IRO

Witness Name: Yvonne Pugh
Statement No: WITN4174001
Exhibits: 0
Dated: 11 May 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF YVONNE PUGH

I, Yvonne Pugh, will say as follows:-

Section 1. Introduction

1. My name is Yvonne Pugh and I was born on GRO-C 1960. I live at GRO-C GRO-C GRO-C. I have been married to my second husband for two years. I retired from my role as Manager in the Department of Social Care and Health about three years ago.

2. I make this statement as the affected mother of Wayne Gathercole, who was born on GRO-C 1981 and was infected with Hepatitis C via contaminated Factor VIII concentrates. He has provided a witness statement to the Inquiry under Witness Number **WITN4003001.**

3. **This witness statement has been prepared without the benefit of access to Wayne's full medical records.**

Section 2. How Affected

4. Wayne has severe Haemophilia A which was diagnosed two days before his first birthday.

5. He was treated at the Haemophilia Centre at the Queens Medical Centre (QMC), Nottingham under the care of Dr Dolan. Around the time he started University his care was transferred to the Haemophilia Centre at the Royal Hallamshire Hospital, Sheffield.

6. He received Cryoprecipitate and a variety of Factor VIII concentrates. I refer to Wayne's statement for further information in relation to the Factor VIII concentrates he was given throughout the 1980s and the early 1990s.

7. I was given absolutely no warning whatsoever regarding the possible risk of infection from Factor VIII concentrates. I was told that Wayne needed these products to keep him alive.

8. I remember attending a routine appointment at the QMC during the 1980s and being told that Wayne "*could be infected with a new virus going around called AIDS*". Wayne's father, my first husband, was also (unusually) present at this appointment. It is difficult to pinpoint exact dates because Wayne and I used to attend the QMC at least three times per week; we practically lived there. I remember asking how Wayne had been exposed to this new virus? I was told by either Dr Dolan, or by one of his team, that "*some blood products purchased from the US may have been contaminated with this new virus and that Wayne had been treated with these imported blood products*". However, it transpired that Wayne had dodged the HIV diagnosis. This should have been good news but the reality was that Wayne was unable to escape the stigma attached to HIV due to the incorrect assumptions that were made by people that "*all Haemophiliacs have AIDS*". I refer to this in the Impact Section of my witness statement.

9. I can't remember exactly when, but I recall questioning Dr Dolan about recombinant Factor VIII as I had heard about this in the news. I wanted to know as much as I could about the recombinant Factor VIII and whether it could be used to treat Wayne. I was told that it was not available due to where I lived. It felt that important decisions regarding Wayne's treatment were being decided upon by the use of a *"postcode"* lottery.

10. I have a clear recollection of being told that Wayne had been infected with Hepatitis C. I attended a routine appointment at the QMC in or around 1992/1993 when Wayne was aged 11 or 12. I was there with Wayne and my other son, Clinton, who is sixteen months older than Wayne. We were sat in the corridor, outside the consulting room, adjacent to an area which had been designated for children to play in. There were lots of parents and children in this area at the time. GRO-D, who was Wayne's current Haemophilia Nurse, sat down next to me and said in the most matter of fact way that you could imagine "*oh, by the way, I need to let you know before you go in and see Dr Dolan that Wayne has Hepatitis C*". I was emotionally distraught on hearing this. This was said in full earshot and sight of all the other parents and children who were waiting in the corridor and of course, in front of both of my children. I tried to hold it together and remain strong but I found myself starting to cry. In desperation, I said to GRO-D "*please don't say anymore until we go into the consulting room".* Despite the fact that I was a young mum, I immediately fully appreciated the seriousness of what I had been told and I was also acutely aware that the manner in which the news had been imparted to me was very wrong.

11. Shortly afterwards, I was called into the consulting room; I went in with Wayne and Clinton remained in the corridor outside. Understandably, due to the shock I was in, I initially struggled to take everything in that Dr Dolan told me. I specifically recall mentioning to Dr Dolan that it was entirely inappropriate to have been told about Wayne's diagnosis in the way in which I had been. To this day, I still don't know why GRO-D chose to tell me in the manner in which

she did; I cannot fathom why she did not wait another ten or fifteen minutes to tell me when I was in the consulting room.

12. I remember questioning Dr Dolan about Wayne's diagnosis and I recall that his response was a dismissive one; it was as if he expected me to already be equipped with a full working knowledge of the impact which Hepatitis C was going to have upon my son. He mentioned that it was contagious and asked me if I had a separate bathroom that Wayne could use. We had two bathrooms at home but I did not want to make Wayne use a separate bathroom in case it made him feel inferior.

13. Dr Dolan also told me that I must now wear gloves when administering Factor VIII concentrates to Wayne. I had been treating Wayne since he was aged 2 or 3 and I could not suddenly start wearing gloves as I did not want Wayne to feel that he was suddenly being treated differently. Dr Dolan also told me that I must store Wayne's toothbrushes separately to the rest of the family's toothbrushes.

14. Dr Dolan practically forbade me from telling anyone from outside of the family about Wayne's diagnosis. I was already mindful of the forced secrecy surrounding such viruses, having already lived through the difficult time when all Haemophiliacs were wrongly thought to be HIV positive. Apart from me, the only people who knew about Wayne's Hepatitis C diagnosis were his father and Clinton.

15. I drove home from the appointment with my sons, trying desperately to hold back the tears. I felt that Wayne had been given a death sentence and I did not really know what to do, or where, or to whom I could turn for support.

16. Wayne self cleared the virus in his late teens.

Section 3. Other Infections

17. Dr Dolan told me that Wayne could have been exposed to vCJD. I questioned him about this, and in particular with regard to how he could test

for this, as I had seen something about vCJD on the news. I was told that "*there was no test and that the only way to find out if someone has vCJD is to conduct a biopsy of the brain once they have died*". This information was imparted to me in such a matter of fact manner; which brought back memories of how news of the Hepatitis C diagnosis was conveyed to me. I can't remember the date on which I had the conversation regarding vCJD.

Section 4. Consent

18. Wayne was tested for Hepatitis C without our knowledge and therefore without consent.

19. Wayne was also tested for HIV in 1985 without our knowledge and therefore without consent. I refer to Wayne's witness statement in this regard.

Section 5. Impact of the Infection

20. I have shed buckets of tears over what happened to Wayne. Despite the very real difficulties he has had to endure, he has somehow managed to remain the most lovely and kind boy; you would be hard pushed to find someone nicer. Wayne is my special boy and he means the world to me.

21. Despite the passage of time, I still feel very raw today and preparing this statement has been difficult as it raked up distressing memories that I have long tried to bury.

22. When I found out that Wayne had Hepatitis C my whole world literally crumbled around me. Dr Dolan practically told me that I must not disclose the "*bombshell*" news to anyone. We did not even tell our extended family so the only people who knew were Wayne's father, Clinton, Wayne and me. In reality, I have had to manage the roller coaster of emotions alone. I never received any emotional support from my mother so it was not a case that I felt that I needed to disclose the news to her. As far as my father was concerned, I had had my children at an age when I was far too young; I had

had two children by the time that I was aged 20. He had never been sympathetic or supportive and I knew that I could not count on his support.

23. When Wayne was diagnosed with Hepatitis C he was aged 11 or 12 and I remember clinicians at the QMC strongly advising that I send him to a specialist Haemophilia school which was located on the Isle of Wight. Their reasoning was that this specialist school could provide him with the level of care that he required. I flatly refused; no child of mine was going to be sent away. It also felt like they thought that I was not capable of looking after Wayne which was upsetting.

24. In terms of stigma, our family did not suffer greatly in this regard in relation to Wayne's Hepatitis C because we did not tell a soul outside of our immediate family; having already been subjected to stigma in relation to HIV, despite the fact that Wayne had not been infected with this virus. As a result of the incorrect inferences made about Haemophilacs and HIV, Wayne used to be treated cruelly at school. He was publicly excluded from the birthday parties of his peers and was often without a playmate at schools during the 1980s. He used to come home from school terribly upset which was heart breaking for him and, in turn, so very difficult for me to witness.

25. I also remember being constantly questioned in the playground by other parents during school drop off and collection times, in relation to whether Wayne had been infected with HIV. They used to say *"Has he got that thing?"* It got to the point where I was also questioned when I was doing the shopping or when I was out and about. It was really tough as I had to constantly fend off these probing questions despite the fact that Wayne did not even have HIV. Looking back, I would say that this was one of the most difficult aspects of the scandal.

26. It may not have been so bad had there been ten or twenty Haemophiliacs where we lived but Wayne was literally one of a few. News channels were reporting that HIV afflicted those who were either gay or had Haemophilia so of course everyone, wrongly, assumed that Wayne had HIV.

27. Growing up, it was abundantly clear that Wayne was not in a particularly good shape in terms of his physical health. As already stated, Clinton was only 16 months older than Wayne but their physiques were strikingly different, with Clinton being much more developed, stronger and less likely to be struck down by ailments. This large disparity in my boys led me to further question the clinicians at the QMC; a resounding theme of my story was that I felt I was constantly questioning clinicians in order to find out as much as possible about Wayne's condition. I was often ridiculed, ignored or passed off as "*an overprotective mother*". I felt that I was treated very badly when all I wanted to do was to place myself in the best possible position to ensure that Wayne's complex health needs were dealt with correctly.

28. I recall one incident when Wayne had a massive haematoma on his eye as a result of hitting his head on a cupboard. Wayne and I joked that he looked like a "*massive bull frog*". We often used humour to get through difficult situations. I remember attending the QMC following this incident and witnessing two consultants arguing between themselves, in front of Wayne and me, about the right treatment for the haematoma. One consultant was saying that he needed to make an incision into the eye to release the build up of blood whereas the other consultant was saying that this procedure was too dangerous. Both consultants then turned to me and said "*well what do you want to do*"*?* I remember challenging them about how inappropriate it was for them to ask me and telling them in no uncertain terms that they were the consultants and were meant to be advising me but instead had argued about it in front of me and my young son. I came across many examples of similar treatment by clinicians throughout our regular attendances at the QMC. Most, if not all, consultations bore the resounding resemblance of me questioning or challenging things and then being rudely dismissed.

29. Growing up, Wayne was often poorly, extremely lethargic and spent a lot of time in bed. His skin and the whites of his eyes were often yellow and his skin appeared both pale and sallow. The lethargy seemed to increase during Wayne's teenage years and I therefore again questioned the clinicians at the

QMC only to be promptly dismissed because his behavior was "*entirely normal for a teenager*". They could not have been more wrong; the Hepatitis C was really taking hold.

30. It is difficult to accurately describe the mental effects of Hepatitis C on Wayne because when he found out he was only aged 11 or 12 and, on the surface, he appeared to have taken the diagnosis fairly well. However, he was acutely aware of the turmoil and sadness which I felt, despite the fact that I desperately tried to hide these feelings from him, which I believe led him to protect me by ensuring that I was not fully aware of the distress that the diagnosis had actually caused him.

31. Wayne went to a private secondary school because we wanted to take advantage of the smaller class sizes afforded by this option. When he left the local comprehensive (junior) school he had been in a class of up to thirty children, whereas at the private secondary school there were never more than nine children in a class. This was extremely beneficial for Wayne as he was already dealing with the stigma of HIV, despite the fact that he had not been infected with this virus. This was on top of attempting to manage his Hepatitis C infection and his Haemophilia. Ordinarily, I would not have preferred a private education over a state one, although I can of course see the benefits of the same. It was a financial struggle to fund Wayne through private education; Wayne's father was self employed and worked long hours in order to meet the tuition fees. I only received a carer's allowance as I was unable to work due to the amount of care Wayne required.

32. When Wayne was aged around 13 or 14 we moved to another village and our new house happened to be right next to a comprehensive school which, remarkably, offered small class sizes. I was also keen for Wayne to make friends locally as the private school had had been attending had been quite far away from our previous house which meant that it was much harder for him to build and maintain lasting friendships with his peers. We therefore placed Wayne in the local comprehensive where his needs were managed well and we also employed the use of a tutor to reinforce and build upon what he had been taught during the school day.

33. Wayne's Haemophilia and Hepatitis C naturally had a knock on effect for Clinton. Clinton used to say to me "*Wayne is always poorly mummy*". He also had to accompany Wayne and me to numerous hospital appointments which then became the norm for him when he was growing up. If the boys were playing and something happened or I heard a shout, I would always have to rush to Wayne first due to his health needs. This was, of course, necessary but it made me feel guilty. We also never discussed Wayne's infection with Hepatitis C with Clinton; he was there (in the corridor) when we found out about the diagnosis but it was never mentioned again due to the very real fear of stigma and the fact that it was more likely that Clinton would inadvertently disclose the infection to someone if we had frequently been discussing the same with him.

34. **GRO-B**

35. I attended the majority of hospital visits without Wayne's father (which in the main was due to the fact he worked long hours) and I felt like I was managing everything to deal with Wayne, both mentally and physically, alone. I was the one how had to learn how to inject Wayne for the home treatment programme. We had initially decided that Wayne's father would take on this role but in the end, it was me. As previously stated, I did not feel that I would have obtained any emotional support from my parents so I did not disclose the infection to them and Wayne's father never provided me with any emotional support so I felt very much alone.

IRO

36. Wayne's father used to say that Wayne always came first; this was correct but it was also the only way things could have been in order to ensure that Wayne's needs were adequately provided for. I am his mother; he is my life and always has been.

37. **GRO-B**

38. **GRO-B**

39. **GRO-B**

GRO-B

40. When I was looking after Wayne it would have been impossible to have a job and even harder to have a career. However, once Wayne had reached the age of 17 or 18, things changed for me and this was brought about in both a memorable and fitting way. During our many visits to the QMC, I had got to know a lot of people at the hospital and had fallen into an informal role of supporting parents of newly diagnosed Haemophiliacs. I provided them with the much needed emotional support because I knew what it was like to be alone; having received no such support myself and additionally no support in relation to the (HIV) or the Hepatitis C matters.

41. Wayne had a lovely social worker at the QMC with whom I had a very good relationship. One day, she commented to me that I should go into this field and that I would make a really good social worker. This was, of course, impossible at the time because Wayne was young and required so much of my time but the seed had been firmly planted.

42. Therefore when Wayne reached the age of 17 or 18, I re-educated myself and obtained two degrees and worked my way up to becoming a Manager in the Local Authority Children's Department which was subsequently renamed the Department of Social Care and Health. I used to deliver training on various issues to include disability awareness. I was equipped with so much prior knowledge as a result of my many negative interactions with the clinicians at the QMC that I felt I knew exactly how to educate other managers and health professionals in relation to how not to treat their patients and their families. I turned the negativity into so much positivity and thrived on sharing my knowledge.

Section 6. Treatment/care/support

43. Clinicians would always gown up and wear gloves when treating Wayne. He was also always last on the list for any dental appointments or procedures.

44. I was never offered any counselling or psychological support in consequence of what happened to Wayne.

Section 7. Financial Assistance

45. We did not receive any financial assistance from any of the Trusts due to the fact that Wayne self cleared the virus.

Section 8. Other Issues

46. I want people to learn from this Inquiry and I want wrongdoers brought to account. I also want to ensure that, so far as is possible, something of such magnitude never happens again and going forward that people are always given the knowledge they need to deal with whatever situation has befallen them.

47. I would have really benefited from someone coming to see me and supporting me when I was dealing with the many and intricate issues thrown up by Hepatitis C. It would have been invaluable to me if someone had sat me down and told me that there was plan and that they were going to try "*a and b*". However, the reality was that I had to ask question after question in an attempt to furnish myself with the knowledge which would enable me to properly look after my son. Every time I asked a question, the clinicians made me feel inferior and often totally dismissed me.

Anonymity

48. I do not wish to be anonymous and. I have, however, redacted a portion of this witness statement from the Impact Section for the reasons explained

therein. I am prevented from giving oral evidence to the Inquiry due to the fact that I now suffer from Chronic Fatigue Syndrome and I also struggle in emotional and stressful situations.

Statement of Truth

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

Signed...

Dated..

Statement of Truth

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

Signed GRO-C

Dated 11-05-20

IRO