the content of the Haemofacts was approved by the Medical Advisory Panel and that the Panel had professional knowledge of contributors.

4.3 Communication on Blood Products

Q44: To the best of your knowledge, please detail the Haemophilia Society's policies with regard to communication on the safety of imported blood products. What information did the Haemophilia Society communicate to members? How did these communications develop over time?

50. Ideally the Society would have wished for self-sufficiency in the U.K. 'at the earliest possible date' - Minute 83.55(b) refers [HSOC0029476_024]. However, the reality was that imported blood products appeared to be essential in the medium term, at least, in order to maintain supplies. With the advent of heat treated products, the imperative for self-sufficiency seemed less urgent and communications with members stressed the importance of requesting heat treated products from their Centre Directors.

4.4 Communication to Healthcare Professionals

Q45: Please detail any activities the Haemophilia Society conducted with the purpose of disseminating information to healthcare professionals during your tenure. If this changed over time please detail when and why.

51. I cannot recall the position other than that Haemofact was sent out to the Haemophilia Centres (as above) with the expectation that the contents would be passed to relevant healthcare professionals.

Q46: Were there other circumstances in which the Haemophilia Society did make "recommendation for action by Centres " or seek to influence UKCHDO policy and practices?

52. I am not aware of other circumstances.

Section 5: Pharmaceutical Companies

5.1 Financial Relationships

Q47: To what extent did the Haemophilia Society rely on financial contributions from pharmaceutical companies manufacturing and/or supplying blood products? In your answer, please provide as much detail as possible on any of the Haemophilia Society's activities, publications, appointments and staff that were funded or partially funded by financial contributions from pharmaceutical companies. Please describe the level and nature of funding that was being provided when you commenced your tenure at the Society and how that changed, if at all, over time.

Q48: How, if at all, did the Haemophilia Society's fundraising activities develop over your tenure? What factors or activities, if any, contributed to increasing or decreasing financial contributions to the Haemophilia Society from pharmaceutical companies manufacturing and/or supplying blood products?

Q49: Please explain any differences in the Society's relationships with the different pharmaceutical companies. For example, were there some pharmaceutical companies that donated more, in terms of frequency and/or amount, than other pharmaceutical companies, to the Haemophilia Society? If so, which ones? Did they have different expectations of the Society? Did they want to fund different activities or functions?

Q50: What, in your view, were the motivations or expectations, if any, of pharmaceutical companies who donated to the Haemophilia Society? Was there an expectation that the Haemophilia Society would provide anything in return and if so, what?

53. In relation to questions 47 to 50 I have no recall of the issues highlighted other than to say that I had no suspicion of the motives behind donations to the Haemophilia Society and that the Haemophilia Society did not have a transactional relationship with any donors. Pharmaceutical companies would sometimes have stalls at the Haemophilia Society's AGMs but they were not permitted to sell anything to anybody. In regards to donations made by pharmaceutical companies, these were made for specific causes, for example air travel for a conference.

5.2 Other Relationships

Q51: What relationship did the Executive Committee-members of the Haemophilia Society have with pharmaceutical companies? Did any representatives of pharmaceutical companies join the Haemophilia Society, either while they still worked for the pharmaceutical company or after they left?

54. I was not aware that individual members of the Executive Committee had a relationship with the pharmaceutical companies. I do not recall that there was a register of

interests. I cannot say if representatives of the companies joined the Society because membership of the Society was not conditional upon disclosure of circumstances.

Q52: To what extent did the Haemophilia Society rely (if at all) on communications from pharmaceutical companies for assurances or opinions on the safety of blood products? If so, please provide as much detail as possible on the points of contact in pharmaceutical companies, the advice provided, the issues raised, and the frequency of these communications. [BPLL0002037 may assist you.]

55. BPLL0002037 does not assist me because the letter is dated 2nd February 1987 and as I have set out above, I ceased to be a member of the Executive Committee in April 1985. I do not recall that this question arose during my tenure.

Section 6: Relationships with the Government

Q53: Please detail the Haemophilia Society's relationships with the Government and individuals in public office. Who were the main points of contact? How were these relationships formed? Were there regular meetings?

56. The only Government contact that I can recall of any significance is Lord Glenarthur, Parliamentary Under Secretary in the Department of Health and Social Security, who met with the Revd. Tanner, John Prothero and David Watters on 8th September 1983. The outcome of the meeting was reported to the Executive Committee on 15th September 1983. Minute 83.112 [HSOC0029476_028]. There was a meeting with Lord Glenarthur scheduled to take place on 7th December 1984 at which a delegation comprising Revd. Tanner, Mr Milne, Mr Knight and David Watters would 'discuss points of concern arising from AIDS.' Minute 84.133 [HSOC0029476_043].There was a subsequent letter to Lord Glenarthur agreed at the Executive Committee meeting of 10th January 1985. Minute 85.04(b) [HSOC002946_044]. I am not aware of any other contacts and meetings other than contact by David Watters with Lady Masham prior to the House of Lords debate on 18th March 1985. Minute 85.30(d) [HSOC0029476_046]. These meetings were not reported in detail to the Executive Committee. I personally became dispirited with the Society's dealings with the Government after undertakings which were made which were not followed through, or little progress made, using Dr David Owen's programme for self-sufficiency in 1975 as an example. I did feel they were at times paying lip service to issues raised by the Society.

6.1 The Supply of Imported Blood Products

Q54: Please identify who was responsible for deciding the Society's positions and representations made to the Government regarding the use and supply of imported blood products.

57. Mr Ken Milne took the lead for the Blood Products Sub-Committee on the question of imported blood products.

Q55: What were the key issues that the Society pursued?

58. The key issues were reliability of supplies of factor concentrates, the heat treatment of blood products and the use of such products for treatment in Haemophilia Centres.

Q56: Why did the Society take the stance that the importation of US blood products should not be suspended? What information, and from whom, did the Executive Committee have when deciding its policy in this regard?

59. I have been prompted to respond to this question by reference to HSOC0029476_024. Minute 83.55(ii) appears to be a record of the decision taken by the Executive Committee in relation to the importation of U.S. blood products. This meeting took place on 12th May 1983 in the wake of the letter issued to members on 4th May 1983 in the name of the Haemophilia Society, incorporating the text of Professor Bloom's statement. Effectively the policy decision in relation to imported blood products had already been made in the letter of 4th May 1983. As above, this was my first meeting as part of the Executive Committee. See my answer to Q23 above.

Q57: Did the Haemophilia Society receive assurances by the Government or individuals in public office on the use and supply of imported blood products? If so, please provide details of the assurances that the Society received, with details of the individual or department that made them.

60. I cannot recall Government assurances being made on the use and supply of imported blood products.

6.2 Self-Sufficiency

Q58: Please identify who was responsible for determining the Society's position in relation to self-sufficiency.

61. The Executive Committee determined that 'full support would be given to self-sufficiency at the earliest possible date.' Final sentence of minute 83.55(b)

[HSOC0029476_024]. The entire Executive Committee was responsible and the Council. Self-sufficiency had been the policy of the Society from 1975, which pre-dated my involvement with the Society.

Q59: Prior to joining the Haemophilia Society, you were chairman of its Cambridge branch during which time you contacted your MP Ian Stewart following the broadcast of the World in Action programme in December 1980. In your letter you set out figures in relation to improvements and a re-build of the blood products laboratory at Elstree. What was the source of your information? What concerns had been raised by your membership and why did you bypass the Haemophilia Society? What, if any reply did you receive from either the MP or any other government department?

62. I was already a member of the Haemophilia Society at the date of the letter referenced as DHSC0002205_004, having joined in 1978. The figures referred to in the letter derived from statements made by Dr Peter Jones and Dr Gerard Vaughan as noted by members of the Cambridge Group following the World in Action broadcast of 22nd December 1980. I didn't see this programme but subsequent sight of the transcript of the programme bears the figures of £2.5 to £3 million and £1.25million out. I cannot verify the other figures referred to in my letter so long after the event but they may have been derived from other sources available to the Cambridge Branch of the Haemophilia Society at the time, for example press reports.

63. Cambridge Group members were deeply concerned about the health and safety issues at the Blood Products Laboratory, Elstree as they were reported in the programme. The additional reporting of the importation of concentrates and the sources of blood products in the United States prompted concerns about hepatitis infection. We did not bypass the Haemophilia Society. We were a branch within the Society as can be seen from the letter head and I believe the Secretary would have sent a copy to the Trinity Street office for information. It is possible given the time passed from the broadcast of the programme in December to the issue of the letter in February that the Haemophilia Society were centrally alerted to this and which may have prompted us to express our concerns though this is speculative and I cannot be certain.

64. I do not recall the reply if one was sent by my MP or any other government department. I also cannot recall why the letter was addressed to Ian Stewart but note from the stamp on the letter that it was passed onto the correct department.

Q60: To the best of your knowledge, did the Government provide any assurances to the Society on its ability and aim to achieve self-sufficiency during your tenure? If so:

a. Please provide details, identifying assurances that the Society received, when they were received and by whom they were given.

Did the Government place any caveats on these assurances?

Did the Haemophilia Society rely on these assurances and if so how?

Were any actions taken by the Society to verify the assurances?

e. Were these assurances communicated to members? If so, how?

65. I cannot recall that the Society ever received direct assurances from Government regarding self-sufficiency. It was the policy to seek a definite commitment (BPLL0001351_076) but other than that it was reported that Government had committed funds (£21million) to the development of BPL, to extend their premises at Elstree as it seemed unlikely to be a reality that self-sufficiency would be achieved by 1986. Minute 83.112(1) [HSOC0029476_028]. The Minister, Kenneth Clarke, in a radio broadcast reported to the Executive Committee on 3rd November 1983 (Minute 83.133(b) HSOC0029476_030) 'had committed himself' to self-sufficiency in blood products but did not appear to be able to give an assurance as to when that would be achieved.

66. By February 1984 the Chairman, the Revd. Tanner, was becoming concerned about the effect of Health Authority budgets on future supplies of blood products. Minute 84.15 [HSOC0029476_033]. I cannot recall what the source of his concern was but at the time the Financial Management Initiative launched by the Government in May 1982 was having an effect on budgets in the public sector and it may be that cost centre factors were beginning to influence policy choices in the Department of Health and Social Security (DHSS) in relation to blood products. 'This was to be investigated further' but I do not recall the outcome of the investigations and any caveats that arose in relation to achieving self-sufficiency.

67. On 23rd March 1984 Norman Fowler laid the foundation at Elstree BPL from which it was hoped that self-sufficiency in Factor VIII would be achieved [PRSE0002925]. A copy of the Secretary of State's speech was received in which it was reported that he had 'underlined once again his commitment to self-sufficiency in blood products.' Minute 84.48(ii) [HSOC0029476_036].

68. In the 1984 Annual Report it was stated that an assurance had been sought from Lord Glenarthur, presumably at the meeting of 7th December 1984, that there would be no

change in the programme for the NHS to be self-sufficient in the supply of blood products [HSOC0019505]. It is not reported as to what assurance had been given in relation to achieving self-sufficiency following the meeting with Medical Advisory Panel that was to frame the response to Lord Glenarthur's reply. Minute 85.17(iii) [HSOC0029476_045].

6.3 Reduction of Risk of Blood Products

Q61: Please identify who was responsible for determining the Society's position in regard to reducing the risk of blood products during your tenure, including by campaigning for recombinant products?

69. Reduction in risk of blood products during my tenure on the Executive Committee focused upon the introduction of heat-treated concentrates, approved by the FDA in the United States and licensed there in February 1984 in respect of Factor VIII. We followed the lead of medical practitioners who made reference to heat-treatment in the Haemofact series, starting with Dr Lee in Haemofact 3 on 11th May 1984 [PRSE0001094_0002] and subsequently by Dr Kernoff in Haemofact 4 of 24th September 1984 [PRSE0002824_0002]. Our campaign was taken to Lord Glenarthur at the meeting of 7th December 1984 as reported in Haemofact 5 on 3rd December 1984. [PRSE0002483_0002].

Q62: What were the key issues that the Society pursued?

70. The key issues pursued by the Society at the time were the heat-treatment of both Factors VIII and IX and its ready availability in Haemophilia Centres. It was noted at the Executive Committee on 10th January 1985 that 'the introduction of heat-treated materials has been ''patchy'' and that at least one Supra-Region had not yet introduced heat-treated materials.' Minute 85.04 [HSOC0029476_044].

Q63: Were any assurances given by the Government in response to the communication of the Society's position? If so please set out what those assurances were, who gave the assurances and when they were provided.

71. In Haemofact 5 of 3rd December 1984 we reported 'The Minister, Mr John Patten and the DHSS have issued the following statements on AIDS:

- Heat-treated products will be available from Elstree from April 1985.

- The U.K. will be self-sufficient in blood products in 1986.' [PRSE0002483_0002].

72. In Haemofact 6 of 22nd April 1985 we reported 'Lord Glenarthur, speaking in the Lords, made it clear that all home produced Factor VIII will be heat-treated from April 1985 [HSOC0008753_0002]. Heat treated factor IX was not available until October that year.

73. I believe the Haemophilia Society took these reported statements as assurances of the Government's position in relation to the reduction of risk to blood products at the time.

74. I attended my final meeting of the Executive Committee on 18th April 1985 and therefore had no involvement in the later recombinant products campaign.

Section 7: Other Issues

Q64: To the best of your knowledge, at any point, did Haemophilia Society staff and committee-members purposefully or unintentionally destroy documents relevant to the Terms of Reference of the Infected Blood Inquiry?

75. To the best of my knowledge no Haemophilia Society staff or Executive Committee members purposefully or unintentionally destroyed documents relevant to the Terms of Reference to the Infected Blood Inquiry.

Q65: Please explain, in as much detail as you are able to, any other matters that you believe may be of relevance to the Infected Blood Inquiry, having regard to its Terms of Reference and to the current List of Issues.

76. Haemofact A.I.D.S. Release No.5 (3rd December 1984) stated that the Haemophilia Society would be pressing for the immediate introduction of heat- treated factor by importing this from the United States. [PRSE0002483_0002].

77. Early in 1985, my wife contacted Dr Muriel Seaman, Head of the Addenbrooke's Haemophilia Centre and asked for our son, who suffered from Haemophilia B, to be treated with heat-treated Factor IX. Dr Seaman replied that there was no such thing. She said that only Factor VIII was heat-treated.

78. Several months later my wife was talking to David Watters about a fund-raising venture for the Haemophilia Society when he enquired whether our child was on heat-treated Factor. My wife explained what she had been told by Dr. Seaman but David replied

that this was incorrect and he knew that Factor IX patients were being treated with heat-treated concentrate at St Thomas's Hospital. We then made an appointment to see Dr Seaman.

79. During our discussion, Dr Seaman shifted her position and said she had no authorization to acquire heat-treated Factor IX from the Department of Health (only Factor VIII) and that she was unlikely to be able to persuade the relevant finance committee to pay for it. She said that as Factor IX from the U.K. Blood Products Laboratory came from a much smaller pool of donors it was unlikely to be contaminated. We were unhappy with this situation as we knew that AIDS was already infecting people in the UK and it was only a matter of time before UK blood products became contaminated, if they were not already.

80. Dr Seaman went on to say that she took advice from Dr Rizza, Head of the Oxford Centre and that he was continuing to treat Haemophilia B patients with untreated Factor IX from BPL. When my wife mentioned that the Haemophilia Society was advising its members to request heat-treated concentrates from their Centre Directors and that they were taking their guidance from the Medical Advisory Panel of which Dr Rizza was a member, Dr Seaman seemed somewhat disconcerted. We assumed that this was because she had inadvertently revealed that some Centre Directors were (like herself) still treating their Factor IX patients with untreated blood products for budgetary rather than clinical reasons. Haemofact 6 (22nd April 1985) reports that heat treated concentrates- both factor VIII & factor IX have been widely introduced at many Centres, despite the increased costs. [The Society] welcomes this development and would encourage all Centres to follow suit [HSOC0008753_0002].

81. Dr Seaman did then agree to look into acquiring some heat-treated Factor IX for our son, which arrived at Addenbrooke's Hospital within a week of our meeting. Therefore, I believe that our son was put on to heat treated concentrate about six months later than most children suffering from Haemophilia A who required Factor VIII.

82. Dr Seaman was extremely brusque and dismissive with us. She behaved in the same way when my wife asked her some questions about Hepatitis C and liver disease on a different occasion. In keeping with many senior doctors at the time she didn't appear to want to discuss issues with her patients and resented any questions which might cast doubt on her expertise. This was before the internet and the wide dissemination of information when it was unusual for patients to challenge their medical practitioners.

83. When our child was diagnosed with Haemophilia in 1978 we had one meeting with the Centre Director at the time, Dr GRO-D He asked if we would like to be put in touch with the local group of the Haemophilia Society. We agreed as we were anxious to find out more about living with this rare and difficult condition. We were NOT told that our child would be at risk of contracting hepatitis from Factor IX concentrate at that time. We had no further appointments with the Haemophilia Centre as we were passed over to the Paediatrics Department and had to take our child to the Children's ward for treatment where we saw the duty doctor- usually a SHO. Most had never seen a child with haemophilia before and on a few occasions we were sent home without treatment (only to have to return later). The average wait for treatment was an hour and a half. We saw the Consultant Paediatrician once a year. Under these circumstances, the local group of the Haemophilia Society provided invaluable practical advice and moral support and the main Society provided much needed information. We were very grateful for this. We also purchased Dr Peter Jones' excellent book "Living with Haemophilia" which we used frequently in the absence of any advice from the local Haemophilia Centre, at that time.

Statement of Truth

I believe that the facts stated in this witness statement are true.
Signed

GRO-C

Dated
09/04/2021