Witness Name: Jonathan Charles Buggins
Statement No.:WITN1045001
Exhibits: WITN1045002 - WITN1045007
Dated: 8 November 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JONATHAN CHARLES BUGGINS

I, Jonathan Charles Buggins, will say as follows:-

Section 1: Introduction

1. My name is Jonathan Charles Buggins (Jon). My date of birth is GRO-C 1980. My address is GRO-C. My mother Elisabeth Buggins [WITN1021001], brother Edward Buggins (Edd) [WITN1040001] and my sister, Dr Rosemary Buggins-Allsop [WITN5512001] have also provided evidence to this Inquiry. My elder brother was Richard Buggins, who died in May 1986 as a result of haemophiliac complications of brain bleeding. I am making this statement to talk about the impact on me of treatment at Birmingham Children's Hospital (BCH), under Professor (then Dr) Frank Hill, with contaminated blood products and the consequences and stigma of infection.

2. I intend to make a second statement about the consequences of infection if there is time. I am splitting it into two partly for expediency because I am submitting this so late on to the Inquiry.

Who I am

3. I am an Engineer, trained in manufacturing systems and general engineering at Cardiff University (Integrated Engineering, B.Eng, failing to complete the M.Eng course I was enrolled on in 1999), and then in 2008 a master's course described by university staff as "like an MBA without the finance" for manufacturing industry/operations at Cambridge University (Industrial Systems, Manufacture and Management, MPhil), emboldening my passion for Lean Manufacturing.

4. Unfortunately, I have limited work experience (for reasons I have realised since hearing other witnesses at the Inquiry that I probably do not need to explain - similarly perhaps of my divorce), but my enthusiasm has always been for innovation, efficiency, and improved satisfaction and empowerment of others through good analysis, problem solving, and change management. I try to be a good listener too.

5. I think the rigorous logical problem solving improvement approach that resulted in Lean Manufacturing/TPS changing the way cars are made would be recognisable to this Inquiry, and it fascinates me that one of the well supported recommendations this Inquiry could make – regarding an enforced duty of candour (in government as well as health services) – was also a pivotal approach that separated Toyota (with their Andon cords: see WITN1045002[1]) from western car makers, who would soon seek to emulate them because of the vast improvement in quality and reduction in cost that resulted.

Writing this Statement

6. I have written this statement with access to most of my medical records, though reading and understanding the thousands of pages is a challenge beyond my skill. I have tried to fit my more errant memories to dates from my notes where

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[1] See WITN1045002 – Andon cords, employee empowerment, and the duty to report problems quickly to limit their impact, even at the cost of stopping a whole factory, in the name of minimising the impact of problems found.

possible. I am happy to share more and to clarify anything if needed – I want to support transparency.

7. For much of my life, I have avoided thinking about what happened to me, denial I suppose. Not talking got me so far, but caused me harm too, and harm to my relationships. Denial and fear made it hard for me to seek the support I needed, which compounded the problem. Stigma lead to fear which lead to me isolating myself further, and not receiving the support I increasingly needed as my life progressed. I suspect the same goes for some of those I felt the need to swear to secrecy.

8. The Inquiry has been compulsive watching, and at the same time felt like forced therapy - I have managed to re-integrate aspects of myself that I have avoided for a long time as a result of things I have learned but, and this is not a complaint, it has really put me through the grinder. I think the version of me that what has come out the other side is better able to deal with the future, I hope. I feel more open to it now than I had before, anyway.

9. When asked my story, I have said in the past that I was one of the lucky ones. My rationale was that I survived mostly intact (my issues now are largely fatigue and brain fog, but I only understood in recent years that could be connected to infection – as a result I have half of the qualifying pension contributions I should have by now). When I look at it all, and when I tell people now that I feel more able to express it publicly as a result of the Inquiry's publicity and the supporting witness narratives, the response is usually one of quiet shock. It makes me conscious of how much I have got used to, or chose to ignore out of an instinct of self-preservation. I have seen a lot of survivor s these last few years who have made their pain public, and I am in awe of them. However, I think 'lucky' might say denial on my part.

10. I have found writing this statement cathartic in some ways but mostly exhausting, which is partly why my submission is so delayed - I would like to apologise for this. It has taken me years.

System thinking and responsibility VS blame and guilt

11. I am angry about what has happened, and increasingly so. As a result of what I have learned since the Inquiry opened, it sounds at the very least like an awful catalogue of errors, and probably some reckless and wilful endangerment. That anger has partly been what has made it exhausting to write about here, especially with chronic fatigue and brain fog. Anger is exhausting and harmful. Blaming someone can be an easy relief.

12. Equally though, my systems training tells me complex problems always have complex causes, and blaming one or two people without first considering that is reactionary and usually misleading - I value the Inquiry's thoroughness, and I would love to see/do the "5Y" analysis. As Edwards Deeming, a significant influence on the Toyota Production System and known as the Father of Quality Control, said "*put a good person in a bad system, and the system will win every time*".

13. I was glad to hear the Panel of Experts from the public health and administration group member offer a similar sentiment regarding in dividual blame vs the role of the system on Wednesday 4 October.

14. I think it is vital to separate blame and guilt from responsibility. Part of the problem has been that the government has avoided taking full responsibility for what happened, which was very clearly theirs, in order to avoid the accepting liability (or blame). It is like they are conflated. A duty of candour would have to allow people to take responsibility for things they have done without assigning them blame as a result (unless they have been negligent, and then I think that ought to

be a separate process), because it creates the possibility for analysis of the problem, for truth to be found, and for measures to be quickly put in place as a result of what is learned, which can prevent aspects of the problem causing more problems. In manufacturing I have found that the useful lessons are often unexpected. I would hope that any inquiry as a result of the duty of candour into errors made in treatment, or in systems that underpin it, would be able to focus on improvement, like with Andon[1], rather than focus on the avoidance of blame, which appeared to me evident even in the discussion of the panel in October 2022. Developing an understanding of what happened is unlikely if those involved are busy dancing around blame, rather than addressing the complex mechanics of how to affect the people working in the system to ensure improvement of outcomes and care quality – it is already a difficult enough thing to achieve! It is better to identify problems early and fix them before they do further harm.

Some benefit I have experienced as a result of the Inquiry

15. Having avoided thinking about much of my history, hearing evidence now and reviewing my past made me realise how often I was just ahead of the wave of medical development. Just enough to survive. I feel equally awful that others have suffered so much more and guiltily fortunate that there was effective medication just about ready when I needed it. Conveniently ignoring what has happened to me helped me get through bad times, but it also bottled everything up. Engaging with the Inquiry has done a lot of unbottling. It is clear to me that this Inquiry has added to my knowledge and understanding, set against a past Governments' line that "…we do not consider that a public inquiry would provide any real benefit to those affected." The Inquiry has fundamentally changed my relationship with what happened, which I think is a deep and important part of healing, beyond just knowledge.

16. I feel personally as though the Inquiry's process has lifted some of the weight off my shoulders. I have puzzled for years why I have felt so tired, dropped out of university, why my business and marriage failed, being told several times in 2017 my fatigue was not resulting from HCV by consultants. It was easy to blame myself. I think living with HCV and its consequences look different from the inside than the external medically accepted perspective, perhaps partly due to the way research is carried out. The internal perspective is important for anyone affected, and in the context of ongoing harm resulting from medical treatment, that is important too. It was not just that I had chosen at times to put a lot of mental effort into figuring it all out, it was that I could not stop puzzling over the inconsistency of what I was told vs my experience, it was like a percentage of my bandwidth was routinely taken up with it. That constant puzzling is exhausting. I do not do that so much anymore because I feel like I understand much of what happened (much more than being told "that's probably HIV" – I've since learned that often it was, but communication of developing understanding in chronic condition care often gets left out, because there's almost an assumption that common knowledge among professionals is common among engaged patients too, when there are actually gaps – for instance, I didn't realise I had seborrheic dermatitis resulting from advancing HIV infection in my teens. I thought it was bad teenage skin, and the dermatologist thought I was picking my nose and then my acne. Research presumably demonstrated that, but I was never caught up).

17. My experience of fatigue chimes with the common reports by witnesses. Back when I arrived at the Inquiry's opening hearings in 2018, I was hoping to persuade someone to look at witnesses' experience of fatigue to see if there was in fact a connection to HCV, and now writing that, having seen parades of witnesses describing the same problems I feel rather silly because it seems patently obvious that there is, and yet I still think some medics would resist the idea. Being unable to let that puzzle go was exhausting. I still suffer fatigue, but at least I am not exhausted by that in particular, and I can accept my poor choices in those past failures because I know they probably were not entirely my own fault (blame vs

responsibility again). I think freeing up even a small amount of capacity increases the potential of life, so as a result of the Inquiry and the way it has conducted itself, I feel like I have more life potential. I would say that demonstrates one significant part of the Inquiry's value, beyond lessons learned. I only wish I could have experienced that a decade ago.

18. I think being denied justice and opportunity tohave evidence heard creates a climate of disbelief and infighting, and I have done my share of that. An earlier Inquiry could have avoided people spending part of the time they had left in conflict with some of the few people who were still motivated to listen. In my view, financial support without an effort to seek the truth of what happened did not satisfy anyone, I think that is why the sick and dying did not rest, and why they, we, still agitate. I am grateful to the Inquiry for doing so much to set this straight, but particularly grateful to the campaigners who carried on fighting regardless, which benefited me as a result, even though I was hiding.

1992 High Court Case

19. In 1992 (when I was 12 years old) I was involved as a minor (with parents as 'next friend' – I had no personal involvement) in a medical negligence action in the High Court. A settlement of £75,000 had been agreed on the second or third day before my doctor was asked to take the stand and give evidence. As a result, I was given a measure of dignity in being able to afford a house as soon as I was old enough to need one, but the capital denied me most benefits (as I understood it, maybe incorrectly). I have never worried about having a roof even if I don't have a meaningful pension. My medical circumstances were not particularly different to others at BCH, and I do not think the difference in our financial circumstances was fair. I wish that they had been treated similarly. With the information I have, I do not understand how my case warranted different treatment.

Section 2: How Infected

HIV

20. I was infected with HIV between 1981 - 1983. My UKHCDO record has my last HIV negative stored sample on 5 February 1981, a sample I expect was taken for my diagnosis with severe haemophilia A, but before I received any treatment.

21. I had my first birthday on GRO-C 1981, then BCH records show my first treatment with Factorate (after one a month earlier with cryoprecipitate) on 27 March that year. I was treated with cryoprecipitate and Factorate until my first HIV+ sample was taken on 13 May 1983.

22. I think I was probably infected by Factorate.

23. In 1992 when I was 12 years old, a medical negligence case was brought with the support of Dennis Collins, of Keith Park & Co, St Helens, as permitted in an exemption in the group action waiver (I assume). I might have more information and contemporaneous medical opinion than many about my infection with HIV because of the case.

24. I have seen solicitors' letters, statements from Professor Frank Hill [WITN1021024], my mother, and Professor Geoff Savidge [WITN1021004]. I do not have the court records, which I think were also sealed, so my understanding of what happened is incomplete and based on things I have heard.

25. As part of that case, Professor Hill gave a statement containing all the things that would be expected - regarding his history at BCH; how care was provided there; treatment policy (along with a contemporaneous example); the availability of different types of treatment at the time; training of new doctors; introduction of home therapy in 1976 which necessitated increased FVIII supplies with commercial ones being more available than NHS; his level of awareness of serum

hepatitis and AIDS; risks from pooled products; the BCH TB outbreak in November 1981 in immunosuppressed cancer patients; and also in haemophiliacs that raised concerns about immune function, plus rationales for my individual treatment, availability of treatmentat BCH, etc.

26. He also comments on the specifics of my treatment and the criticisms of it alleged in the case.

27. The allegations made were:

    a. of the failure to treat me exclusively with cryoprecipitate;
    b. if the use of concentrate was unavoidable, using commercial concentrate rather than NHS concentrate; and
    c. failing to properly inform my parents of the risks attached to the treatment adopted.

28. Professor Hill's statement consists of arguments that most campaigners and watchers of the Inquiry would be very familiar with, and it is sensibly defensive, given its purpose.

29. I understand that the Inquiry has a copy of DrFrank Hill's statement dated 11 April 1992 [WITN1021024]. The statement was referenced during the evidence before the Inquiry on 6 October 2022 when my mother, Elisabeth Buggins gave evidence as part of a Panel about the experiences of parents whose children were infected at children's hospitals. I was present at the hearing when my mother gave evidence to this Inquiry.

30. In his statement, Professor Hill draws attention to a note in my records on 29 October 1982 suggesting my mother told a doctor I had had an allergic reaction to cryoprecipitate previously, and vomited – he says this explains why I was not treated with cryoprecipitate after this date. My mother's assertion to me has always been that that had not happened to me, but it <u>had</u> happened to my brother,

specifically into a drain grate outside Winson Green Prison which we passed on our way home from BCH. Her recollection has always been clear on this.

31. Because I have not had access to the court records, or had the arguments explained to me by those who made them, I have limited understanding of the reason my case was thought to merit being described as medical negligence under the waiver when presumably others with almost identical circumstances were not. I was told as a child that the argument seemed to hinge on an allegation that my notes could have been altered after the fact by BCH staff, e.g. to indicate an allergic reaction which would make my treatment with commercial concentrates rather than cryoprecipitate seem a more reasonable choice. This argument does not make sense to me because the alleged allergic reaction happened after I believe I was likely to have been infected with HIV – there may be something I've missed given I don't have the court papers. The staff at the hospital were understandably offended by the allegation, and in fact my mother wrote to them to apologise that that argument was made, I do not think my parents had been aware before hand – my parents' issue was that I had been infected at all, they did not suspect some fraud in my notes. We still felt dependent on BCH for the regular medical attention we seemed to need.

32. I can understand how having a member of staff (not necessarily connected to medical treatment) with access to medical records, who was minded to change them in order to limit the liability of the hospital would be a problem that would need challenging – I understand there have been other cases like that outside of Infected Blood. If that was done in my case (I am not aware of evidence that it was), I do not think it would have prevented my infection.

33. I do think it is interesting though how my early treatment records [WITN1045003] appear to be written in one hand and perhaps in one sitting, with little apparent changes of writing style and position. I can understand why a treatment record might be set out after the fact, perhaps from a messier outpatient record, before

an audit (my speculation, with no evidence), I have done that myself in adult life. It is not *necessarily* suspicious, but I can understand how in an adversarial situation small clues could be deemed important in the absence of the broad evidence that an exercise like the Inquiry can obtain and analyse.

34. As others said when my mother gave oral evidence[2], we seemed to be treated with whatever came to hand in the treatment fridge, and I had already been treated with a variety of batches of Factorate. I think this all supports Professor Savidge's allegation that control of treatment practices at BCH were negligent, which is more the issue, and if that was the case it was probably one common to all of us at that time.

35. Regarding whether it was me or Edd vomiting, I understand that it is easy to mix up brothers in a high paced hospital environment - when we were treated at St Thomas', a doctor inadvertently disclosed my HIV status to Edd in my absence trying to work out who was who – I can imagine doctors getting mixed up between haemophiliac brothers is familiar to some families, and some treating doctors. It would not alarm me if errors of identity were made between me and Edd at BCH, it would alarm me if a note about one of us three resulted in treatment decisions being made that put another in harm's way.

36. I think Edd also had some other allergic reactions to cryoprecipitate, but continued to be given cryoprecipitate afterward (with Piriton perhaps) until 8Y became available and most importantly, as Professor Hill wrote, he avoided HIV infection. If my mother's memory of Edd's vomiting after cryoprecipitate is correct (and she has always been exceptionally clear about it), and Professor Hill's assertion in his statement that in that case, cryoprecipitate would be contraindicated was followed in Edd's case, and he had been put on Factorate (which he had been treated with three times before, contrary to that 1992 statement) for all his remaining treatment until 8Y was available, then following

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[2] https://www.infectedbloodinquiry.org.uk/evidence/transcript-london-thursday-06-october-2022-panel-about-experiences-parents-whose-children, p57 line 14.

that treatment policy I would not be surprised if both me and Edd had contracted HIV, not just me. Maybe that was lucky. It might be immaterial to my infection, but I find it disturbing to think about.

37. I find the contrast between the defensive confidence in Professor Hill's 1992 statement in the approach of the centre, and the seeming randomness in the decisions made in treating me, and the fact that inspite of his allergic responses to cryoprecipitate Edd managed to avoid HIV as a result of the way he was treated, being born 15 months after me and starting treatment around the time when AIDS was becoming common in the press, it all seems to beg the question. If there was no "conclusive proof" that HIV was a risk to haemophiliacs, it seems peculiar that Edd was being successfully protected from such a risk, just as it was being questioned by patients and journalists, and being denied by senior haemophiliac doctors (of whom Professor Hill was not one at the time) and politicians. I wonder if Professor Hill may have been taking steps in 1982 to limit possible fallout at that time. Maybe that wasn't luck.

38. Incidentally, my HIV is now well controlled, but I developed Pneumocystis pneumonia (PCP), and consequently AIDS, in 1997, and I believe it caused HCV to worsen at a more rapid rate than it might, resulting in the debilitating fatigue I have experienced since my early 20s (but those conclusions are all my own from evidence I have heard at the Inquiry, and have not been supported by medics I have discussed it with – I hope that knowledge might develop through study of 'Long Covid').

My early treatment for Haemophilia A

39. With this statement, I have exhibited a copy of my early treatment record from the short period when I was known to have contracted HIV [WITN1045003], and the related Outpatient notes [WITN1045004] which contains a record of the contaminated treatment(s) that infected me. I have shared them so that anyone

who reads either Professor Hill's or Professor Savidge's statements can look at the medical records they are referring to in parallel.

40. I do not think I would have avoided HIV at that point whether I had an allergic reaction or not. The choice to treat with Factorate at all was the issue, I think, as the original allegations said.

41. I was given almost as many units of Factorate (3416iu from five batches) before the alleged allergic reaction (which seemed to become so pivotal in the court case) apparently prevented me from receiving cryoprecipitate as I did afterward (4070iu from seven batches). I would think it as likely I was infected before as afterward, and perhaps just as likely, both.

42. I do not see that decision to stop treating me with cryoprecipitate as materially affecting whether or not I was infected, though I might have had a better outcome knowing what we know now about superinfection, and what Professor Savidge wrote about the impact of virus loading on infection. I think I would only have avoided HIV if I had been treated only with cryoprecipitate or maybe NHS FVIII.

43. If that is the case, I do not see any difference between my case and any other patients at BCH purely in terms of infection with HIV.

44. Given the volumes of Factorate Professor Hill bought and used, the same allegations made in paragraph 27 could probably be made of any of my fellow patients who were similarly infected, and that payment I received could equally have been made to them in similar circumstances. I find it deeply inequitable.

45. I have heard, and I do not know if it is true, that there were other cases of alleged medical negligence which were brought in the UK, but that all were settled before reaching court, and that my case was the only one that went to hearings, perhaps

because my doctor or the Health Authority were more determined not to back down.

46. I understand that my mother gave evidence in court, and the Health Authority settled the case before Professor Hill had to give evidence.

47. I think it is interesting that the Central Birmingham Health Authority (as they had been at the time) made settlement to end the case at that point. I expect I was already infected by the time of the alleged incident of mistaken identity around an allergic reaction, and Professor Hill's rationale for my treatment at that time chimes with what many doctors giving evidence to the Inquiry have said, and generally the Government repeatedly defended the pattern of treatment. It is not that I think that treatment rationale is right – I think my infection could have been avoided given better strategic choices in government and at the hospital – but the rationale of Professor Hill would have been roundly defended at the time by other doctors and still would today judging by the evidence the Inquiry has heard. Other than the allergic reaction that received focus, I doubt my treatment was substantially different to my contemporaries at the hospital.

48. The settlement was for £75,000, and it was reported in the papers, but I think the actual court records were sealed, perhaps with something like a Tomlin Order (I have never seen the court records).

49. On 24 October 1992, the Birmingham Post reported "HIV boy wins £75,000 in Children's Hospital fight" [WITN1045005] (which noted it was also the day when three former French health officials were jailed for treating Haemophiliacs with blood products known to be contaminated). Aside from the fact that my case was brought and others were not, I do not see why my case in particular would merit that "win". Included in WITN1045005 are two further news articles published prior to the court case.

50. Was it was purely the timing of the case (more luck?), or that the Health Authority wanted to avoid scrutiny in open court in front of the press, perhaps it was just the cost of avoiding bad publicity. Is that justice though?

51. On a wider scale, I think this kind of adversarial court approach is not a good way to see justice done in cases like this where we were all affected in similar ways by similar means in the same place. Neither the settlement nor the case revealed the truth of what happened, which went much further than Professor Hill's involvement, or invited much understanding or reconciliation. The need to demonstrate blame or liability as a means of receiving justice results in a limited exposure of truth, and little examination of the root causes of what happened, just a local examination of aspects of Professor Hill's interaction with me. It does not create much opportunity for improvement or the prevention of harm, apart perhaps from the cost appearing on a balance sheet. Cash helps, but alone it is not justice, I think there has to be knowledge transfer and agreed recognition what happened too. I blame the system rather than Professor Hill specifically, only digging into that can reveal the problem, and start the process of preventing anything that shares root causes from happening to others. If he had not had to avoid liability, or accusations of personal fault hanging over him, Professor Hill could have said sorry and taken account of the scope of his responsibility, and there might have been some reconciliation, rather than what happened next, I would have liked him to have obtained some relief in his life as a result, as I think I might in mine. Arguments need resolution else they cause ongoing harm – the body keeps score. The centrally organised aim to avoid liability allows those who should carry blame (like some of the compelling stories I have heard about unethical trials) to be protected in a crowd of people who should hold responsibility <u>without</u> blame, some of whom will inevitably be the good people in a bad system that Deeming referred to. That serves to obstruct justice, in my view. It avoids the root cause and allows bad people to thrive without challenge.

52. I do not know if my court case sparked others, as the Birmingham post article suggested. I heard that there had been wider support for legal action among the parents of children infected at BCH – I have a report of a meeting along those lines.

53. What I heard though, well after the fact, was that Professor Hill had told parents that if he was defending legal actions in London he would not be available to treat their sick children. I suspect that had a cooling effect.

54. I am not aware that any other parents at BCH bought a case.

55. Professor Savidge was asked to give an opinion on my treatment, criticising the choice of treatment as negligent, possibly with sight of Professor Hill's statement. Professor Savidge's statement has been provided to the Inquiry as an exhibit to my mother's statement [WITN1021004], and was read out during my mother's oral evidence[3].

56. Professor Savidge would presumably have had access to my notes from BCH where I still received care, complete with my printed blood test results. Those results have since been destroyed. For some reason blood test results sheets are in Richard's and Edward's scanned notes, but removed from mine. I was told by Sue Hobday at Birmingham Women's and Children's Hospital (BWCH) that the old Lab computer (rather than the overlapping printed chits which would be unreadable in the most part when scanned) were relied upon for archiving blood test records, and that machine was destroyed in a flood. Apparently no backups were maintained, which I find surprising. I have attached an email from Sue Hobday at BWCH regarding loss of blood test results [WITN1045006]. It is curious that Edd and Richard have what blood test results that can be seen in

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[3] https://www.infectedbloodinquiry.org.uk/evidence/transcript-london-thursday-06-october-2022-panel-about-experiences-parents-whose-children; page 9 line 12.

their scanned notes from BCH, and I have none, given what I was told by the Archivists about them being removed to save space. It is curious too that the letters regarding the refusal of care by BCH in 1993 do not exist in my notes, but do in theirs. I think notes Professor Hill made in routine Outpatient clinics are also missing from the archive. I wonder if there was a separate set of my notes that were not archived which contained these. I would expect to see notes of my HCV testing, the disclosure of my HIV status, my HIV tests or any mention of discussions with my mother, and don't, just inpatient and outpatient treatment. As it is, there is a lot of useful evidence about the important aspects of my treatment relating to infection which are missing. For instance, Professor Hill and I discussed HIV soon after it was disclosed to me in August 1989 around the time we were forced to move schools as a result of Richard's HIV status being speculatively made public by an excited Birmingham Coroner. Professor Hill explained HIV to me, and I had the opportunity to ask him questions. I would expect to find that in my notes, it was a significant event. It isn't in there.

GRO-D

57. Though Professor Hill was responsible for our treatment, I do not mean to suggest that all of the factors that led to that lack of control was entirely under his control – he should have been able to rely on the medical regulators blocking access to unsafe medicine, and he should have been given access to more NHS concentrates through better government policy than there was, to give two obvious examples. I think both of those should have given him better options. There are many more system root causes. I shouldn't have been required to take him to court to get justice, the government should have taken Armour to court on mine and his behalf. The system pitted us against each other, and avoided its own responsibility.

58. As soon as 8Y became available, Professor Hill transferred both me (April 1985) and Edd (August 1984) on to it, and I do not think either of us were treated with anything less safe afterwards up until we left in 1993 – in that I think he demonstrated his preference for NHS material over Factorate later on, but the

sheer volume of Factorate he bought as evidenced by the BCH's returns exhibited at the Inquiry tell a story of their own.

59. I would be interested to see an inventory of the benefits (which I understand were legally permitted) in cash, goods, or trips, or other benefits that Armour gave to Professor Hill & BCH while he was such a good customer, given evidence other doctors have given of lavish conferences etc. I would be interested to know how they sold to him and understand what other motivations he had for running the centre in the way that he did. It would be understandable that his career prospects would be determined in part by his reputation with his superiors at the Health Authority, and their priorities would likely have been a significant influence. I would be curious to understand how they influenced his choices. I think however that they are secondary to government medicine regulation and policy on self-sufficiency.

60. I have heard widespread evidence that cryoprecipitate and NHS FVIII products were hard to come by (and Professor Hill says as much in his statement), and I could understand how treatment decisions were challenging in the treatment environment Professor Hill was working with, and I cannot imagine how soul destroying and traumatic it would be to realise that your treatment decisions led to suffering and death, and then being taken to court over it and having your career in the balance – I do not think any doctor goes into medicine to experience any of that. I really feel for him and everyone else who had to rapidly learn how to manage the fallout of what happened. We were all harmed.

61. I find it truly remarkable that the UK Government permitted the sale of dangerous products supported by false claims of safety measures, and then when they were shown to be dangerous and the claims evidently fraudulent, they didn't demand justice on our behalf. Rather than the NHS/DHSS taking those suppliers to task (as would likely happen with any ordinary business transaction), by making themselves an obstruction they defended US pharma against us, the people who

were harmed. Another case perhaps of those avoiding responsibility protecting those who should carry the blame. Why did the DHSS not sue Armour?

62. For us though, the facts are that after the court case, in 1993, Professor Hill refused to treat either me or Edd at BCH. I find it interesting given the story I related in paragraph 53, that Professor Hill was alleged to have said that fighting medical negligence cases would make him unavailable to treat his patients. In 1993 he made himself unavailable to us, refusing treatment, blood testing, anything but emergency care and home treatment supplies until we could find alternative care. I understand that the Hospital and Health Authority supported him too. There were several meetings between them and my mother to challenge the decision, and the option of being treated by Dr Williams (Professor Hill's independent peer at BCH by that point) was also denied. Having moved centre, and received prophylaxis, we were no longer dependent on being able to attend hospital unlike the situation I describe in paragraph 31.

63. It sounds like a climate of fear was fostered somehow within the haemophilia centre around interacting with our family and staff refused to talk with us, and we had to figure out an alternative patchwork of arrangements to fill the gap for 6-12 months, eventually moving to St Thomas' in London, which happily improved the quality of our care (we were given prophylaxis and had access to specialist joint clinics, so didn't bleed or need inpatient haemophilia care).

HCV

64. I am not aware of a positive HCV PCR test result until 1998, I did not know I had it until after I developed PCP/AIDS in 1997.

65. Professor Hill had tested both me and Edd when we were patients of his in the early 1990s, while Edd tested positive, I apparently tested negative, and I held fast to that understanding while I struggled with HIV and eventually AIDS. In

retrospect given the debates around the error rates of the tests, I am surprised I was not tested again until I was 18. I think my infection was assumed at St Thomas' though, looking at my notes, even though I was ignorant.

66. I was in fact HCV+, and given my only treatment with unheated products was at BCH, I assume I would have been infected in a similar timescale as HIV, or perhaps before I was switched to 8Y. It is not something I have had clarity on.

67. I was treated for HCV, unsuccessfully for 52 weeks with Peg-interferon and Ribavirin from November 2005, and successfully with Harvoni in 2016.

68. I almost missed that 2016 opportunity because I arrived in Australia on a three week trip the day I was phoned about it on the 11 March. I was asked to visit the hospital the next day, and when I said I could not, I was told that I would not be able to have the treatment if I did not attend because the funding would not be available again for several years. It was a fluke that my phone even worked (I had had to set up an app to receive calls) I think if my phone had not been able to receive calls I would have likely missed the opportunity. I thought I would have to buy a ticket at the airport to return to the UK, but eventually I was told that if I did not attend the hospital by the end of the month I would have to wait probably for a few years for funding to be available again. Fortunately, my return flight was booked to get to the UK on 29 March, and I was able to start treatment on the 31 March. I think being put in that position was immoral. It fits with my experience and what I have heard of hepatology at GRO-D though.

69. I think Fibroscan results give me the lowest liver stiffness score, though I have found ultrasound results indicating suspected portal vein hypertension and changes in the size of my spleen, but nothing else untoward otherwise. I would still prefer to be monitored for liver changes, since HCV is so new - I think we should have that option. My doctors at GRO-D are not concerned about my Liver health, and have once opted to give me an abdominal ultrasound as a

precaution when I had a blip in my ALT results. I am conscious that although we have effective treatments now, the wave of medical advancement that has kept me alive is a wave of new knowledge of new disease, and we do not have anyone yet who was born and infected in the 1980s who has lived into old age. I think there could still be things we do not know, and there could be dangers we still need to guard against to avoid adding insult to injury. I would support something like an annual ultrasound scan.

Section 8: Other Issues

70. When I was tested for immunity to HBV in Cardiff in around 2005, the test result showed a positive result for HBV core immunity.

71. In light of this, it is curious that Professor Hill makes an unnecessary diversion in his 1992 court statement in paragraph 10 to "*point out that the Patient [me] did not contract hepatitis B from his treatment with Factor VIII concentrate*." No one had made allegations about HBV To me it seems like he was trying to point out the positives of my treatment at BCH, contrasted against the allegations, and the nature of treatment decisions without clear rationale.

72. In Cardiff in 2005, the Nurse Specialist told me the result following that test with a little hesitance, like he was aware he might be about to give me objectionable information that I was not aware of (and he was right). I think he told me that it meant I had been exposed to HBV at some point other than the vaccine.

73. I asked my mother if she knew, and she said she would have remembered being told that, because it would have been alarming news, so she did not think so.

74. I was not aware prior to that test that I had been exposed to HBV.

75. Since I have received my BCH medical notes, even though I do not have access to any blood test results, I have found hand written sets of HBV testing results from 1987 onward for several years, all but one showing positive HBV core tests. An example from my 1987 records can be found at WITN1045007.

76. If I was exposed to an infectious agent, I assume it would have likely been prior to being treated with 8Y, when I was treated with cryoprecipitate, Factorate, and NHS FVIII.

77. I think others have mentioned an HBV outbreak at BCH in that time, so it could be related to that. I have been told by Professor Hay that 90% of exposures to HBV result in 'spontaneous' remission as I assume mine did.

78. I think the Inquiry heard from Professor Tedder that in some cases, HBV causes an immune overdrive, causing it to attack the Patient's liver, causing death, with no effective medical intervention. Presumably that would have been a risk in my case.

79. Professor Hill was right that I had not developed chronic Hepatitis B, but he would presumably have had access in 1992 to records of my HBV core tests from 1987 onward when he wrote his statement to that effect, and so I think it is a deeply misleading fact. I wonder how many other patients at BCH were exposed to HBV and not told by him. I would not have known I was tested unless I had received copies of my notes for this Inquiry.

80. I have almost finished a longer statement detailing the impact on my life of infection, interactions with support organisations, etc, which I hope to share with the Inquiry, but I expect it would support other accounts rather than providing new evidence (which I think this and my mother's statement do). I hope to submit it when I am able and apologise again for the lateness of my submission.

Anonymity

1. I do not wish to be anonymous.

2. I would give oral evidence to the Inquiry, if it would be deemed useful.

Statement of Truth

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

Signed GRO-C..............

Jonathan Charles Buggins

Dated 8th Nov 2022