Witness Name: Rosamund Mary Cooper

Statement No: WITN1168001

Exhibits: WITN1168002

Dated: 15 March 2019

#### INFECTED BLOOD INQUIRY

F	RST WRITTEN WITNESS STATEMENT OF ROSAMUND MA	ARY COOPER
I, Rosa	amund Mary Cooper will say as follows:-	
Section	on 1. Introduction	
1.	My name is Rosamund Mary Cooper. My date of birth is the	<b>GRO-C</b> 1974 and
	My name is Rosamund Mary Cooper. My date of birth is the GRO-C	I am married to
	Adrian Cooper (Ade) we married in 2003. Unfortunately, we have been unable to	
	have children. I have been unemployed since 2007. When I last worked, I was an	
	IT consultant, and later I became a Development Team Leade	er.
2.	This witness statement has been prepared without the bene	efit of access to my
	full medical records	

# Section 2. How affected

3. I have severe type three Von Willebrand disease, which I was diagnosed with when I was 8 months old in GRO-C 1975. As a result of this condition, I have been treated with blood products from the time I was first diagnosed.

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- 4. According to the records I have received from the United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO) (Exhibit WITN1168002) I have received the following treatment:
  - 1975 Cryoprecipitate (Cryo). I believe I was treated with Cryo a lot longer than an average child with a similar condition, potentially to protect me from being infected with Human Immunodeficiency Virus (HIV) and other virus'.
  - 1982 Factor VIII 8Y produced by BPL and from 1988 onwards until I received Haemate P.
  - 1995 to 2017 Haemate P.
  - 2017 Voncento and I am still currently in receipt of that treatment.
  - I also received a one-off treatment with Wilfacto in 2009.
- 5. I also had platelet transfusions when the clotting factor did not work and similarly, I had blood transfusions when the clotting factor did not work. I think when I was young they were whole blood transfusions, when the factor did not work and in the last ten years or so, platelet transfusions.
- 6. I was first registered at the Manchester Children's Hospital (RMCH) under the care of Dr David Evans and after some time a clinical nurse specialist was appointed called Alex Susman-Shaw. I was there for my entire childhood, until I transferred to the Manchester Royal Infirmary (MRI), which was an adult hospital. Unfortunately, I had heard a lot of negative comments about the hospital and Dr Evans was not keen for me to go to MRI, so because I had been under Withington Hospital for gynaecological issues I opted to see Dr Taberner the haematologist there instead. I received treatment in hospital, but from the age of 14 I also brought bottles of Factor VIII home and self-administered it.

- 7. In 1992 I went to the University of Huddersfield, and that is when I registered at the Manchester Royal Infirmary. I was able to be seen at Huddersfield Hospital, but they were not a comprehensive care centre. I moved back to Manchester in 1995 and remained registered there until 2000 under the team lead by Dr Charlie Hay.
- 8. In 2000 I moved to Birmingham, and I transferred to the Queen Elizabeth Hospital, Birmingham, and my new haematologist was Dr Jonathan Wilde.
- 9. My parents were never informed about the potential risks of me being exposed to infection from blood products prior or during the treatment I received. I was also never made aware of the risks. They recall being told about a thing called non A non B hepatitis but this was played down as not being a problem.
- 10. My parents had received some information about the blood products being contaminated with HIV during local patient events held by the Haemophilia Society in the North West. However, they were never informed about it by the NHS, nor were we ever given an option to opt out of the treatment. The impression was given that this was the best and only treatment.
- 11. As a result of being treated with contaminated blood products for my Von Willebrand's disease, I was infected with Hepatitis C (HCV).
- 12. In 1993, when I was 18, I discovered by accident that I had HCV. I needed an operation on my ankle at St. Thomas' Hospital in London which was a different hospital from where I normally received treatment. During the pre-operation chat with the Haemophilia doctor it was mentioned in passing that I had HCV, in terms of precautions to be taken during the operation. I was shell shocked by this information. My mother had just left the hospital and I was alone. The doctor discussing the diagnosis was surprised that I was not aware of the infection.

- 13.I assume my condition was referred to in my notes from Manchester Royal Infirmary, which had been transferred to St Thomas' for the operation. I had never been told of the diagnosis prior to this. Having since tried to access my medical records and been told they were no longer available; I have been unable to discover when I was tested for HCV. I also tried to get copies of my notes from RMCH from my entire childhood with the help of my specialist nurse. However, having said, "yes, no problem, leave it with me", she then rang us back to say my notes had, "gone down a black hole" and she could not understand it. I was not aware I had been tested for HCV and no information was given to me about the virus whenever that was.
- 14. After my ankle operation I returned to my centre in Manchester. I do not recall the information I received from them about HCV, it was not a lot. I did my own research. My mum recalls that we spoke to Dr Evans at the childrens' hospital and were told it was a strange virus that could take up to 20 years to become active. It ruined my trust of the doctors and my centre, MRI, as they had known about my condition but not told me. I wanted to find out about the condition but not from them, I am not sure I would have believed them.
- 15.1 have a good network of fellow haemophiliacs and I learnt about the condition through them as much as anything.
- 16. The only advice I recall being given from MRI was not to drink too much alcohol, although even this was vague. I was also told not to share toothbrushes with my housemates at the university and not to have sex without protection.
- 17. Whilst I did not know much about the infection, I did get the impression that it was a serious illness, but I am not sure I realised how serious. I was also told that HCV could be dormant for 20 years before any symptoms showed. This struck me as less than reassuring as I was also being told I might have been infected since my first treatment 18 years before.

- 18.1 do not believe that I was ever provided with adequate information about my infection and how to manage it. I was also not provided with any support once I was made aware of the diagnosis, which is very disappointing.
- 19.1 do consider the information about HCV should have been given to me earlier. My parents and I had been hearing some information at patient events about HIV, so we knew information was out there. In my view, being counselled about the possibility of infection before my diagnosis (and preferably being actually informed of my diagnosis) would have been a better approach.
- 20.I am a severe bleeder, so I am aware that I did need some form of treatment to survive; however, I am aware that there were safer alternatives at the time, so I or at least my parents should have been informed about the risks and given the option to choose.
- 21.I am very unhappy with how my diagnosis was communicated to me. As somebody with a lifelong condition, I do rely on a good relationship with doctors and nurses. To me, going to hospital is like going to my second home, it is like being part of a family. It is meant to be a safe environment. I feel the hospital has been disrespectful and negligent by not providing me with my diagnosis and I do now lack trust towards medical staff.

## Section 3. Other Infections

- 22.I am not aware of having any other viral infections as a result of being treated with contaminated blood products. I am aware that I was tested for HIV multiple times.
- 23. I am not aware that I have been tested for anything else.

24.1 was informed via letter that I had been exposed to Variant Creutzfeldt-Jakob disease (vCJD) through a contaminated batch of treatment. This felt inadequate and again, very little information and support was offered.

### Section 4. Consent

- 25.1 was tested for HCV without my informed consent, as I was not aware of the tests taking place. I was also never informed about the results of those tests. I still do not know when I was first tested for HCV.
- 26.In my UKHCDO record it appears that I was tested for HIV in 1985, 1986 and 1987 but I do not recall being made aware of this or of my parents' consenting to the tests at the time.
- 27.I also have reason to believe that I was tested for research purposes. In the UKHCDO record there is a mention of Dr Craske's HIV research. I have no knowledge of this, and my mother cannot remember it either.

### Section 5. Impact

- 28. Finding out about my HCV infection has had a massive mental impact on me. I was only 18 when I first found out about it, and I had no idea as to how long I had had it for. I was also told by a nurse that I could have been potentially re-infected with it every time I had my treatment, which is very concerning.
- 29. My initial reaction was that I did not understand what it was, but I thought it was serious and that it was life threatening. I was scared to drink alcohol because I knew it would harm me but had no idea how, because of the lack of advice. I drank anyway because I was a student trying to act normal and kept my worries to myself, even though with every drink I thought I might be damaging my liver. I do not believe that as a student I should have been worried about it.

- 30.1 am also not able to tell the difference between my life prior to the infection and after infection, as I am not aware how long I actually have had it for. However, my life altered irrevocably at the point of discovery that I had it.
- 31.I was always a very optimistic person. Being born with Von Willebrand disease in the first place had a massive impact on me; however, I have learnt to live with it and to overcome any limitations. However, having found out about the HCV was a massive shock to me. I feel this did take away a lot of my positivity.
- 32.1 turned from being a positive, determined, ambitious individual to one who cannot cope and cannot overcome the state I am in. This has had a huge negative impact on my mental health.
- 33.1 have been dealing with a lot of frustration due to my mental and physical limitations caused by HCV.
- 34.1 often become angry at myself, particularly when I injure myself and cause a bleed, because it means having treatment and who knows what that may result in? This relates to the fact I am still on blood derived products and that despite the claims for safety, my experience has shown me that risks are there.
- 35.1 also hate myself subconsciously. This manifests in not having treatment when necessary, not getting medical attention when perhaps I should, wanting to hurt myself, I am aware of it but not in control of it.
- 36. I have a great sense of guilt: that I am not as ill as some, that I am still alive, that I am a bad wife, that I have not given Ade children and our parents grandchildren.

- 37.1 struggled with relationships. I felt the need to disclose my infection to men at the beginning when I first met them, which put off the vast majority of them except Ade, who might now regret that he was not put off by my infection!
- 38.1 am also constantly exhausted. I have not felt well since before my treatment for HCV, with fatigue affecting my personal and work life since I was in my 20's. I probably operate between 10% 65% of my energy levels.
- 39. My entire lifestyle has changed as a result of my illness. I had to adjust to a mentally challenged life. I have to list everything, prioritise things and I often put things off until I have energy or the ability to do them.
- 40.1 struggle with short and long-term memory issues. I will forget a conversation that I have just had, I also have very little recollection of life as a child and I rely on my parents to tell me a lot of what happened. What I remember is a life punctuated by bleeds and hospital visits.
- 41.1 struggle with constant brain fog. I often use incorrect words, such as do you need some meat for the fire, when I mean wood. Sometimes without realising I have got it wrong. I recall that when my father had mini-strokes and lost partial use of his brain which affected his memory and ability, it seemed exactly like what I have. I have always suspected actual brain damage from Interferon; however, there is no way to prove this.
- 42.1 struggle to multi-task, or even to do one thing at the time; whenever there is any distraction, I cannot focus on what I am doing, for example I cannot have a conversation while the radio is on. I find following instructions and recipes tricky, as I forget what I have read the moment I look away.
- 43.1 have also been struggling with depression due to the loss of the life as I had expected it to be. I have lost abilities; I have lost my career, my working life and

achievements. I have the sense of a life in limbo, I am constantly waiting for something: waiting to feel better, waiting to get on with my life, waiting for closure, waiting to become more ill and waiting to die. This is a sense also felt by my parents and my husband too.

- 44.I deal with constant fear. Due to the nature of my bleeding disorder I still have to use heat-treated blood-based products. Despite the fact I know the products are "much safer", I am scared of the next viral attacker to be discovered within me. Therefore, I hate treating and avoid it where possible making the side-effects of my bleeding condition worse and hating myself for doing this as well.
- 45.1 was treated with Interferon in 1998-9, which lasted for 12 months. After three months of being on this treatment I was told that the virus had cleared from my bloodstream. I stayed on it for the whole 12 months. Unfortunately, the treatment did not prove to be successful as the virus returned.
- 46. In 2003, I was treated with Pegylated Interferon and Ribavirin. This was a six month-long treatment, and although it successfully cleared the virus, I was unable to work during or after it and suffered hideous side effects once again.
- 47. Regardless of the treatment proving to be a success, I was never the same as I was prior to it.
- 48. If I had known about the long-term side-effects of my treatment, I would never have agreed to receive it. I was well enough to wait for the treatments that at that time were in development. I started the second course of treatment a year before my wedding. Ade and I were planning a family and were convinced that in order to consider having children, I would first have to clear the virus.

- 49. I believe that the treatments provided to me were the only treatments available at the time; however, knowing what I know now, I would have opted to wait for a new treatment with less severe side-effects.
- 50. There are a number of physical side-effects which I am dealing with. Some may be as a result of the HCV itself and some due to the toxic medication, which I have been given to treat it. These include hot sweats, cold shakes, pain akin to feeling like my bones were rotting, glomerulonephritis (inflammation of the filters in my kidneys), cognitive decline, sore throat, liver pain, chest infections, headaches, intermittent dizziness, heartburn, and restless legs and body.
- 51. There are a number of further medical conditions that I have been diagnosed with, such as fibromyalgia (widespread musculoskeletal pain accompanied by fatigue, sleep, memory and mood issues), high blood pressure, Chronic Fatigue Syndrome (CFS), formication (insects crawling on the skin sensation), insomnia, depression and decline in my immune system.
- 52. One of the most upsetting side-effects of my treatment is the infertility. After many failed attempts to conceive post-treatment, I discovered that I am infertile and that this could be as a direct result of the Interferon treatment. This is one of the main reasons why I would not have started it if I had been advised that this was a potential side effect.
- 53. Ade and I really wanted to have our own family and since we were not able to conceive naturally, we decided to try in vitro fertilization (IVF).
- 54. After various failed attempts a friend of mine offered to be a surrogate. We went through it with her, but I did not produce any viable eggs.
- 55. Before the IVF I had to get proof that my exposure to Hepatitis C and vCJd would not cause a problem for any pregnancy or child I carried. Then we had to get

- special permission when we tried surrogacy with our friend to implant one of our embryos in her. Unfortunately, the embryo did not take.
- 56. After this we made the decision not to carry on because it was too much mentally but also because I was so unreliable and ill that I felt I would not be a good mother.
- 57. Due to my involuntary childlessness I avoid situations with children, (including my own nieces and nephews) and family occasions, such as attending church at Christmas or babysitting.
- 58. At this point I even struggle to look after my pets, and I feel I am unfit to have even them.
- 59.1 have struggled mentally and physically during my treatment; however, I was still not offered any physical or mental support. I was only regularly tested in order to check whether the virus had cleared or not.
- 60. My low self-esteem affects my relationship with Ade, I wonder why he stays with me and I expect that he will find someone who can give him a family and be an active part of our farm. I also worry that his family wonders why he is still with me, although I am pretty certain that they do not think that. This is a vicious circle and I am not being myself with Ade and I feel awful about myself.
- 61. My HCV has affected many aspects of my private, family and social life.
- 62.I have had some support at the Queen Elizabeth Hospital in Birmingham. In about 2012 I happened to be at the hospital and said to my specialist nurse that I was really struggling and that I needed somebody to talk to. The person who I spoke to at the time was surprised that I was not aware of the fact that they had a

social worker and a psychotherapist both of whom worked alongside the haemophilia team.

- 63.I had some psychotherapy for 6 months; however, once my therapist retired, she was never replaced, so I was not able to benefit from her support.
- 64. I also saw the social worker, Mark Simmons. Mark pointed out that I had made massive adjustments to lead some resemblance of a "normal" life. However, I believe that what is "normal" life for me at the moment is not what I actually desire to have. Mark has since retired GRO-C and he has not been replaced.
- 65. Both, the psychotherapist and the social worker proved to be of a great support, and I am truly upset that I was not able to continue with my therapy.
- 66.I returned to my GP and asked if any mental health support might be available given my history. I was referred to a website upon which I could opt to attend a mental health support group for a few weeks. However, this was around 10 miles from home and at that time I was often unable to drive. I have attended group sessions before and do not find them to be as helpful as one-to-one sessions.
- 67. It also makes me uneasy knowing that if it was not for me going to the hospital and informing them that I was struggling I would have probably never been offered any psychological support. I do not think that this is right.
- 68.I am aware that I am the cause of worry and anxiety for many people in my life. I am unable to help my mother, who is nearly 76. She is a full-time carer for my father and she still often needs to help me.
- 69. My father was seriously ill with non-Hodgkin's lymphoma around five years ago. He was told that he had only five years to live. He recovered; however, he now

requires full-time care, as he is not able to drive or look after himself. I know that my mother needs help, but she never asks me because she knows how much I struggle.

- 70. My mother suffers from panic attacks and anxiety, and it upsets me that I am not able to help her.
- 71.I have tried to arrange to arrange for my mother to have some time for herself and go to Pilates classes, whilst I look after my father. However, we can never predict whether I will be well enough on the day to care for him. As a result of this we could not commit to the idea.
- 72. My infection has had a massive impact on Ade, as he feels a huge sense of responsibility for us both and this has caused problems with his own health. He admits his own life is far off track also and that he suffers because of my inabilities and disabilities.
- 73. Ade tries not to worry me with his work stress and protects me from helping him with the difficulties he faces, this leads to tension and anger on his behalf, which has a negative impact on our relationship.
- 74. He never complains about what we have been through as a result of HCV. However, in order to cope he throws himself into work, he works very hard. He used to be a farmer by birth, but he had to diversify as farming was very difficult to make a living. He currently builds sports pitches, which requires him to travel wherever the work is.
- 75. As it is his own business he is under a lot of pressure, especially as I no longer work. I try to help him as much as possible; however, I am not very reliable, as I tend to forget things, or get things done only half right. He helps his mother as well and if I needed more care he would not be able to cope.

- 76.I also suffer from no sex drive. Originally the fact that I could pass HCV on through sex was off-putting. It is sometimes extremely painful for me to have sex. The risk due to my being a bleeder and the HCV being transmitted via blood was never explained to me.
- 77.I have become unreliable and I often have to cancel social or medical appointments for health related reasons. I sometimes miss social meetings because I get the times and locations wrong, which is a direct result of HCV and the treatment on my mental functions. I feel that I let friends and family down as a result.
- 78. I never kept my infection a secret although I did not broadcast it. I believed that I should disclose it to friends and family. I was very open about it, and whenever anyone had any questions for me, I would try to answer them, even if at the time I had very few answers.
- 79. Luckily, I do not think that myself or my family have been explicitly been stigmatised due to the contamination. However, I have felt stigmatised and isolated by my own infected community, on occasion:
  - for being a woman, therefore the infection was not as serious in terms of
    its impact, as I am not "the breadwinner". It was frustrating, as I was in fact
    the main breadwinner at one time when Ade was farming, when he turned
    over around GRO-C per year,
  - for not suffering as badly from the effects of the virus (perhaps because I tended to put on a brave face),
  - for bleeding less than male haemophiliacs, therefore it could not be as bad. Despite having a similar clotting level to a severe haemophilliac

- for having only one virus compared to other people having multiple viruses. To some in the affected haemophilia community, my situation was comparably not as bad.
- 80. All this stigma and discrimination has been made much worse by the government schemes dividing us up into categories of seriousness.
- 81.I did a communication arts and theatre studies degree. I originally aspired to be an actress. My degree involved subjects such as theatre, linguistics, computer studies, Marxism and logical argument.
- 82.I found out about my infection between my first and second year of university.

  This massively impacted my studies and social life. I was afraid that I would infect my housemates. I was terrified and I felt I could not talk to anyone about this at the time.
- 83.1 have also missed out on exploring my sexuality, because I was too afraid to pass HCV onto other people, in case the contraception did not work.
- 84. I was not able to drink and party like other students were able to. I asked the doctors if I could drink alcohol at all; however, I was never given any clear guidance, so I drank but not during the week and binged at weekends thinking that might be ok.
- 85. Notwithstanding all the obstacles thrown my way, I still managed to do well at university.
- 86. I did further training after my first course of Interferon to enable me to work in IT from home if I became ill. I completed the course and forged a career in IT but I became more and more ill especially after the second course of treatment. My brain did not work as well and my memory was rubbish.

- 87. I still try to persevere through all of this; however, I get very discouraged as many things prove to be impossible. I have managed recently to do some training in Emotional Freedom Technique (EFT) a tapping therapy, but I cannot remember the simple steps. I already suffer from a lack of confidence in my abilities, this has added to that. However, I am persisting to try and help myself get better.
- 88. My career prospects have completely diminished. I lost my job at John Lewis in Manchester post my Interferon in 1998/9, for failing to recover quick enough.
- 89. I worked in the John Lewis shoes and accessories department originally, but I struggled to be on my feet for 10 hours per day, particularly after my ankle operation, due to severe arthritis. This was when the fatigue started becoming a problem too.
- 90. I was then promoted to a different job at John Lewis, where I was looking after and running events for the staff. I really enjoyed this job.
- 91. I tried to work through and overcome all the symptoms of HCV and the sideeffects of the treatment.
- 92. I kept on falling asleep due to my severe fatigue, I often could not remember names, having previously known 85% of the 1000 staff within the branch. My work was hugely affected and my functioning slowed.
- 93. My employers tried to accommodate my needs, so that I could keep the job. For example, I would not work on the days post injection, as I was always very poorly then.

- 94. After I had finished my treatment I still felt very unwell, as if I was still taking Interferon. I was unable to return to even an adapted role.
- 95. Eventually I lost my job as I simply was not able to do it. As a result I lost my flat. I moved in with friends who helped me to recover and work out what to do next.
- 96. I felt that I could build up a career in IT, as it would allow me to work from home.

  Once I had recovered enough I took out a Career Development Loan to study
  IT, I did a 6 week database course and got a work placement in Chester. I then
  moved to Worcester as this was about the time I met Ade.
- 97. My IT career went well regardless of the fatigue and lack of concentration. However, in 2003 I began my second course of treatment and I was no longer capable, on a physical and mental level, to perform my job. This first resulted in a pay cut, which affected me financially, but eventually I had to retire due to ill health in 2007. I am currently on benefits as I am not able to work. I am in receipt of Employment Support Allowance, although I had to go to Tribunal to receive it having been turned down. I was awarded Disability Living Allowance for life as a teenager but lost this in the changeover to PIP. I had to reapply and be assessed for that and was successful but only for five years in the first instance.
- 98. I earned a maximum of £43,000 per annum when I was working in IT. If my career had continued, I would have been earning considerably more. This was very important for our household, as Ade was not earning a lot from his farming. As a result of all of this he had to give up farming, which was his great passion, in order to provide for both of us.
- 99. Due to my ill-health I have not only lost the opportunity for a great career and stability financially, but I have also lost my independence. I am no longer able to

make independent financial decisions. I was always very keen on being independent, considering that I was born with a medical condition which made me dependent on other people and on my treatment.

- 100. I have also been unable to get life insurance. I have tried a few times, most recently in March 2019, but the combination of my infection and bleeding disorder negates it. I hate the fact that when I die, I will leave Ade with nothing.
- 101.1 was adopted by my parents when I was a baby. I connected with my birth mother in 2008. She already has a massive sense of guilt and loss from giving me up when I was a baby. I had to explain my bleeding disorder to her and my infection. This made her feel even more guilty, as she knows that I have the disorder from her as the von Willebrands is a genetic abnormality. Therefore, in her mind the infection resulting from the treatment is her fault. She believes she is responsible for what happened to me, and therefore I avoid talking to her about it as it upsets her, even though we have a good relationship. She lives in Northern Ireland and never had any more children, due to the guilt of giving one away.

## Section 6. Treatment/Care/Support

- 102. There were no obstacles to me in accessing any treatment per se; however, I found it difficult to get an appropriate mental health support.
- 103.I have received a treatment for my HCV, but the psychological support after it was lacking.
- 104.In about 2005/6 I had six weeks of counselling through my GP, which the counsellor thought was very helpful. However, I felt it had not even scratched the surface. After those six weeks I was discharged and have not received any help after that from my GP.

105. When the Skipton Fund was put into place there was the option to have overthe telephone counselling appointments; however, I did not feel that I would benefit from those.

## Section 7. Financial Assistance

- 106. I found out about the Skipton Fund either from a support group for people with HCV and haemophilia, or the Haemophilia Society.
- 107.1 applied to it and received £20,000, due to being infected with chronic HCV. This helped us buy our second home.
- 108. I have not received any ongoing payments. I applied for the second stage 2 payments, which were subject to having cirrhosis or a certain score on a fibroscan. I did not receive it as my liver specialist told me that my liver damage was not severe enough.
- 109. I applied for help towards things pursuant to my condition, such as a mattress, a brain scan (which was eventually approved; however, I had to argue my case), and psychotherapy.
- 110. The process of applying for help was so intrusive that I stopped applying. It was not the case that I did not need help. Applicants were completely scrutinised, their applications picked apart and any funds given had conditions attached.
- 111.1 am now receiving an income top up of around £200 per month.

112.I was also registered for the Caxton Foundation now the England Infected Blood Support Scheme (EIBSS). I had to go through another hideous application process for the Special Category Mechanism (SCM). This was to prove the infection with HCV has caused me any long term problems. My specialist supported my application and I now receive £1,500 per month from them. This is very helpful as I am now able to contribute to the household bills and make independent financial choices, which has given me back some level of self-worth. Also I can afford a cleaner rather than my mum cleaning for me.

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- 113. However, the process of applying for this was horrendous. It put me back massively. I had to explain the mental and physical effects of my illness, and argue my case for them to understand. I found it very difficult.
- 114. The problem that I have with various trusts and funds set up is that they are discriminatory. I believe that anybody who had been infected should be compensated, regardless of the severity of resulting illness as many factors play in to that.
- 115. A friend of mine is a self-clearer and because of that she does not receive any financial help. I do not believe that this is fair and she is showing many signs that the virus has caused her issues.
- 116. The process of applying for any help is a degrading process. In order to apply an individual needs to prove their incapacity caused by illness.
- 117. There are always various pre-conditions put into place. Whenever one applies for something they need to get three different quotes from three different suppliers. The money also does not go to the individual, but the supplier after the purchase is made, which can be very embarrassing and forces potential disclosure.

- 118. Ade and I have not been able to save enough money to be able to purchase our own house, however we have been gifted a significant amount of money from my uncle and aunt, in order for us to be able to buy a house. Unfortunately, this was not something that we could get help with from the funds and trusts available.
- 119. After paying for our IVF I applied to the Caxton Foundation for the cost of the surrogacy, which was substantial. They turned us down as surrogacy was not deemed to "meet a charitable need". This was a massive rejection and felt like a punch in the face.

### Anonymity, disclosure and redaction

- 120.I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.
- 121.1 do wish to be called to give oral evidence.

Statement of Truth I believe that the facts stated in this witness statement are true. **GRO-C** Signed..... Rosamund Mary Cooper March 2019 Dated