Witness Name: Lucy McGrath
Statement No: WITN5428001
Exhibits:
Dated: 7 April 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF LUCY MCGRATH

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 20 January 2021.

I, Lucy McGrath, will say as follows: -

Section 1: Introduction

1. My name is Lucy McGrath, my address is GRO-C, and my date of birth is GRO-C 1966

2. My professional qualifications include a Diploma in Social Work from South Bank University 1995, and a Certificate in Counselling skills from Westminster Pastoral Foundation 1997. I set out brief details of my employment history below:

   January 2016 – date
   Lead Chaplain, YMCA DownsLink Group
   My responsibilities included providing leadership of YMCA DownsLink Group's chaplaincy services, to ensure that chaplaincy support is offered to young people and staff across YMCA DownsLink Group. This role includes developing positive relationships with the Christian & faith/belief communities, organising services on special occasions, coordinating prayer support and acts of reflection, and supporting the leadership team and trustees in developing the vision and mission of the organsiation with a special focus on our Christian foundation and inclusive vision.

   January 2008 - June 2015
   Influence and Service Development Officer, Parkinson's UK
   My role was to improve local services for people with Parkinson's across the South East. This involved listening closely to the cares and concerns of people affected by Parkinson's to understand what they wanted and working closely consultants, specialist nurses and commissioners to improve Parkinson's services. Sometimes it also involved campaigning involving media and local and national government.

   July 2002 – January 2008

During this period I took a career break to care for my young children. In 2007 I worked briefly as an exam invigilator, and as a school supervisor

September 2001 - July 2002
Administration, Haemophilia Society
I worked one day a week for the Haemophilia Society carrying out administrative jobs

January/February 2001 - September/October 2001
Maternity leave

July/August 1997 - January/February 2001
Hepatitis Worker, Haemophilia Society
My responsibilities included providing support, advice and information to people with haemophilia who contracted Hepatitis C (and sometimes HIV) through their haemophilia treatment. In the course of this role I co-ordinated a youth project, a self-management project, developed publications and became involved in campaigning.

1995-1997
Hospice Social worker, Trinity Hospice Clapham
My role included providing advocacy and advice on practical matters including help with welfare benefits. It also included offering emotional support to individuals and families/friends, and the opportunity to talk about difficult issues as well as some bereavement counselling. It included some work with family groups and children.

1992-1993
Welfare Rights Advisor, Shepherd's Bush Advice Centre
I provided specialist advice on every aspect of welfare rights and represented clients up to tribunal level. I also delivered training to other staff on welfare rights issues/ benefits.

1988-1991
Actuarial trainee, Commercial Union
I undertook training to become an actuary

1987-1988
Hostel Worker Oxford Cyrenians, Simon House, Oxford
My role included supporting ex-rough sleepers

3. In relation to whether I have had any past or present membership to any committee, group, association, society or working parties relevant to the Inquiry's Terms of Reference, I can confirm that other than as set out in this statement, I have not held any past or present memberships to such groups set out above

Section 2: Previous evidence

4. In relation to whether I have provided any evidence or been involved in any other enquiries, investigations, criminal or civil litigation in relation to HIV and/or hepatitis B

and/or hepatitis C, and/or vCJD in blood and/or blood products, I can confirm that I have not been involved in any other such inquiries or investigations.

Section 3: My role and the structure of the Haemophilia Society

Q5. The Inquiry is aware that you served as a Hepatitis Worker from 1997 to 2001 HSOC0023019; HSOC0016616]. Please confirm and explain what your role and responsibilities were in relation to each position and how your role and responsibilities changed over time. If you held any other positions within the Haemophilia Society, please set them out.

5. In my role as a hepatitis worker at the Haemophilia Society between 1997 and 2001, my responsibilities included providing support, advice and information to people who were infected or affected by hepatitis C through their haemophilia treatment. This was in the context of there being a huge variability in the information available to people across the country and with regard to the support/treatment offered to people who had contracted hepatitis C through blood products for a bleeding disorder.

6. A pilot study commissioned by the Haemophilia Society into the social and economic impact of hepatitis C and haemophilia, and conducted by Dr Jennifer Roberts of the London School of Hygiene and Tropical Medicine as mentioned in *C Issues March 2000* (HSOC0016623), found that "there appeared to be no national strategy to inform staff about the appropriate way of dealing with the issue with respect to testing, informing people about the illness or conveying information about treatment options". Dr Roberts also found that the provision of information was largely left to voluntary agencies, health care professionals in many cases did not appear to be fully aware of the disease or its implications, and that hepatitis C had not been handled well in the care of haemophilia in many parts of the country. The Haemophilia Society used the outcome of this pilot study to try to press for better services for people with bleeding disorders and hepatitis C, for example, the Haemophilia Society raised several of Dr Roberts' recommendations with the Department of Health.

7. The Haemophilia Society produced written materials included "*C Issues*" which was a newsletter, Fact Sheets, and a range of booklets (please see section 4.2 below for further detail on publications and my involvement). I also coordinated a youth project aimed at supporting young people (and their parents/carers) who had contacted hepatitis C through their treatment, and three booklets were produced as part of this project (please see section 4.2 below for further detail on publications).

8. In addition to this, I helped to helped coordinate a peer telephone support network, and I also assisted in coordinating day, evening, and weekend events around the UK where people affected by haemophilia and hepatitis C could come together to attend talks and meet each other for support and information sharing. I was also responsible for developing a self-management programme to help people with haemophilia manage their condition(s). We took part in the initial piece of research which eventually resulted in the "Expert Patient Programme Self-Management" programme which has been adopted by the NHS.

9. During my time at the Haemophilia Society, I was also involved in campaigning work to try to get best possible support, information and treatment for people affected, as well as recompense. The Hepatitis C campaign aims changed slightly over time (please see section *6.1 Hepatitis C Campaign* below for further detail on this) but essentially the main purposes were to try to get recompense for people affected by haemophilia who had contracted hepatitis C, to get the best treatment for hepatitis C, to get recombinant (a type of treatment/blood clotting factor which is artificially derived and so carries significantly less risk than blood products) for all, and also for an investigation into the circumstances around how people with haemophilia contracted hepatitis C and HIV.

10. In January/February 2001 I went on maternity leave. I returned to work at the Haemophilia Society in the autumn of 2021 but not in a hepatitis worker role. I carried out administrative and project work (I cannot recall the details). In approximately July 2002 I went on my second maternity leave and after this leave did not return to the Haemophilia Society.

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

11. We were there to support people in a number of ways - though information, advice, and bringing people together for peer support either physically or over the phone and in other ways. We also had the role of pressing for the best treatment and care for people with haemophilia and other related bleeding disorders. My understanding is (although this happened before my time with the organisation) that when people contracted hepatitis C and HIV through blood products, the Haemophilia Society responded by working to ensure people received the best possible treatment for hepatitis C and HIV, as well as advice and information about these conditions. In addition, the Haemophilia Society worked to try and obtain an explanation of why these infections had happened, plus recompense/ financial support in order to try and compensate in some way.

Q7. Please describe how the organisation was structured, including the governance arrangements and the day to day management and running of the Society. Please set out the line management arrangements of staff including who your line manager was and the nature and extent of their management of you and oversight of your work. If this changed over the period of your tenure, please out those changes.

12. In terms of how the Haemophilia Society was structured, it was a charity to represent the interests of people with haemophilia and other bleeding disorders and to help them live life as well as possible. The Haemophilia Society was a small organisation during the time that I was employed there with about 10 staff, including, a Children and Families worker, a HIV worker, a hepatitis worker, a fundraiser, a finance worker, an administrative worker, a benefits adviser, and the CEO (Tony Wilson and then Karin Pappenheim from my recollection). The work and priorities of the Haemophilia Society

were overseen by the Trustee board. It was a membership organisation and many people affected by bleeding disorders were members of the Haemophilia Society. When I first started, I believe I was managed by Graham Barker (who was possibly the Director of Services and Development at the time), and later I believe I was managed by the CEO but I am not entirely sure. I cannot remember how actively they were involved with overseeing my work and I cannot recall what the supervision arrangements were.

Section 3.1 Sub-committees, task groups and advisory bodies

Q8. Please list all the different Society sub-committees, task groups and advisory bodies that you were involved in and describe the purpose, functions and responsibilities of each committee, task group and advisory body. In your answer, please include a description of the following:

a. Hepatitis Task Group / Hepatitis C Task Group [HSOC0026292]; and

b. Campaign Task Group [HSOC0026302].

13. In relation to the Haemophilia Society's sub-committees, task groups and advisory bodies, and the purpose, functions and responsibilities of each committee/ group/ body, I have a very limited memory of such sub-committees, task groups and advisory bodies. From reviewing the minutes of meetings that I have been provided with, I can see that I attended those meetings and would have been involved, however I cannot recall if I continued attending meetings and being involved on an ongoing basis and would assume not. If the Inquiry does have any further minutes of meetings to which I attended, please do let me know.

    a. With regard to the Hepatitis Task Group, and from my review of the minutes provided, the members of the group must have included staff, trustees and members of the Manor House Group. I believe that the aim of this group was to influence and support the staff (and help set the direction of the 'Hepatitis work') to ensure people with bleeding disorders who were affected by hepatitis C had access to the best information, advice, treatment and support for their condition/s. I am not sure if this group was also involved with campaigning for recompense.

    b. With regard to the Hepatitis C Campaign Task Group, and from my review of the minutes provided, the Campaign Task Group comprised of staff, trustees and members of the Manor House Group, with some legal representatives involved as well. From memory, the purpose of the group was to decide on the strategy for the campaign and to work to realise the campaign aims. The campaign aims were revised/tweaked over the years (please see section *6.1 Hepatitis C Campaign* below for further detail on this) but the campaign was ongoing.

14. I cannot recall what other sub-committees, task groups and advisory committees were involved and I cannot recall my personal involvement in any such sub-committees, task groups and advisory committees.

<u>Q9. Please outline the relationship between the Haemophilia Society (including the hepatitis task group) and the Manor House Group. Please set out any differences or disagreements in opinion, approach and/or actions taken by the two entities.</u>

15. I do remember that two significant groups existed which influenced our work – the Manor House Group and the Birchgrove Group. I think these were "Special Interest Groups" but cannot remember whether or not they were technically part of the Haemophilia Society. The Manor House Group consisted of a group of people infected or affected by hepatitis C and bleeding disorders, and the Birchgrove Group consisted of a group of people infected or affected by HIV and bleeding disorders (most of whom also had hepatitis C).

16. These groups had a number of functions – they were support groups for their members, but they also worked to influence the work of the Haemophilia Society to ensure their members got maximum support (in its widest sense) in managing their conditions. By support I mean best information, treatment, care, emotional and psychological support, and financial help. Both groups also wanted, as did the Haemophilia Society, an investigation into the circumstances around how infections had occurred, including whether these had been preventable. At some point the Manor House Group parted ways from the Haemophilia Society.

17. I have been asked to comment on the relationship between the Haemophilia Society and the Manor House Group. Manor House Group worked closely with the Haemophilia Society to try to ensure maximum support for its members to help them live with hepatitis C. This included working with the Haemophilia Society on the Hepatitis C campaign to get recompense for people with hepatitis C and also the best treatment and care (in a holistic sense) for hepatitis C, as well as an investigation into why and how these infections had happened. The Manor House Group also worked with the Haemophilia Society to help produce and disseminate information to help people manage their hepatitis C and to ensure people got access to the best care/treatment options. Members of the Manor House Group were part of a peer support network coordinated by the Haemophilia Society.

18. From memory, some members of the Manor House Group were on the Haemophilia Society's Trustee board, some were part of the Campaign Task Group and some were part of the Hepatitis Task Group. It was a very emotive time in the Haemophilia world – some people were very ill because of their infection(s) on top of a bleeding disorder, many people had died with HIV, some with hepatitis C. Many people expressed very understandable anger that the treatment that they had been led to believe would give them (or their loved one) a more normal life had in fact led to them being infected with hepatitis C and/or HIV.

19. My memory is that the Manor House Group sometimes felt that the Haemophilia Society was not doing enough to help people with hepatitis C get what they needed. In addition, there were sometimes tensions because there was a sense that people who had been infected with HIV (most of whom were also co-infected with hepatitis C) were able to access financial help through the Macfarlane Trust, but people with

hepatitis C alone could not access any assistance. I remember the severe disappointment felt by both the Manor House Group and the Haemophilia Society when Frank Dobson, the then Health Secretary of the new Labour government which came in in 1997, turned down our request for compensation and for an enquiry.

Section 4: Communication and Dissemination of Information by the Society

4.1 Knowledge of Risk

Q10. When you first joined the Society:

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

20. When I first joined the Haemophilia Society, my understanding of hepatitis C transmission from blood/blood products, was that many people with bleeding disorders who had been treated with blood products prior to 1985 were likely to have contracted hepatitis C from those blood products, including those who may have only had 1 or 2 treatments. My understanding initially was that in the UK from 1985, blood used in the manufacture of state-produced clotting factors was heat-treated which was believed to destroy the hepatitis C infection (and HIV) so that those who received treatments only *after* heat treatment was introduced were not likely to acquire the hepatitis C infection.

21. The sources of my knowledge were from colleagues at the Haemophilia Society, haemophilia nursing and medical staff, hepatology doctors, people affected by hepatitis C, and by reading widely and attending conferences etc. Over time, I remember becoming aware that in Scotland, effective heat treatment had been introduced later and so we realised that people who received blood products pre-1987 may be infected. I was not aware of this when I started. At some point I also became aware that even after 1985/7 some products still occasionally transmitted hepatitis C (see booklet "*Hepatitis C, Meeting the challenge – a guide for adults with hepatitis C"* produced in February 2001 and *"C Issues, March 1998"* (**HS0C0016631)** which contains article about a child diagnosed in April 1986 who was infected.)

b. What did you know and understand about the health implications of HCV infection? What were the sources of your knowledge? How did your knowledge and understanding develop over time?

22. The hepatitis C virus had not long been discovered (1989) and a test for the virus only came along in 1991, so when I started with the Haemophilia Society in 1997 it was early in terms of knowing all the health implications of hepatitis C. My understanding was that some people (about 20%) cleared the virus naturally but that the rest went onto develop chronic infection. Many of these people had no symptoms, but some developed a wide range of symptoms including fatigue, nausea, problems with concentration. Hepatitis means inflammation of the liver and some people developed

much more severe symptoms related to liver damage including oesophageal varices, cirrhosis, and liver cancer. My memory from when I started work at the Haemophilia Society was that this was a relatively new field and that there was still much to learn about health implications and treatment options for hepatitis C.

23. My sources of knowledge included from reading, publications (including using *Pubmed*), talking to hepatologists and haemophilia specialists, talking to people affected and infected, attending conferences, and voluntary sector organisations including the British Liver Trust, Mainliners. I cannot clearly recall how my understanding and knowledge developed with time, although I do remember that there were developments with potential treatments.

c. What did you know and understand about the prevalence of HCV infection amongst haemophiliacs? What were your sources of their knowledge? How did your knowledge and understanding develop over time?

24. My understanding of the prevalence of hepatitis C infection amongst haemophiliacs was that most people who had received unheat-treated blood products before 1985-7 had contracted hepatitis C even those who had only had a few treatments. The exact number of people infected was never counted as there was no requirement to test people. I remember the estimate figure of 4,000-5,000 people being used. There was huge variation in what different haemophilia centres were doing generally, for example in terms of testing, the provision of information, the provision of support, treatment options, and working with local hepatology departments.

25. I cannot recall how my knowledge and understanding of this developed over time, although I do remember becoming increasingly aware of the huge variability in what different haemophilia centres offered in terms of testing. Some centres were much more 'on the ball' in terms of testing their patients and discussing options. Others did not even test (or offer tests) to their patient cohort. Some centres worked closely with hepatologists, whilst others did not.

Q11. When and in what circumstances did you become aware of any risks of transmission of vCJD associated with the use of blood and blood products? What were your sources of their knowledge? How did your knowledge and understanding develop over time?

26. . I cannot remember when/if I became aware of such risks, however from looking at the *Bulletin, Winter 2000* (**HSOC0023036**) it appears that a study in the Lancet that year indicated that there was a theoretical risk of transmission of vCJD.

Q12. What actions did the Society take in relation to the risk of transmission of vCJD via blood products? What representations (if any) were made to Haemophilia Society members, the Government or the UKHCDO in relation to these risks?

27. I cannot remember personally what actions the Haemophilia Society took in relation to this, however from reviewing the *Bulletin, Winter 2000* (**Exhibit HSOC0023036**) it appears the Haemophilia Society wrote to Lord Hunt (parliamentary under the

Secretary of State for Health) for an urgent meeting raising the issue of fears about transmission of vCJD and other viruses through blood. It appears that the Haemophilia Society used this to further press for recombinant for all (at that time it was not available to everyone in England – mostly only to people under 16 years of age).

4.2 Publications

Q13. Please identify the members, groups and/or committees of the Society responsible for editing and selecting material for the Society publications during your tenure. In your answer, please detail your role as "Editor of the C Issues" [HSOC0016633] and the extent of your involvement with other Haemophilia Society's publications.

28. With regard to editing and selecting material for the Haemophilia Society publications, I can only remember the publications with which I was involved. I edited "*C Issues*" (for an example, please see **HSOC0016622**), which from recollection was a quarterly newsletter which I believe had been started by the previous Hepatitis Worker Deb Gillespie. In this newsletter, we aimed to provide information about hepatitis C, updates on the Hepatitis C campaign, news about hepatitis C across the world, information about events and publications which may be of interest to people, information about support groups and sources of support, information about the impact of hepatitis C, articles about peoples' lived experiences. This newsletter was produced in conjunction with the Manor House Group for some of my time with the Haemophilia Society. I also wrote a column about hepatitis C in the "*Bulletin*" (**HSOC0023033**); the magazine which went out to our members. I cannot recall the frequency of this magazine publication. I cannot recall any other members, groups or committees of the Haemophilia Society responsible for editing and selecting material for publications during my tenure, other than those already set out in this statement.

29. I also coordinated the production of the hepatitis C "*Fact Sheets*" (**HSOC0019596**) (which included titles such as: *Tests for Hepatitis C, Routes for Transmission, Managing Stress and Fatigue, Liver Biopsies, Financial Issues, Nutrition, HIV and Hepatitis C co-infection, Benefits, Traditional Chinese Medicine*). My memory is that the subjects chosen for these were based on common areas of interest/queries that we received from people living with Hepatitis C. Experts and professionals were involved with writing these, including haemophilia and hepatology doctors. The Fact Sheet publications were sent out as and when requested.

30. I also coordinated the project writing of three booklets about hepatitis C aimed at young adults, teenagers, and parents and carers. These booklets were written in conjunction with health care professionals and people affected. The booklets were :
    - *Alive and Kicking* - a guide for young adults on living well with hepatitis C
    - *Living life to the full* – a guide for young people on learning to live with hepatitis C
    - *Being there* - Helping your son or daughter to live with hepatitis C: a guide for Parents and carers

31. In addition, I coordinated production of a booklet (again with the input of health care professionals) called *Hepatitis C – Meeting the Challenge* which was a guide for adults with hepatitis C. The booklets as set out in this paragraph were sent out as and when requested.

32. As previously noted in this statement, all the information produced in the various publications set out about was in the context that people throughout the country received very variable information and support around hepatitis C.

Q14. Please detail the publications that the Society sent out to its membership during your tenure. Please describe the frequency with which each type of publication was disseminated and whether they were all sent out to all members of the Society. If this changed over time please detail when and why. The Inquiry is aware of:

a. The Bulletin [HSOC0023033];
b. Fact Sheets [HSOC0019596, page 10]; and
c. C Issues [HSOC0016622].

33. I have answered this question in large part above. The Bulletin went out to members but I cannot recall the frequency with which it was disseminated nor whether there was any change in frequency with this. The Fact Sheets were sent out on request to anyone who requested one, and I cannot recall whether there was any change in frequency with this. The C Issues publication was a quarterly publication and was sent to anyone on the mailing list who requested a copy, so this would have included those infected and affected by Hepatitis C, as well as possibly some healthcare professionals.

Q15. 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).

34. I only vaguely remember the Medical Advisory Panel but I do recall that haemophilia centre directors were involved with publications at times. For example, the Fact Sheets (Dr Charlie Hay assisted with *Routes of Transmission*, Dr Chris Ludlam and Dr John Hanley assisted with *Liver Biopsies*). I think there may have been some hepatologists on the Medical Advisory Panel as well as haemophilia specialists but I am not certain.

Q16. To what extent, if any, did representatives of pharmaceutical companies assist I proposing and/or editing and/or selecting material for the Society's publications? If you have already answered this question in other sections of your response, please identify the paragraph number(s).

35. I recall that pharmaceutical firms supported the Haemophilia Society's work financially, but from memory, firms had no input in terms of proposing and/or editing and/or selecting any material for the publications with which I was involved.

4.2.1 C Issues

Q17. The Inquiry is aware you were the Editor for C Issues during your tenure [HSOC0016633]. Further to question 13, please answer the following questions to the best of your ability:

a. Were C Issues distributed, or otherwise made available, to healthcare professionals by the Haemophilia Society? What was the Haemophilia Society's understanding of the extent of its reach amongst those who provided medical care and treatment to haemophiliacs?

36. From memory, I believe that anyone could sign up to receive *C Issues,* however I do not have any knowledge of whether the publication was actively distributed to healthcare professionals, nor do I have any knowledge of its reach.

b. To what extent (if any) did the Haemophilia Society verify medical and scientific information and/or opinions published in C Issues? If verification took place, please describe the process by which this occurred.

37. I cannot recall whether there was a verification process for medical and scientific information and/or opinions published in *C Issues.* Medical professionals and other health professionals, including hepatologists as well as haemophilia specialists, wrote articles on occasion, and we encouraged readers, through the publications, to discuss medical treatments with their doctors and nurses.

c. Did the Haemophilia Society know of haemophilia clinicians who felt that their views on imported blood products and/or the risks of infection were not being represented or communicated to members of the Haemophilia Society? Please provide details, identifying clinicians where possible and the issues

38. I cannot recall being aware of this, and if I was aware of this at the time I have no memory of this.

4.2.2 The Bulletin

Q18. The Inquiry is aware of your contribution to The Bulletin, in particular your column "Hepatitis Update". To what extent (if any) did the Haemophilia Society verify medical and scientific information and/or opinions in the Bulletin? If verification took place, please describe the process by which this occurred. [You may find the following documents helpful in your answer HSOC0023036, page 9; HSOC0023033, page 9; HSOC0023034 page 9; HSOC0023026, page 8]

39. I cannot recall whether there was a verification process for medical and scientific information and/or opinion published in the *Bulletin.* Dr David Evans was the editor of the *Bulletin* for some, possibly all, of my time with the Haemophilia Society

4.2.3 Other communications

Q19. 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. [You may be assisted by HSOC0023027, page 10].

40. The Haemophilia Society did receive inquiries from people about all types of issues relating to haemophilia, hepatitis C and HIV. I would usually speak to someone if the query concerned hepatitis C, and the HIV worker would speak to people with queries concerning HIV. I believe that we did receive inquiries about the safety of blood products but I cannot remember any examples. I am unable to recall details, but can guess that we would contact our Medical Advisory Panel if we needed assistance with information for answers to queries.

41. There was a large Hepatitis C campaign spearheaded by the Haemophilia Society to try to get recombinant for all as people were understandably worried about using blood products (even if they had been heat-treated). Throughout my tenure I do remember that from time to time we would receive calls from people who did not realise they may have contracted hepatitis C and had just found out that they may have been at risk (for example, people who may have had just one treatment with blood products over their lifetime). I remember particular issues with Hull Haemophilia Centre. I cannot remember the details, but I do remember that several of us from the Haemophilia Society travelled up there to meet people, as there were issues concerning the information and treatment they had received from their centre.

Q20. Please detail any other activities that the Society conducted with the purpose of disseminating information to its members during your tenure. If this changed over time please detail when and why.

42. Haemophilia Society had Hepatitis events over weekends, as well as day events and evening events, and these included relevant medical and nursing specialist speakers from across the country.

Section 5: Relationship with pharmaceutical companies

Q21. A number of the Haemophilia Society Bulletins thanked a range of pharmaceutical companies for providing "valuable support" including Aventis Behring, Baxter, Bayer, BPL, Novo Nordisk, Roche, Schering, Plough, Wyeth/Genetics Institute [e.g. HSOC0023040, page 2]. Was that record a requirement of their funding? What was agreed in this regard? If so, how was this agreed?

43. I do not recall and have no memory that the Haemophilia Society was required to thank pharmaceutical companies, and I do not remember that the pharmaceutical companies were involved very much at all.

Section 6: Relationship with the Government

6.1 Hepatitis C Campaign

Q22. The Inquiry is aware of your involvement in the Society's Hepatitis C campaign [you may be assisted by ***HSOC0002089, page 3****]. Please explain, giving as much detail as you are able:*

a. Your role and responsibilities in relation to the Society's campaign for compensation for haemophiliacs infected with HCV as a result of contaminated blood products?

44. With regard to my role and responsibilities in this campaign, I was quite heavily involved with campaigning work. I helped to prepare briefings for meetings with MPs and government officials, and I met with MPs on occasions. I also listened to members about their experiences which helped influence the aims of the campaign, and I kept members and *C Issues* readers informed about the progress of the campaign. I helped with lobbying work and petitions.

b. The role and responsibilities of the "Hepatitis Campaign Group" in relation to the Society's campaign for compensation for haemophiliacs infected with HCV as a result of contaminated blood products? [HSOC0026302; HSOC0026341];

45. With regard to the "Hepatitis Campaign Group", I cannot remember much about this group, but I believe that its role was to steer the direction of the Hepatitis C Campaign

c. The aims of the campaign;

46. The aims of the campaign(s) over my tenure were around recompense, best treatment/care for hepatitis C, an investigation into the circumstances around the infection, and everyone being able to have access to recombinant

d. Whether those aims changed;

47. The aims of the campaign(s) changed slightly over time. From memory, and looking through the old editions of *C Issues*, in 1997 there were two campaigns – one campaign to get recombinant available to everyone (this had some success in 1997 when Frank Dobson made the announcement that recombinant would be made available to everyone under 16 and all new patients), and the second campaign to achieve financial recompense for people with hepatitis C. By December 1998 the aims of the Hepatitis C campaign were to :
    - i. persuade the Government to provide assistance to meet the needs of people with haemophilia infected with hepatitis C
    - ii. keep the issues of hepatitis C infection through contaminated blood products high on the public and political agenda
    - iii. press for better treatment for people with haemophilia infected with hepatitis C, and
    - iv. raise public and political awareness of hepatitis C

48. In the autumn/winter of 1998, the Haemophilia Society also called for an inquiry into how people were infected in the 1970s and 1980s.

    By Winter 2000 the campaign aims were to:
    - i. persuade the Government to provide financial assistance to meet the needs of all people with haemophilia and related bleeding disorders affected by hepatitis C
    - ii. press for the best treatment and care for people with haemophilia and related bleeding disorders infected by hepatitis C
    - v. persuade the Government to hold a full public inquiry into contaminated blood products
    - vi. ensure recombinant was available to all throughout the UK regardless of age or viral status

e. <u>Who was responsible for the campaign</u>

49. I believe that ultimately the Trustees were responsible for the campaign – Karin Pappenheim was our CEO from about April 1998 until after I left and she was very heavily involved with the campaign. Within the staff team, she led the campaign and I supported her while in post.

f. <u>The actions taken by the Society to further the campaign</u>

50. During my tenure there were many different actions to further the campaign, including: meeting with health officials/ministers; media coverage of the issues, including personal stories; early day motions; commons debates; petitions; lobbying; members writing to MPs. It was a very user-led organisation and the membership, the Manor House Group and people who were affected were heavily involved.

g. <u>Any obstacles the Society faced in achieving those aims including, but not limited to, internal disagreements within the Society and its associated campaign groups, such as the Manor House Group [you may be assisted by</u> ***<u>HSOC0026292</u>****<u>];</u>*

51. In terms of whether there were any obstacles the Haemophilia Society faced in achieving its aims, I believe that the main obstacles were external, including, in my view, politicians, ministers and governments that did not want to face up to the appalling tragedy and take appropriate action. There were also obstacles that arose because the Haemophilia Society did not have complete and accurate information (for example, knowing how many people were infected and when and how, including tracing those people).

52. The campaign was high profile and in the news both during and after my tenure, which I believe is a sign of how much effort was put into the campaign by the Haemophilia Society, and by the people affected. We were a very small charity with a large profile given our size. It was a very emotive time when I worked for the Haemophilia Society, as people were ill, some were dying and many of those infected with hepatitis C (and/or HIV) were living with a lot of uncertainty about how the disease would progress. Most of the Trustees were personally affected and they cared deeply, and sometimes tensions would flair as a result.

53. The document that I have been referred to (**Exhibit HSOC0026292**) are minutes of a meeting where I first met GRO-A from the Manor House Group, which was very soon after I had started in post. I remember that he was very angry that I had met with people infected by HIV and hepatitis C so early in post. As I came to understand more about the context, I realised how the setting up of the MacFarlane Trust had led to divisions within the membership between people who had received compensation and people who had not. After this tricky meeting, our relationship improved and we worked together to improve the support and information available to people affected, and we also worked to forward the aims of the Hepatitis C campaign. I do not remember the details of any particular internal disagreements, and I believe that the main reason the campaign did not realise all of its aims was due to the unwillingness of the Government to act.

h. What the response of the Government was to the campaign, including whether the Society was given any assurances by the Government in relation to the campaign. If so, what the assurances were, when they were given, by whom and whether the assurances caused the Society to change their approach to the campaign;

54. With regard to what the response/any assurances of the Government was to the campaign, in September 1997, Frank Dobson who was the Secretary of State for Health at the time, met with representatives of the Haemophilia Society and the Manor House Group. After this meeting, Frank Dobson agreed that recombinant should be made available for people under 16 years of age and new patients (I believe this came into effect for most in 1998).

55. In July 1999, Baroness Hayman, a minister for health, gave the assurance that she had made it clear to health authorities that people with hepatitis C and haemophilia in 'clinical need' should be given treatment where there was a 'clinically effective' treatment available (at that time a new treatment of Interferon and Ribavirin had just

been licensed). Despite her assurances, some people who wanted treatment were not receiving it. In terms of other campaign aims I do not remember any assurances given by the Government at any time.

i. Whether the Society achieved its aims;
j. If so, when the Society achieved its aims
k. If not, what the result of the campaign was;

56. I have been asked to comment on whether the Haemophilia Society achieved its aims and if so when, and if not, what the result of the campaign was. Some of its aims were realised (see paragraph h above), and at a later time, I cannot recall when, recombinant for everyone became available. The aim for a public inquiry to be held was also eventually realised in 2017. As far as I am aware, I do not think compensation has been made available except in a limited way through the support offered by the Macfarlane Trust. The aim of 'best treatment and care' is difficult to measure but improvements were made during my tenure for example, the better provision of information so that people were more empowered to make decisions about their care and treatment. I also recall that NICE Guidelines came out for the management of the treatment of Hepatitis C and so this improved standards across the NHS.

i. To what extent (if any) was the campaign for compensation informed by the views of Society membership? Did these differ from the views of the Society, as you understood them?

57. With regard to what extent the campaign for compensation was informed by the views of the Haemophilia Society's membership, the Haemophilia Society was very user-led, and people affected by haemophilia and other bleeding disorders were very involved. Many Trustees were personally affected and the membership was heavily involved in campaigning (lobbying MPs, writing, petitions, sharing their personal stories etc.). The Haemophilia Society and the membership both wanted compensation and worked hard to try to make this happen.

Section 7: Other issues

Q23. To the best of your knowledge, at any point, did Society staff and committee-members purposefully or unintentionally destroy documents relevant to the Terms of Reference of the Infected Blood Inquiry?

58. I have been asked whether, to the best of my knowledge, at any point the Haemophilia Society staff and committee-members purposely or unintentionally destroy documents relevant to the Terms of Reference of the Infected Blood Inquiry. I can confirm that to the best of my knowledge, this did not occur.

Q24. 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.

59. I have reviewed the Infected Blood Inquiry's Terms of Reference and can confirm that I know of no other matters that I believe to be relevant to the Inquiry.

Statement of Truth

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

Signed **GRO-C: Lucy McGrath**

Dated 7 April 2021