Witness Name: Jacqueline Britton
Statement No.: WITN1838006
Exhibits: WITN1838007-
WITN1838022
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INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF JACQUELINE BRITTON

Section 1. Introduction

1. My name is Jackie Britton. My date of birth is GRO-C 1962 and my address is known to the Inquiry.

2. I have previously submitted a personal witness statement to the Inquiry detailing my experience as a person infected with Hepatitis C (HCV) from a blood transfusion.

3. I make this statement to describe my involvement in and with the various campaigning activities, committees, working groups and the financial trusts and funds. I have been involved with the following: Contaminated Blood Campaign, Tainted Blood, Contaminated Whole Blood UK, Bloodloss Families, the Hepatitis C Trust, the Liver Trust, a DWP Working Group,

meetings with my MP and the All Party Parliamentary Group, and working with the Caxton Foundation Partnership Group and an EIBSS Focus Group.

4. When I was first diagnosed, I knew nothing about any support organisations, so I went to my local paper, the Evening News, and told my story. I also spoke to Radio Solent. That is where I met a fellow infected person from my local area. We discovered we had been infected at the same hospital within a year of each other. We subsequently became lifelong friends.

5. The following summer I organised a table at a local gala and displayed photos and stories from the Hepatitis C Trust (WITN1838007). I was there for people to come up and speak to, and it was surprising the number of people from our community who came up to me and said they had had a blood transfusion in the at-risk period.

6. Ever since diagnosis I have continued my campaigning activities to raise awareness of Hepatitis C.

Section 2. Organisations involved in campaigning activities

Contaminated Blood Campaign

7. When I was first diagnosed I was unaware of any support groups. After applying to join the Caxton Foundation Partnership Group (see below), I met a member of the Contaminated Blood Campaign ('CBC') and was invited to join the group. I joined the campaign as a member only and did not have a campaigning role within the organisation.

8. CBC told me when and where meetings were taking place and I would go along. I often found that there was little representation of people who had received contaminated blood by transfusion. I found myself speaking out, not just for me, but for all transfusion victims, and particularly for those who

were undiagnosed, which has always been my big thing: to reach out to those who are dying but who do not know it.

Tainted Blood

9. Around the same time as joining CBC, I also tried to find out who else was involved in campaigning and came across Tainted Blood. I knew they campaigned on behalf of haemophiliacs, but they said they were still happy for me to become a member. Through Tainted Blood I eventually became the administrator of Contaminated Whole Blood UK.

Contaminated Whole Blood UK

10. Tainted Blood started a new group called Contaminated Whole Blood UK. I was made the administrator. The group developed into a support network for people who had been infected through blood transfusions. I helped run the group for some time but took a step back after the death of one of the other main organisers of the group, who was a very close friend of mine.

Bloodloss Families

11. In the lead up to this Inquiry, I felt that whole blood victims were still underrepresented, even though whole blood recipients make up 50% of all those infected. When I was diagnosed in 2011, few people infected through transfusion were coming forward to tell their story, so it was very difficult to find other people like me. I have always been motivated to raise awareness for those people who had a blood transfusion pre-1991 but are not aware they are at risk.

12. In response to these concerns, I set up Bloodloss Families in 2018 to demand justice for all and to ensure everyone, however infected, had a voice. As a result, it is a mixed group and members can post messages

freely on the group. There is also a closed group where people can post messages in confidence, allowing for open discussion.

13. The group provides support to anyone who gets in touch. Sometimes I am the first contact for someone who has just been diagnosed.

14. I post information about meetings I attend and invite people to give me questions to ask on their behalf at such meetings. Sometimes people feel unable to tell their own story, but they tell me that, in me telling my story, I am helping tell theirs too.

15. I also post information on the latest developments, for example, in terms of the treatments available. I also invite others to post useful information, in case there are things they have come across which I have not yet seen.

16. The aims for Bloodloss Families are to provide support for individuals, to provide a platform for information sharing and to provide representation for all, regardless of how you became infected. I am trying to empower others to speak out for themselves, or to ask me to do it on their behalf. I am also trying to raise awareness of this virus, and get justice for those it has infected and affected.

17. I feel a great weight of responsibility on my shoulders through running the group: I feel I represent many people. I push myself to do these things because there are people depending on me. At the moment I still feel that I cannot walk away, however, if this Inquiry does not give us justice I will have to walk away: I cannot continue to campaign for the rest of my life. This is my last chance.

Hepatitis C Trust

18. In 2014, the Hepatitis C Trust invited participants to take part in a research project called 'The Hepatitis C Treatment Journey', looking at experiences of Hepatitis C testing and diagnosis, conducted in collaboration with The

London School of Hygiene and Tropical Medicine. The purpose of the study was to explore the context of a delayed hepatitis C diagnosis in order to inform effective hepatitis C testing and awareness interventions. The study would be used to help develop better services for people who are going through hepatitis C treatment and would involve focus groups and interviews in order to inform the development of a survey.

19. I participated in the study by joining a 'Newly Diagnosed Focus Group' in 2014. Through this focus group I was given the opportunity to help promote testing for HCV and design posters to raise awareness of the virus. The group was made up of people who had been infected in different ways, with the aim being to communicate the importance of testing and think about the best places for the posters to be displayed. There were other focus groups too, which I was not involved in, but I know the work of each group was correlated by the project.

The Liver Trust

20. I accessed the Liver Trust website for information after I was diagnosed. The Liver Trust provided me with posters and leaflets when I did the gala in my hometown. I later found that others did not know about their website so I try to pass this information on through Bloodloss Families. I still receive the Liver Trust magazine so I read the magazine and post links to articles which I think might be helpful to others. For example, the Liver Trust recently went around the country offering liver scans, so I shared this with the group.

21. It was through the Liver Trust that I was able to access financial support for counselling for myself after diagnosis. I found out that they were offering £800-£900 towards counselling costs. I applied and was given the grant. Unfortunately, I think this grant is no longer available, but at the time, I highlighted this to others so that they too could benefit from this financial provision.

Section 3. Involvement in committees and/or working groups

DWP Working Group

22. I have attended meetings of the 'DWP Working Group with people affected by contaminated blood'. I was invited to join the group from the outset, around a year before this Inquiry started. I have attended around half a dozen meetings, but have had to miss those which fell on days when I had pre-existing commitments, or where the meetings were outside of London. I continue to attend this group whenever I can.

23. According to the Terms of Reference, the idea of the Working Group is to 'provide a collaborative and mutually beneficial interface between DWP and individuals representing people affected by contaminated blood'. The Working Group specifically addressed policy and operational issues relating to Personal Independence Payment (PIP) and Employment and Support Allowance (ESA).

24. I have used my time with the Working Group to fight on behalf of those who received contaminated blood through transfusions.

25. In relation to PIP, I explained to DWP officials how the reassessment process for PIP or ESA could be traumatic for individuals and how it had deterred me from applying. Changes were made for haemophiliacs result of the Working Group, meaning that haemophiliacs would sometimes not need to go through the PIP re-assessment process. I asked whether the same could apply for recipients of transfusions. I was advised that work was underway to improve the assessment process, but to date I have not heard of any further developments in relation to this.

26. I also asked whether victims of the contaminated blood scandal could receive priority NHS treatment in the same way that veterans do. I explained

to DWP officials that I believe we are owed a duty of care, due to the way in which we have been infected, and ought to be given treatment without having to fight for it. I was told this point would be raised with the minister but have not heard anything more about it.

27. I have also sought to increase the representation of those infected by whole blood transfusions by recommending individuals to the Working Group when they have expressed an interest in getting involved in issues affecting the contaminated blood community.

28. My experience of being part of this Working Group has been mixed. I feel the DWP officials treat members of the group with respect and do listen to what we have to say. However, there are times when I have been told that nothing can be done without legislative change, even when the minister herself is present. This makes it feel like I am banging my head against a brick wall: I remember looking up and addressing the minister directly, explaining that the gift for legislative change was in her hands, not ours. The minister said she would go away and look at it, but I never heard anything more.

29. I do constantly have to re-evaluate whether it is worth participating in the Working Group, especially when I am told that nothing can be done. I've noticed the numbers of attendees for the group have dropped off, and the last meeting was cancelled for this reason.

30. I have been involved with many such groups and I wonder to what extent officials, MPs and ministers, realise what it takes for the infected to get to these meetings and participate. I explained at one meeting that just by attending the meeting in person I would fall foul of the PIP rules, yet I was there, despite all of my medical issues. Nevertheless, I always feel obliged to attend in case I can help make changes to the system.

All Party Parliamentary Group

31. I have always been aware of the work of the All Party Parliamentary Group on Haemophilia and Contaminated Blood (the APPG) and have attended meetings when possible. I have only managed to attend three or four APPG meetings and mostly listen, however, I asked questions on one occasion. I have found the meetings very informative and useful, as there are often guest speakers.

32. I received a letter from the APPG in September 2014 notifying me that they were launching an inquiry into support for people with contaminated blood and appealing for information via an online YouGov survey, which I completed online. Alistair Burt MP provided an update in November 2014 on the responses to the survey and information about the results, asking individuals to contact their own MPs to ensure they were engaged in the issue.

Contaminated Blood debate, House of Commons 11 July 2017

33. I attended the parliamentary debate raising the issue of contaminated blood in 2017, which was delayed from 12 noon to 6.30pm due to a steel debate taking precedence. Many infected and affected individuals attended, waiting for the debate to start, and of those, some were terminally ill. I thought the delay was a very poor way to treat the victims of the contaminated blood scandal.

Meetings with the Cabinet Office

34. In around 2016, I was part of a group of campaigners who were consulted by the Department of Health in relation to the proposals to reform the infected blood payment schemes. We met with a facilitator, Gerard Hennessey, in London, to look at the government proposals for reform. Mr Hennessey listened carefully to our group of around 15 campaigners and appeared genuinely moved by what he heard. He informed us he would be writing a

report based on our meeting. I never saw the resulting report and, in retrospect, felt the government was insincere in proposing the meeting, doing so simply to pay lip service to the victims.

35. In January 2018 there was a meeting between campaigners and Jackie Doyle-Price, Health Minister, and civil servants to discuss financial assistance. Jackie Doyle-Price listened to what we had to say and was very respectful. I said that the majority of victims around the table were dead men walking and asked why we should still be campaigning when people are dying daily. It felt like a very positive meeting and we asked for feedback, which we were told would be forthcoming in a relatively short timeframe. Instead of coming back to us directly, a statement was put out direct to the media, timed to coincide with the opening of this Inquiry. Although the announcement was good news, as it was helpful to so many people, I felt we were again being used to make the government look better, and that the timing of the announcement was used to take the focus away from the victims, both living and dead, and the Inquiry.

Section 4. Research and investigations

36. I have not undertaken any investigative or research work relevant to the Inquiry's Terms of Reference.

Section 5. Individual campaigning activities

Meetings with my MP

37. When I was first diagnosed, I started corresponding with my MP, Mark Hoban. I told him about my situation and wrote in particular on the subject of the availability of treatment for me. He did correspond with me on this subject and liaised with the local hospitals several times asking that the issue be looked into.

38. I also asked to meet with Mr Hoban in 2012 to discuss wider issues related to hepatitis C. I explained in my letter how I felt I was the tip of the iceberg and that the government simply didn't want to find me and others like me because the blood transfusion victims were so many that it would be too much of a financial burden. I remember receiving replies to these letters expressing 'deepest sympathies' but felt nothing was getting done or moved forward.

39. Mr Hoban did agree to meet with me and I attended the meeting with my father. I explained how, as a lay person, I felt a simple method to screen for the risk of HCV would be a tick box question on pre-operative assessments asking whether the patient had received a blood transfusion pre 1991. If this had been in place, I explained, someone like me would have been picked up time and time again. This would also have meant not only that I would have been diagnosed with HCV before I became cirrhotic, but would also protect all NHS staff treating me. When I proposed such a tick box to Mr Hoban he said it would not be possible for data protection reasons and that people might not want to know if they were infected. I believe people should be empowered and offered the choice of testing if they are at risk and introducing testing has been an opportunity repeatedly missed. I told Mr Hoban that I felt the government did not want to find those infected by transfusion because treating those infected would be expensive, and the government would have to admit that there were still undiagnosed people out there. My father and I were ushered out of the meeting.

40. I continued to lobby Mr Hoban on the contaminated blood scandal from 2011 to the end of his term in 2015. In 2014, Mark Hoban wrote to me, in response to an email I had sent on financial assistance, updating me on the actions being taken in Parliament to improve the financial support schemes, Exhibit WITN1838008.

41. On 16 January 2015 Mr Hoban wrote to inform me he had attended the debate in the House of Commons and heard the speeches by the two co-

chairs of the inquiry into contaminated blood. He confirmed he would be writing to Jeremy Hunt MP, the Secretary of State for Health, to let him know that he supported the considered recommendations outlined in the All Party Parliamentary Group for Haemophilia and Contaminated Blood's recent report. This letter is at Exhibit WITN1838009.

42. On 16 February 2015 Mr Hoban wrote again, at Exhibit WITN1838010, to enclose the holding response from Jane Ellison confirming work to improve the financial support schemes was ongoing, pending the final report of Lord Penrose, and the APPG report.

43. When Suella Fernandes replaced Mr Hoban as my MP in 2015 I continued to lobby. Exhibit WITN1838011 is my letter of 27 January 2015 asking for a face to face meeting to discuss the consultation process and the reforms of financial and other support for infected blood that the Department of Health had put forward. I explained my shock at the proposals and asked to discuss with Ms Fernandes how she might support and represent my views, and that of the majority of the victims, to ensure our lives would not be further crushed if the measures were instated.

44. In May 2015 I again wrote to Ms Fernandes highlighting the issue of denial of access to hepatitis C treatment in England due to cost. My letter is at Exhibit WITN1838012.

45. In July 2015, Ms Fernandes wrote to me enclosing a copy of the statement made by Ben Gummer MP in the House of Commons, and the question on treatment Ms Fernandes raised on my behalf in response, Exhibit WITN1838013. Ben Gummer responded to the Urgent Question of Diana Johnson MP (which was to ask the Secretary of State for Health to make a statement on the support available to victims of contaminated blood). Mr Gummer then announced the public consultation on financial support. Ms Fernandes said as follows in relation to treatment:

'I welcome today's announcement. It represents progress on a tragic issue that has affected thousands of people in this country. My constituent, Jackie Britton contracted hepatitis C in 1982 following a blood transfusion during childbirth, although she was not diagnosed until 2011. Will my hon. Friend provide the House with guidance on the availability of drugs, particularly sofosbuvir, which has been approved by the National Institute for Health and Care Excellence? Will it be made available for the treatment of cirrhosis?'

To which Mr Gummer responded:

'NHS England has just announced a major package in respect of the drugs my hon. Friend mentions. I will ensure that my hon. Friend the Life Sciences Minister write to her with further details.'

46. Exhibit WITN1838014 is a letter from Ms Fernandes dated 20 August 2015 enclosing the response from George Freeman MP, Minister for Life Sciences, advising that, on 29 July 2015, NICE issued draft guidance on three new hepatitis C treatment options, that NHS England is now required to fund two other hepatitis C drugs, that NHS England has put steps in place to help fund the three new drugs, and explaining the launch of an Accelerated Access Review to make recommendations to Government on speeding up access to new medicine.

47. On 7 September 2015 Ms Fernandes wrote again regarding my enquiry about patient access to off-label drugs, informing me of the government's progress in this area, including the Accelerated Access Review by the government which aims to develop ways to speed up access to innovative drugs. Her letter is at Exhibit WITN1838015.

48. In 2016 I met with Ms Fernandes to discuss the proposals to reform the infected blood payment schemes, explaining how those infected and affected would end up worse off than we were to begin with. I took along paperwork from the Caxton Foundation which illustrated how the proposed

changes to the financial assistance schemes would disadvantage the beneficiaries. Ms Fernandes took away copies of the information I gave her.

49. On 12 April 2016, Ms Fernandes wrote to me following our meeting at her surgery, confirming she had written to the Minister, Jane Ellison, expressing my concerns about the implications for Caxton Foundation beneficiaries, and enclosing the Minister's reply, which confirmed that no decision will be made on the scheme reform until consultation responses had been collected and analysed, Exhibit WITN1838016.

50. I again wrote to Ms Fernandes on 12 April 2017 informing her of the date of next meeting of the APPG for Haemophilia and Contaminated Blood and explaining that the Department of health had refused the APPG's request to allow those affected by the scandal and campaigners to attend. I asked Ms Fernandes to attend the meeting (or send a representative) and convey (i) my deep dissatisfaction that the DoH had betrayed the goodwill built up over a number of years, (ii) the widespread discontent at the current government consultation, (iii) that it appears the government is working to a predetermined budget, and (iv) in my opinion payments in England should be at least at the level of Scottish payments. I do not know whether she attended any APPG meetings or whether she made any representations on my behalf in respect of these issues.

51. I wrote to Ms Fernandes on 10 July 2017 asking her to attend the emergency debate the following day to support me and many other MPs across all parties in calling for a long overdue public inquiry. I also asked that she attend the APPG on 12 July 2017.

52. Ms Fernandes spoke in the House of Commons on 11 July 2017, the day the full public inquiry into the scandal was announced, and said as follows:

- '*Many colleagues on both sides of the House have been tireless in their advocacy for the victims of this unspeakable tragedy over many years. I am a relative newcomer to the issue, but I speak today on* *behalf of my constituent, Jackie Britton, who lives in* GRO-C *Jackie has met me on many occasions, for she, too, has not given up on this fight. She contracted hepatitis C in 1982 from a blood transfusion during childbirth, but she was only diagnosed in 2011. For many years, she has been afflicted with and has suffered from a debilitating illness.* GRO-C *has also been very ill with various medical conditions.*

- *I am sure that Jackie would welcome today's news about a public inquiry into this matter. It is clear that the Government are seriously reflecting the concerns and voices of those who have been tragically affected by the incident. The inquiry is the latest in a series of actions taken by this Government over several years. The Government have increased the amount of money spent on payments to victims to record levels since 2016, with an additional £125 million in support of funding for those who need it. I am pleased that the Government announced last year that they would reform the package of support measures for those affected. For the first time, almost 2,500 beneficiaries with chronic hepatitis C were eligible to receive an annual payment of £3,500 a year. That progress results from listening and action on the part of the Government.*

- *I will conclude my comments because I am aware that other colleagues want to contribute. There is nothing that anybody can do to change the past, and this awful incident and tragedy, but I hope, for the sake of Jackie and all those victims about whom we have heard today, that the inquiry – the process of discovering the truth and bringing some justice to those affected – will provide some solace and finality to this heart breaking tragedy.'*

53. On 19 July 2017 I wrote again to Ms Fernandes, this time bringing to her attention the response of the campaign groups to the DoH proposed meeting on 20 July 2017 regarding the Inquiry. The response of the groups was to

universally reject meeting with the DoH to discuss the proposed Contaminated Blood Inquiry as we believed they were an implicated party and should not have any involvement investigating their own conduct. The campaign groups united in this response were Tainted Blood, Forgotten Few, Positive Women, Manor House Group, Contaminated Blood Campaign, Contaminated Whole Blood UK (of which I was the representative), Factor 8 Campaign, The Fatherless Generation, Haemophilia Wales, The Birchgrove Group and Contaminated Blood – Public Inquiry. I wanted to make Ms Fernandes aware of the strong feelings of our community on this issue.

54. I continue to lobby my member of parliament on issues relating to the contaminated blood scandal, but I have not contacted her as much as I once did as I feel I have had to push every step of the way. I have reached a point where I am not sure what else I can achieve in continuing to lobby and find the effort it takes exhausting, given my state of health.

Letter to the Prime Minister

55. I wrote to the Prime Minister, David Cameron, in May 2015, letter at Exhibit WITN1838017, to raise with him the issue of denial of access to Hepatitis C treatment in England due to cost, which I had also raised with my MP, Suella Fernandes. I received an acknowledgement of my letter, but no substantive response.

Demonstrations

56. The only demonstration I have attended took place on 11 July 2017 on the day of the Contaminated Blood debate in Parliament. Exhibit WITN1838018 is a photograph of Suella Fernandes, my MP, and me at the demonstration.

Media

57. I set out at the beginning of this statement my initial involvement with my local newspaper when first diagnosed. I have retold my story to anyone willing to listen ever since, whether it has been local or national media, because I know I am not the only one who has lived with an infection for decades without knowing it was there.

58. An example of my early campaigning is at Exhibit WITN1837019, an article dated 7 August 2012, appearing in a local GRO-C paper, The News, '*Living in the shadow of hep C*'. At the time I was undergoing treatment for HCV and the article highlighted how I had been undiagnosed for thirty years, contracting the infection during a blood transfusion after the birth of my daughter. The newspaper explained, 'as many as 250,000 people in the UK are thought to have been infected with hepatitis C but fewer than half know about it because they have no symptoms'. I think raising awareness like this is vital so that people can choose to get tested if they are worried. The article also mentions the Skipton Fund so that anyone reading it would know that financial help was available.

59. Another article was published on 17 June 2014 by the same newspaper, '*I feel that something positive must come out of this*', again describing my experience of late diagnosis with Hepatitis C, awareness raising initiatives at our local GRO-C Gala, and my work with the Hepatitis C Trust, Exhibit WITN1838020.

60. Later, in around mid 2015,The News published another article, '*Anger over delay in NHS introducing new hepatitis C treatment*', this time on the delay in obtaining new treatments for Hepatitis C, Exhibit WITN1838021. The story describes how members of the Contaminated Blood Campaign wrote to the health minister, Jane Ellison, pleading for treatment, but that there continued to be delays in obtaining the new treatment with Sofosbuvir.

61. As I have described above, my main motivation for campaigning has been to raise awareness of HCV for people who had a blood transfusion pre-1991

and are not aware they are at risk. Such people have been denied the choice of getting tested because they do not know the risk. In September 2018 I went on the Victoria Derbyshire programme to highlight the risk of acquiring HCV through transfusion ('*I gave birth, and got Hepatitis C*' https://www.bbc.co.uk/news/health-45590203). After the programme went out the Hepatitis C Trust said they received lots of phone calls to their helpline from people who had had transfusions and had never thought about getting tested for HCV. I will continue to tell my story if I know it is making a difference. For me, this makes it all worthwhile.

62. Exhibit WITN1837022 is a newspaper cutting of an article from 2018, '*Blood scandal mum slams government*' regarding the appalling way victims continue to be ignored by the government. We met with government officials in January 2018 to talk about an increase in annual payments for victims of the scandal (see above). We explained the extremely precarious financial position of many of the victims, asking they inform us of their decision. Instead, the Department of Health and Social Care announced the new regular annual payments directly to the media, without informing us first. I gave this interview to the newspaper to highlight how appallingly we were, and continue to be, treated by the government.

63. When Private Eye reported on the opening of this Inquiry in October 2018, I again gave my story. The article led with a description of the opening of the Inquiry and the unreserved apology given by the barrister representing the Department of Health and Social Care. Under a further subheading, 'Silent killer', the article describes my story, highlighting again the risk of transmission by transfusion, and consequent infection with HCV leading to cirrhosis. The article notes, 'No one knows how many transfusion patients were infected. Inquiry chair Sir Brian Langstaff said it was "a truly sobering thought" that there may be many more who feel unwell but have yet to be diagnosed.'

64. I have tried to keep telling my story, in whatever way I can, to keep the spotlight on the scandal and the way victims have continued to be treated unfairly. I will continue to use the media to raise awareness of contamination by transfusion to try to reach the undiagnosed. I feel very lucky not to have encountered any negative feedback from having put myself into the spotlight. It was not something I did lightly, and I do worry about my identity, and that of my family, being in the public domain. However, I know I had to take this risk because I would not have been able to live with myself if I did not try to give others the opportunity, if they were infected, to find out. If I did nothing I would be the same as the government, sweeping it under the carpet.

65. I do feel the contaminated blood scandal has not received the media attention it deserves. There is still so much ignorance and stigma associated with the infections that the victims suffer with. I hope the Inquiry can help raise awareness of the scandal and reduce this stigma.

Section 6. Complaints to the police, ombudsman or regulatory bodies

66. I have not made any complaints to the police, ombudsman or any regulatory bodies.

Section 7. Litigation

67. I have not been involved in any historic litigation relevant to the Inquiry's Terms of Reference.

Section 8. Other Inquiries

68. I have not been involved with any other inquiry. I was diagnosed just as the Penrose Inquiry was making its findings. One recommendation from the Penrose Inquiry was to try to find those infected. I would welcome tests for everyone (and their family members, as appropriate) who has had a pre-

1991 blood transfusion. Until this is done, we will not know the true numbers involved.

Section 9. Haemophilia Society

69. I have not had any involvement with the work of the Haemophilia Society, but I have occasionally attended meetings alongside trustees from the Haemophilia Society and have worked with them on other campaigns.

Section 10: Trusts and Schemes

Caxton Foundation Partnership Group ('CFPG')

70. In 2012, I received a letter from the Caxton Foundation saying they had a Partnership Group and were inviting people to apply to become part of this group which would meet with their trustees. My outlook is that it is easier to change things from the inside, rather than from the outside, so I applied.

71. The application process was like a job application and I was lucky enough to be accepted to the group. The Partnership Group was made up of Caxton board members and senior staff, together with beneficiaries. The aim of the meetings was to hear about changes at Caxton and to give feedback, put forward ideas and take part in discussions. I travelled to London for the meetings and, in total, I attended around three or four.. The meetings ended with the establishment of EIBSS in around 2014/2015.

72. I found those meetings invaluable because they gave me the opportunity to question the people who were looking after the beneficiaries of the fund.

73. I questioned why there was no direct route to gain financial support. I explained that in order to apply for financial support for Stage 2 payments as an infected individual, I needed to prepare my application, and then hand this over to my consultant for him to complete the documentation and verify

what I had said. At the time, I was struggling financially and unable to pay my mortgage, and had to keep contacting my nurse to ask whether the forms had been signed and sent off. Eventually the forms were signed and submitted, but it was a traumatic and stressful wait. I believe applicants should be able to apply for financial support directly, without their application depending on sign-off from others, and I raised this issue with the CFPG.

74. I also asked about the Caxton Foundation budget. It was explained that the Caxton Foundation would not give to anyone if they could not give the same to everyone. There was also a Skipton Fund look back exercise which led to an increase in beneficiary numbers but no increase in the fund itself. I suggested that the Foundation ought to request a bigger budget, to ensure they could provide for everyone. I pointed out that there appeared to be a conflict of interest, as the Caxton staff ought to be working for the benefit of the beneficiaries, not for those who are in control of the budget, and also happen to be paying their wages. I told them they seemed reluctant to rock the boat and bite the hand that feeds by asking for a bigger budget. I do not think they ever asked for an increase in their budget.

75. I also remember raising the issue of retrospective payments. When I was first diagnosed I had taken out a bank loan and used my credit card to pay for private treatment and a liver biopsy. I applied for and was given a retrospective Caxton grant, which paid off the bank loan and credit card borrowing. However, when I became part of the CFPG, I discovered that such retrospective payments had since been abolished. I do not know when this decision to stop such payments was made, but understood that the reasoning was that retrospective grants were not generally considered, as it was hard to demonstrate charitable need if an item had already been purchased. I explained how helpful such a payment had been in my case and said I believed their new rules about retrospective payments were not in the beneficiaries' interests. For example, I explained that often a funding decision by the Foundation will take so long that you will have to buy whatever is urgently needed before their decision is made (for example, a

replacement boiler in winter). The Foundation came back to me on this issue in a subsequent meeting by making provision for emergency grants, which could be provided within 24 hours of a request, but only for small amounts. I don't think the Caxton Foundation ever changed their stance on retrospective payments, save for these emergency grants, but this was an issue I raised time and again as individuals frequently asked me to do so.

76. An issue that I repeatedly raised was why the fund was not known about or clearly signposted. Unless you knew the questions to ask you did not get the right answers. It was as if the Caxton Foundation had a budget which they wanted to keep hold of, unless forced to give out. I asked why there couldn't be a newsletter publishing information about the fund, particularly for the newly diagnosed. I also suggested that such a newsletter could signpost beneficiaries to support groups and networks. I brought up my past experiencing working in youth work, explaining how important I felt it was to empower people, pointing out that signposting beneficiaries to support groups and networks would help do this. I was told this could not be done. I believe they did not want fellow beneficiaries reaching out to each other and having a conjoined voice that might be more difficult to ignore. I felt this was a very negative response from the Caxton Foundation as it actively prevented beneficiaries from supporting each other.

77. In 2014, Caxton did send out a survey to all beneficiaries, asking for views on how they would like to be kept informed about the Foundation's work and any changes. The survey feedback found an overwhelming interest in receiving newsletters, with that 96% of responders selecting a newsletter. As a result of the feedback, a newsletter was finally sent out in the same year. The newsletter gave details of all the different sorts of financial assistance available, including:

- Winter Fuel Payments
- Regular Payments

- Grants (whilst undergoing treatment; respite; repairs and adaptations; support with debt and money management; financial assistance with the purchase of essential household items; support with vehicle maintenance costs; financial support to enable people to undergo re-training)
- Prescription Charges
- Benefits and Money Management Advice.

78. I think the newsletter was very helpful to existing beneficiaries in explaining what was available, however, that was the only newsletter I ever saw from the Caxton Foundation. When we asked for data about applications for grant funding and how many recipients there were for the various grants, we were told this information could not be provided for data protection reasons. However, we were not asking for names, only figures, so I feel the Caxton Foundation was not forthcoming in this regard.

79. One drawback with the newsletter was that it would only have gone out to existing beneficiaries, and did not target those who were unaware of the financial support available. It would therefore not have resulted in new beneficiaries coming forward and I am not aware the Caxton Foundation tried to reach out to new beneficiaries in any other way, such as advertising, etc.

80. I used my time as a member of the CFPG to try to fight for things that I knew could really help people in my situation. During my time with the CFPG I also asked for a face to face meeting with the trustees themselves, but this never happened. I also asked whether vacancy positions for trustees were ever advertised among the community of victims, but cannot recall getting an answer to this question.

EIBSS Focus Group

81. I attend the EIBSS Focus Group meetings and always offer to take questions to the Focus Group on behalf of others.

82. I have attended this group from the very start. The first meeting was really positive, and EIBSS seemed to listen and take on board everything the Focus Group said. When they didn't have an answer, they would take it away and come back to us once they did.

83. The Group is open to anyone who wishes to attend, which is a welcome improvement on the CFPG. One great benefit of this is that, as a campaigner, these meetings allow me to make contact with individuals who are attending such meetings for the first time. I am able to pass on details of support groups, such as Bloodloss Families and Contaminated Blood Campaign, to help them find the support of others. For some, especially the newly diagnosed and those new to campaigning, this might be the first time they learnt of the existence of others in the same situation as themselves.

84. EIBSS invite all beneficiaries to attend the Focus Group, and the meeting location moves around the country to give more people the chance to attend. I attend whenever the meetings take place in London, though sometimes the meetings are oversubscribed, as they can only accommodate a set number of attendees. The process is transparent and I feel as if I am being listened to and have a voice.

85. Although grants are available through EIBSS, again it seems as if they are on a need to know basis. If you do not know the questions to ask, then you cannot find out the right information. I relay as much information as I can to the Bloodloss Families group so that people are aware of what they can apply for. I have asked EIBSS to produce a detailed Q&A on their website so that all the information is accessible.

86. Things have improved a little and EIBSS do now publish a booklet, 'Discretionary Support Guidance Booklet', giving information on the sorts of financial assistance available, such as income top-up payments, accommodation adaptations, respite, etc. When changes are made this does get updated, but sometimes not very quickly, and EIBSS can be slow

too in updating the application forms. It is very frustrating for beneficiaries to spend time completing forms only to be told a form is now out of date. I have asked that they keep their website as up to date as possible, to help people access the correct information. So many of those infected are ill and suffer from brain fog, so the process should be made as user-friendly as possible.

87. Like I did at CFPG, I have questioned the requirement to obtain a doctor's letter in support of an EIBSS grant application. My view is that if you have HCV and are in receipt of SCM that should be enough to satisfy EIBSS, without the additional need to obtain a doctor's letter in support and to have to pay for that letter. Many individuals contact me saying they have been refused their requests for grants, even where the request is accompanied by a doctor's letter. I raised this with the Focus Group, explaining that where someone has cirrhosis they should not require further evidence. Although I have raised this on several occasions I do not think this issue has been resolved.

88. Again, like at CFPG, I have raised the issue of emergency payments. As I left one of the Focus Group meetings I mentioned that I did not know if I would have any heating when I got home and explained about my daughter's ill-health. One of the officials said that if there was an issue I should get the gas company to confirm a replacement boiler was needed, which they did, and within 48 hours the money from EIBSS to replace the boiler was in my account. I did not expect that response and would not have known it was possible had I not attended the Focus Group on that day. I have explained how helpful it would be if this sort of information was available on the EIBSS website.

89. I have also questioned the need for repeated applications for the same thing. For example, someone with cirrhosis will not get better and will always require prescriptions. I do not see the sense in requiring such individuals to

reapply for a new prescription certificate every year. This has been raised with the Focus Group.

90. Sometimes the EIBSS systems themselves are not straightforward. For example, when I applied for a travel grant for hospital appointments by sending off all the travel expenses and hospital letters, they sent it all back and told me I had to apply for a low-income certificate instead. If I did not qualify, they said I could reapply for the travel grant at that stage. I did apply and qualified for the low-income certificate, but feel that the EIBSS systems such as this one is not necessarily straightforward and can be confusing and time-consuming for beneficiaries. Again, this is something I have explained at meetings of the Focus Group.

91. Another issue I have raised is the different sources of income EIBSS will take account when considering eligibility for financial assistance. Although they disregard ex-gratia payments and Carer's Allowance, they do take into account pension income and, GRO-C ESA GRO-C GRO-C as she lives with me. This means that, in order to qualify for financial assistance, I have to ask GRO-C about her personal finances, and supply photocopies of her income to EIBSS. I think it is unreasonable that GRO-C finances are taken into account for my eligibility, and even worse that I have to supply evidence of this when they are benefits she receives from the state and could be checked by EIBSS directly. I have raised this a number of times with EIBSS but as yet nothing has changed. I know this is also an issue for other infected individuals who have to disclose the income of members of their household to EIBSS.

92. I have also raised the situation of what is to happen in the event of my death. Widows and widowers now receive ongoing payments after an infected person dies, but when I die, my adult daughter, GRO-C GRO-C will not qualify for any such ongoing payment. GRO-C GRO-C The situation is the same for parents who have lost children: there has never been any financial

support as far as I am aware, although the issue has been raised at numerous meetings I have attended.

93. It is an ongoing battle to bring all these different situations that beneficiaries find themselves in to the attention of EIBSS.

Further information

94. Despite all I and others have tried to do, there is still no mass testing for HCV. The Penrose Inquiry recommended national testing and yet nothing has been done. I feel we are losing time and, two years after this Inquiry started, we have lost yet another opportunity to introduce testing. More people will have died of liver issues during this time, not knowing they had HCV and that they risked infecting their families. The government can act swiftly if it chooses to, yet it continues to choose to do nothing. I feel the government continues to compound the mistakes other governments have made for over 30 years.

95. The contaminated blood scandal hangs over me every day, even in preparing this second statement. Campaigning does take its toll from an emotional perspective. Even when I have been unwell, or on treatment, I have felt as if I need to keep attending the meetings, particularly when I may be the only blood transfusion victim in the room. I want to ensure our views are represented. I hope that the outcome of this Inquiry will mean I no longer have to campaign, but I find I cannot yet walk away from this as I feel too much responsibility to others, especially those with no voice.

96. Being a campaigner is not something I would have chosen for myself, but it is part and parcel of how I feel let down: not only was I given dirty blood in 1983, not only did no one bother to find me for nearly 30 years, not only was I not diagnosed until 2011, but added to that is the fight for treatment, and having to watch other dies, and knowing that that is my future. I hope this Inquiry signals an end to the scandal, and that the Inquiry does what it says

it is going to do, but I am fearful of the power of those who do not want the truth to come out.

Statement of Truth

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

Signed GRO-C

Dated 22nd July 2020