Witness Name: P Wakefield
Statement No: WITN1582001
Exhibits: 0
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PAULA WAKEFIELD

I, Paula Wakefield, will say as follows:-

Section 1. Introduction

1. My name is Paula Wakefield of GRO-C Manchester GRO-C My date of birth is GRO-C 1979. I live with my husband and our 8 year old daughter. I am a councillor and I work for an MP. I have been involved in campaigning and have attended protests at Westminster since my father was still alive.

2. I prepare this statement in relation to my late father Russell Eric Carbery who was born on GRO-C 1954 and passed away on 9 July 1993 as a result of receiving contaminated blood products.

3. My mother, Anne Carbery, and brother, Stuart Carbery, have also provided witness statements to the Inquiry.

4. **This statement has been prepared without the benefit of access to my late father's medical records.**

Section 2. How Affected

5. I always knew that my father had Haemophilia A. I regularly saw him taking Factor VIII concentrate and self administering at home. As a child, I was always interested in my father's health and it was a normal way of life for me to see my father have to receive Factor VIII. I felt quite protective of him as he had disabilities and developed very bad arthritis due to the Haemophilia which meant that he struggled to walk.

6. I was very close to my father. It was the norm that he attended appointments at the Manchester Royal Infirmary Hospital and underwent tests. We used to go regularly as a family to all the appointments.

7. My father also, later on, attended Monsall Hospital after my mother consulted the family GP about transferring him to a different hospital in view of receiving better care and treatment as she felt they were not diagnosing him correctly at Manchester Royal. My mum felt that a previous Hep B infection had returned as he was presenting similar symptoms, but she felt it was being dismissed.

8. As my father became more poorly and suffered with more severe bleeds he attended the hospital a lot more regularly. I could tell that he was unwell as we had to cancel a holiday and he was having longer stays in hospital.

9. My father was infected with HIV, Hepatitis B and Hepatitis C as a result of receiving contaminated blood products.

10. To the best of my recollection, I figured out that my father had been infected with HIV shortly after seeing a news article about AZT treatment on TV and I knew that my dad had been taking AZT. The nurses at Monsall Hospital took me into a room and asked me if I knew what HIV was and that my father had it. Following this, I recall that my mother had a conversation with my brother and me as my father's health was deteriorating very quickly.

11. I was 13 years old when my father passed away at home.

Section 3. Other Infections

12. I am not aware of any other infections that my father may have been exposed to.

Section 4. Consent

13. My father consented to a HIV test.

14. My mother told me that my father was tested for Hepatitis C without his knowledge as shown by his medical notes from Manchester Royal Infirmary Hospital obtained by Monsall Hospital.

15. In the early 1980s, Haemophiliacs from the North West and their partners were asked to attend a communal meeting with health professionals and blood company representatives. They spoke to the group about *"this new virus called HIV which you may have heard about"* they were told, as a collective, that "*You may or may not have it but it is nothing to worry about*". They had a buffet put on for them which blew my mind – I just can't believe the casual, blase and non-confidential manner in which they were informed of something so catastrophic. The health professionals did not take the prospect of a HIV test seriously and in passing they mentioned they could get a test if they wanted " *the next time you are passing the hospital or coming to collect treatment*".

16. When my father was told about his HIV diagnosis he was provided with no information in relation to risks to himself or family or about counselling. He was left to his own devices. When the health service has messed up massively the red carpet should have been rolled out for these people, including my father, who had been affected by this huge wrongdoing by the establishment. They basically asked for patients to go away and the people

with authority did not want to deal with this or with them. When the stigma permeated through the horrendous portrayal of HIV at the time it was not in the Government's interest to disprove the myths. It suited them that people remained quiet about the situation.

17. I do not know whether I have been tested for HIV or Hepatitis C. I do remember giving blood on various occasions for strange reasons such as when I had teeth out and, looking back, I do question whether my blood has been tested without my knowledge. I would not be surprised if it transpired that this was the case.

Section 5. Impact

18. My father was a normal dad. We had season tickets for Manchester United football games and we used to go together all the time. Towards the end of his life, he became yellow and he had longer stays in hospital. When he was at home he slept for long periods of time as he suffered with fatigue. He eventually went into a coma which he did not wake up from. I did not realise what this meant because, as a little girl, I thought he was just tired from being ill and was in a deep sleep.

19. My father passed away in the summer holidays so a lot of people did not know that he had died when I returned to school. I did not know anybody else whose father had died and I just wanted to blend in so I did not mention it.

20. My mother told me that if I brought it up or if anyone asked; I should tell people that my father died of cancer.

21. I personally did not experience much stigma but the family as a whole has received hate mail through the post such as "*AIDS scum*". We lost a lot of family support on my mother's side as there was a lot of stigma in relation to all of the viruses but HIV in particular at that time. For example, my father had to bring his own cutlery whenever we visited family members. I was also very

aware that I should not talk about HIV or Hep C in relation to my dad. People used to make jokes about AIDS at school.

22. The parents of the children at the primary school where my brother and I attended said that they did not want their children to attend the school if my brother and I went there and went to see the headteacher about it.

23. I did not want to discuss my father's death at school due to the stigma and I felt that if I brought Haemophilia up it would invite people to make negative assumptions.

24. Recently, my mother told me that many funeral directors did not want to deal with my father's body. I cannot imagine what my mother went through at that time. I am still finding things out today which are shocking. My mother tells me that there is still a lot I do not know but she does not want to discuss them with me as she feels too upset/ traumatised / embarrassed and also doesn't want to further upset me or my brother.

25. Due to the HIV diagnosis my dad lost his life insurance which in turn meant they also lost the mortgage on our home. We then had to move into a council house. At the time, I did not know why we were moving and I did not know that it was a council house until later in my life. I recall that my father also lost his job as a result of his infections.

26. I felt like I did not really get a chance to grieve for my father properly. I did not want to bring it up at home as my mother was too upset. She tried to carry on as best as she could and she tried to give us a normal life. We continued doing things that we had done when my dad was alive. My mum felt she had to go on for me and my brother and I suppose we were a distraction for her at the time. When myself and my brother became adults I think it hit her as she no longer had to think as much about us and she had more time to think about what had happened.

27. My mother suffers with PTSD. She has never got over losing my dad and she speaks about my father as though they are still married. She attended many of my father's friends' funerals which was a constant reminder of what happened. As a woman in your 30's and a single mum of two young children I don't suppose you expect to see many of your friends die in such a short space of time as my mum did.

28. My mum worked in a hospice but took medical retirement as she could no longer cope with another constant reminder of illness and terminally ill patients who reminded her of my father's suffering.

29. My mother ended up being a secretary for one of the campaign groups which I think at the time helped her to try and seek justice for what had happened. Unfortunately, it all became too much for her as, again, it was a constant reminder of what had happened to my father and it was too much for her to cope with. She has never been the same since my father passed away. She was forever changed. I can tell my mother is depressed and traumatised with what has gone on and what she has seen.

30. At school I did well in my GCSEs. Unfortunately, due to the fact that we were struggling financially after my father passed away, I did not tell my mother about many school trips or extra-curricular activities as I did not want her to worry that she would not be able to afford them.

31. I did not stay on for sixth form college. Instead I went to college to study hair and beauty as I wanted to get away from school. During this time, I worked part-time in the evenings and I thought that after college I would just be able to earn money to be financially self-sufficient. I decided not to go to University as it would also be another financial strain which I did not want to put my mother through.

32. I met my husband at the age of 16. When we got married, I missed out on my father giving me away at my wedding.

33. I grew up with the notion of not wanting any children because I am a carrier of Haemophilia. My experience of Haemophilia was horrific. My father actually said to me "*Whatever you do, don't have any haemophiliac children and don't put them through what I have been through*". I knew that I could not cope with bringing Haemophillia back into the family and it would also crush my mother.

34. The fact that I did not contemplate having children due to the way the condition and subsequent infections impacted my father's life is awful. At the age of 30 I knew we needed to decide for definite if we wanted to consider having children. We decided to find out more information about medical advances as I had been out of the loop about Haemophilia for many years at this point. At the time I had decided that if I was carrying a boy I would terminate the pregnancy. We attended a Genetics Clinic at St Mary's Hospital in Manchester because I felt that we needed to gain more up to date knowledge. The staff were very good and explained to me the genetic tests available.

35. I was offered an early test to see if I was carrying a boy or a girl. It was a girl. I continue to be worried that when my little girl becomes older, I will have to explain everything about Haemophilia to her and the risks associated with it. I do not know whether she is a carrier as the test will not be carried out until necessary. If she is a carrier, it will continue the story of my father and these sad memories will once again have to be revisited. She is also growing up without a grandfather which is really upsetting as I would have loved for her to know my father and I know that my father would have made a brilliant grandfather.

36. After college, I worked in IT sales for 4 years with my husband and we eventually set up our own company.

37. I am now a councillor and I assist an MP. I have always been politically aware about the decisions which the Government has made and this career change was influenced by what happened to my family. I saw how my father was mistreated as he was disabled and I witnessed the lack of support my mother

received following his death. I feel very passionately about equality and social justice.

38. I suffered with depression later in life. I also suffered with post-natal depression but looking back I realise that my depression had not been diagnosed properly for many years before that.

39. For years, I did not want to talk about my father and instead I would change the topic quickly. I hated Father's Day as I could not talk about him as it was a constant reminder of him being dead. He died so young and I was so young when I lost him. People would naturally ask the question of how he passed away and I went through a turmoil of thoughts such as whether to trust people to tell them the truth. I knew that if I told them the truth they wouldn't understand anyway.

40. My mother is constantly reminded about the pain my father and she have gone through. She is constantly worried about having to apply for grants and reapply for payments and having to prove that she is worthy of the financial assistance. It also ties in to her PTSD, she is constantly reliving my father's passing because it has never gone away and has never been settled. Every time a new application comes around or a piece of news is shown on TV, she is constantly reminded. If my father was still around or had died of natural causes, their mortgage would have continued which would have allowed for financial security.

41. To think that the impact will stop at my generation is simply not right. The impact of this tragedy will continue for generations. My daughter is growing up without a grandad, my mum is not the person she would have been if my dad had not died and we will have to relive the entire story if my daughter is a Haemophilia carrier. GRO-C who was also a Haemophiliac, also passed away as a result of the scandal which has a knock on effect on his family.

42. The impact of people constantly dying from receiving contaminated blood and blood products and families constantly reliving it prevents everyone from moving on from this.

43. During my time campaigning, I have seen documents which contained warnings of viruses spreading and which said that heat treatment was available earlier than it was implemented. Advice was provided that blood should be heat treated but someone clearly ignored this advice and has not taken it on board. Further down the line the Government was choosing who to give the 'good blood' to and those who had already been infected did not seem to matter so the Government continued to give them the 'dodgy stuff'.

44. Factor VIII concentrate was sold as a miracle cure which would enable haemophiliacs including my father to do more with their life. My father's life did initially benefit from having Factor VIII as he never expected to get married or to have children prior to this. It transformed his life. He never thought in a million years that it would kill him. Instead of transforming his life, it ended it.

45. Prior to this, Cryoprecipitate was available which was usually frozen and required defrosting before use.

46. At around the age of 9 I went to protest outside of Westminster with my father as part of the Manor House Group. I was not scared of going and I remember there were other children around at the time. As the years went by these protests became angrier. We also used to go on holidays with other Haemophilia families organised by the North West Haemophilia society to Blackpool. At the time I did not realise that there were heated discussions occurring in the background of these events. As I became older, I found out more and more and I understand why these people were so angry with what had happened to them and that they felt they were not getting the answers they deserved.

47. After my father died, I attended a few protests but as my mother's health deteriorated we did not go as often and I was too young, at that time, to go on

my own. To be able to pick up the campaigning from social media has been an eye opener. I am able to speak with people who have been in a similar position to me through the Fatherless Generation, Factor 8 and Tainted Blood Facebook pages.

48. I struggled without my father being there. He was my best friend and I was very much a tom boy as we used to go to football together. He taught me how to ride my bike and I have many lovely memories of us laughing together. I would have liked for my daughter to know her grandad.

49. I saw my father's deterioration and I saw my mother deteriorate as well.

50. The real sadness is that had this tragedy been dealt with years ago, people would have had the opportunity to move on and live their life in private and have had some dignity. I do not campaign just for myself but also for the memory of my dad and for the people who are still suffering and the people who are still dying.

51. People were not looked after at all. Patients had to prove that they were ill enough in order to receive treatment for Hepatitis C which is horrendous. Patients were desperate to get their liver scans back with negative results so that they could be given better treatment and upgraded to a different "stage". I believe that all the stops should have been pulled out for these people because of the wrong doing which happened. They should not have to prove anything or jump through hoops to receive help. They should be receiving the very best help, treatment and support available.

52. My father found it difficult to get dental treatment as many didn't want to "deal with him".

53. I feel angry that conversations about Haemophilia, HIV and Hepatitis C were the norm for a little girl like me at the time. I should never have had to know or needed to know or understand these issues. I should never have known about Government cover ups and going to protests as a child. It annoys me now as

the impact will continue if I have to explain everything to my daughter and also the implications of the future is we should we find out that she is a Haemophilia carrier.

Section 6. Treatment/Care/Support

54. I received counselling from the NHS but I had to go through the usual rigmarole of a long waiting list and receiving only 6 sessions. It was a little bit helpful but I still take medication for depression to this day. This counselling was not in relation to my experience with my dad – it was generic counselling through the GP and I have never been offered bespoke counselling.

Section 7. Financial Assistance

55. Once my father died, I realised we were in financial difficulty. My father's payments from the MacFarlane Trust stopped. My mother was "*too young to be a widow*" and she was not eligible for much support. She had to declare herself bankrupt which inevitably had a knock-on effect on my finances and my credit rating.

56. The MacFarlane Trust helped me out with a grant to buy equipment for college. They may have helped me with a home appliance when I first moved.

57. At first I was reluctant to apply and I felt that the financial support was not set up for me and I felt cheeky having to ask for the money because nobody ever wrote to me to say that I was welcome to apply. Had my father been alive, he would have helped me financially.

58. When I applied for financial assistance the application forms which required completion were lengthy and they asked for personal information . Once I sent them off, I did not hear whether my application was successful for months. I found the thought very uncomfortable that a panel of people would sit around a table to decide whether I am worthy enough of financial assistance.

Section 8. Other Issues

59. I believe that the Government and Health Ministers were warned for many years of the possibility of contamination to blood products when plasma was pooled from many people from high risk places. I feel those warnings were ignored. I believe that they knew what was in the blood but due to money and the fact that we did not have own blood resources in the UK, they put money over people. I believe people were tested without their knowledge.

60. I believe that when HIV diagnoses were being made, they were swept under the carpet. The 1991 litigation pay-out was unfair as people were blackmailed into signing the waiver under the condition that if one person did not sign, nobody would get the money. I know, from what I have seen, that Government was covering their back for what was around the corner at the time; which was Hepatitis C. I know that my mother has said that there is evidence that Government knew about the possibility of Non A Non B Hepatitis in the same year when people signed the waiver. There were various documents I have seen floating around on social media and the documents my mother saw during her time at Manor House campaign group. Since then, she has given these documents to Pannone Napier and believes GRO-A may have some.

61. I think the way the whole thing has been treated by the Government has been absolutely shocking. When I tell people what happened, they can't believe it's true and that they did not know about it.

62. When Andy Burnham was my MP he suggested that the contaminated blood scandal did not have as strong an impact as, for example, Hillsborough because it was not an isolated incident in one area, it did not happen within one moment and also, due to stigma, victims were afraid to speak about it. The secrecy created by the Government AIDS campaign and doctors advice at the time played straight into the hands of the authorities who sought to sweep this scandal under the carpet.

63. People did not want to speak about contaminated blood as they were simply unable to due to the stigma. There have been drips and drabs in the news over the years about it and I am pleased that the Inquiry has started properly now and that the Chair of the Inquiry is taking it seriously. However, the practicality of the Inquiry is that it brings very sad memories back. Whereas, had it been dealt with many years ago, people would have had a better chance of being able to heal by now.

64. I believe that people were murdered through bad-decision making. Officials were aware of the warnings and did not follow them.

65. I want the truth to finally come out. I am glad these stories are now out there in the public domain and it is not being hidden anymore. There are still people who only now feel like they can stand up after so many years.

66. I want to know the truth of what happened. I want someone to accept liability and say that it should never have happened.

67. I want my mother to be taken care of properly and I want proper security for her and not having to fill out forms and reliving it every time the annual payments need reviewing. I do not want her to feel like she is begging or thinking about whether she will be eligible and worrying whether she will be able to pay rent the following month. She needs closure. It has been a horrific journey therefore not to have to worry about finances is the least support the Government can provide.

68. I would have my dad back any day of the week but this is not possible. People have suffered emotionally, physically and financially. They never asked to have these viruses. They were forced to live in secret because viruses were given to them by the very people they trusted to help them, who in turn, turned their backs on them.

Anonymity, disclosure and redaction

69. I would like to give oral evidence to the Inquiry.

70. I do not wish to apply to retain my anonymity. I understand this statement will be disclosed and published as part of the Inquiry.

Statement of Truth

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

Signed GRO-C

Dated 6/1/20