

Witness Name: Dr Benjamin Walker

Statement No.: WITN6390001

Exhibits: **nil**

Dated: 15 September 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DR BENJAMIN WALKER

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 10 June 2021.

I, Benjamin Walker, will say as follows: -

Section 1. Introduction

1. My name is Benjamin Walker. My date of birth and address are known to the Inquiry. I received a PhD in Philosophy from the UEA in 2012, where I am an honorary research fellow. I founded and run a teaching charity, The Crito Project, and work with the University of East Anglia in delivering higher education to those in prison. I was inspired by my mother who briefly taught in prisons. I do not live with my partner, and I do not have any children.
2. I intend to speak about my late mother, Annie Walker, who was born on GRO-C GRO-C 1954 and sadly passed away on 27 March 2016, at the age of 62. I will refer to her as 'Annie' throughout my statement. She was infected with Hepatitis C ('HCV'), as a result of receiving a blood transfusion following an ectopic pregnancy. She was a tireless social justice campaigner despite suffering the tortuous effects of HCV upon her health and mental wellbeing.

3. In particular, I will discuss the nature of her illness, how the illness affected her, the treatment received and the impact it had on her and our lives together.
4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

Section 2. How Affected

1. My mother, Annie Walker, was born on GRO-C 1954. On 1 October 1974, at the age of 20 (before I was born), she had an oophorectomy in an East London hospital to excise a ruptured ectopic tubal pregnancy and, in the process, received a blood transfusion which infected her with HCV. It was not until fifteen or twenty years later that the effects of the virus became pronounced and debilitating.
2. Annie started getting ill when I was around 13 or 14. However, I did not realise this at the time as she kept her health worries to herself.
3. Annie was a veracious individual, who was well liked and committed to political change and activism. Annie came from a poor background in East London and moved to Norwich in 1980. In her spare time, Annie was very creative, and loved creating botanical illustrations, stained glass and charcoal drawings.
4. In 1993 Annie completed her degree with the University of East Anglia in Politics, Philosophy and Economics, and immediately began an exciting new phase in her life. Annie had a brilliant yet undeservedly short career as a strategist with the Labour Party and the Transport and General Workers' Union, moving to London and rapidly making a name for herself as a fearless, sharp-minded, fastidiously organised and likeable colleague. During this period, however, she began experiencing increasingly acute waves of exhaustion and general fatigue which curtailed her ability to work effectively,

forcing her to give up her job and return to Norwich. She spent days in bed completely wiped out. Sometimes the fatigue was triggered by exercise, other times it just seemed to come out of nowhere; her attention, energy levels and focus were all deteriorating.

5. In Easter 2002 Annie was informed, by phone, that she had been diagnosed with HCV. This was following a series of blood tests Annie had asked for and consented to. She did not know she was being tested specifically for HCV. My mother was perplexed that the diagnosis was delivered over the phone rather than face to face and she was baffled that the doctor had no idea about the virus he was diagnosing her with.
6. The doctor who told Annie about the diagnosis was incapable of telling her what the prognosis was for her health, what she should do now, or whether the virus might be responsible for her deteriorating health, simply because *he did not know*. This left Annie completely nonplussed; 13 years after the virus had first been discovered, how could the doctor reporting her diagnosis not know the first thing about what he was talking about?
7. What does the diagnosis *mean*? What can she do to combat the virus? Is it fatal? Can her diet have any impact on its progression? How many people have it? How long will she live for? Is it a threat to her son? All these and many other questions raced through her mind, and were met with complete silence by her GP and by any health professional she spoke to in the next few months.
8. It was in this state of frustration and disbelief that my mother turned to her best friend, Professor Liam Dolan, to help her to understand the virus. An expert in biology and genetics, Liam spent four months reading the emerging research on HCV, seeking to formulate a consensus from the different experiments and papers he read. Liam 'translated' the technical research into understandable English, and in doing so, in about four months he and Annie became experts in the virus.

9. During those first four months she received no advice or follow-up, no counselling, no help at all. Annie waited two months just to secure an appointment with a gastro-specialist (there were no liver specialists at the time in Norwich for her to be referred to) and was none the wiser for the meeting.
10. Annie decided to use her expertise in organising and advocating for unions and the Labour Party to start up a small local charity, called Norwich Hepatitis C Support Group, along with a friend who had been diagnosed with HCV, GRO-A GRO-A Prior to my mother's charity, there was no support in Norwich for those suffering with HCV.
11. GRO-A and Annie managed to secure a Millennium Lottery Grant to hire space at the Norwich Unemployment Centre, and there, often with Liam, they began to hold regular meetings. Alongside this Annie and I designed a website for the charity, norwich-hepc.org.uk. No one was quite ready for the overwhelming level of need and interest that would follow.
12. What was conceived of as a local initiative soon became global in its outreach: people diagnosed and suffering with HCV got in contact with my mother from all over the world; she had visitors from Lithuania and America and she was constantly on the phone with people from Germany, Ireland, France and the UK.
13. The scale and human cost of the virus dawned overwhelmingly clear on Annie, as did the gaping hole in the support and care that should have been provided to those who were suffering and dying from HCV. It took the British health services quite a few years to catch up with what my mum's little charity was providing to the HCV-infected population.
14. In her testimony for my mother's funeral, Samantha May (the Hepatitis C Trust's Information and Support Service Manager), really captured the incredible work my mother did supporting fellow sufferers, and recalls the care and steadying influence that she received from Annie: "Annie was one of my own first points of contact for getting informed and coming to terms with

hepatitis C when I was diagnosed back in 2002, as aside from the newly formed Hepatitis C Trust, there were no sources of support for people around at that time. For a while she was my own personal helpline and would patiently respond to my many questions and long emails with great humour and sometimes tough love during my own treatment journey. This both inspired and informed my own approach to providing support when I started here at The Trust on our own national helpline in 2004, and we continued to stay in touch over the years, as despite her worsening illness over time, she continued to take the time to campaign and raise awareness whenever she could.”

15. Charles Gore, The Hepatitis C Trust’s Chief Executive added: “the thing that really stood out for me about Annie was that she was always doing things for other people. She was always asking how she could help, what she could do for the Trust. She was a truly lovely person and it was such a pleasure when from time to time Sam would call me and say ‘I’ve got Annie on the line for you.’ She will be greatly missed.”

16. Without the help of Professor Liam Dolan Annie would have been kept in the dark about her HCV infection. Moreover, despite medical information being much more available in 2004-2005, it was Annie’s persistent character that led her to gaining further information from health professionals.

17. Annie struggled with people, especially health professionals and social services, not knowing the severity of the virus.

18. To confirm, I have never been offered a HCV test despite my mother being infected with HCV before I was born.

Section 3. Other Infections

19. I am not aware of any other infections that Annie was infected with other than HCV itself.

Section 4. Consent

20. As far as I am aware, Annie fully consented to all treatments and was not tested without her knowledge.

21. My mother advocated to take more advanced treatment to clear her HCV infection and was therefore aware of the risks before she consented.

22. I cannot comment on whether my mother consented to receive a blood transfusion, but quite possibly her mother (as her next of kin) would have provided consent.

23. Annie advocated for herself to take more and more advanced treatments to get rid of her HCV. Annie knew all the risks, however she consented as she was so desperate to get better.

Section 5. Impact

24. Annie lived many years of her life bed ridden and in constant pain. HCV was a fight that marked the majority of her adult life with suffering and alienation.

25. From 2002 to 2016, I watched my mother struggle to continue her support and campaign work, in the face of her constantly deteriorating health and the many secondary conditions brought on by the virus and by the course of treatments she went through. During that period she undertook four exhausting courses of treatment of pegylated interferon and ribavirin. This treatment was brutal in its impact on her memory, eyesight and alertness. Annie described interferon treatment as feeling like she was being slowly erased.

26. The first course of Interferon treatment was offered shortly after Annie was diagnosed with HCV. She was given an adequate demonstration on how to self-inject the medication. This course of treatment was unsuccessful in clearing the HCV viral load and a second course was offered with the addition

of Ribavirin (an oral medication taken daily in tablet form). Annie's viral load was monitored regularly throughout the treatment and she had to argue her case for continuing beyond 12 weeks as the medication had no effect. Annie underwent a further two courses of pegylated Interferon, but none of the attempts were successful in clearing the virus. I believe there were a couple of years break between each of the courses of treatment.

27. From her own research, Annie advocated to trial new treatments and trials in an attempt to clear her HCV infection. Unfortunately, the pegylated Interferon was unable to permanently eradicate the viral load. In 2013, Annie became aware of Harvoni, but this new medication was never offered.

28. Annie's liver was monitored from approximately 2006 either at the Royal London Hospital or Addenbrookes. The liver biopsies were very painful, but my mother had become pretty resilient because of the daily pain and physical degradation caused by the virus. A liver biopsy taken in 2006 confirmed that she had cirrhosis of the liver. In 2008, Annie met the criteria to be put onto the liver transplant list, but a prerequisite to receiving a new liver was that she had to clear the HCV infection first.

29. From 2010 and as the symptoms became worse, there was an escalation in the monitoring of Annie's liver. It would be accurate to say this was a result of her own persistence with the health service.

30. She was eventually given a liver transplant on 12 September 2014 and immediately after her fourth course of treatment (which had temporarily cleared the viral load). Without the transplant, my mother would have died.

31. The infection caused Annie to experience dread and hopelessness, exponential fear, the feeling of being betrayed by her own body, the shame of always being in bed despite not wanting to be, and most significantly, the feeling of mismatch between what she wanted for her life and what she was now doing. Annie was so angry at how she was alienated, silenced and at the lack of public recognition of what was happening to her. For a woman

dedicated to social justice, it was disgusting to her that individuals could be treated that way after being infected through negligence.

32. Annie suffered from sweating, inflammation, sleeplessness, dizziness and fatigue. From her diagnosis to her death, as a result of the virus and its treatment, my mother suffered with osteoporosis, collapsed vertebrae, parotitis and Paget's disease; portal hypertension, internal bleeding and cirrhosis; memory and eyesight loss; Splenomegaly; insomnia, anxiety and depression; jaundice; and eventually the liver cancer that took her life on 27 March 2016.
33. Annie informed her dental practice about her HCV infection – she suffered with asymmetric swelling and therefore required a lot of dental work. She found some of the dentists understanding, but others were melodramatic and made her feel awful. Often, she would have to wait until the last appointment of the day to be seen and the dentist would be fully gowned. Outside of the hepatology department, Annie felt humiliated by medical professionals as a result of her HCV status.
34. Socially, Annie felt like she was disappearing before she died. This was not through negligence, but her friends started to forget that she existed after Annie had been in bed for so long. Annie's charity gave her a life line socially, however this also affected her as it reinforced all the negative impacts of the HCV infection in her life.
35. Workwise, Annie's HCV infection hindered her professional career from developing and her abiding regret was that she never got to discover her full potential. Annie started her working life as a secretary for a transport union, who agreed to enrol her on a scholarship to study PPE at the University of East Anglia – the first in the family to obtain a degree. As a graduate, she immediately moved to London to work as a strategist between the unions and Labour Party and was given a taste of a successful political career. After a year or two, this role became impossible for Annie because of her ill health and all of what she had achieved was taken away.

36. Before the diagnosis, Annie blamed herself for not being able to work at the expected level. In turn, this led Annie to believe that she was not good enough as she was unable to do the required work without getting exhausted.
37. After giving up her political career, Annie tried teaching English. Despite a career change, Annie still struggled and was reduced to part time and then voluntary work. Annie's ability to work was reduced to the point that she realised there was something really wrong with her.
38. The effect of Annie's HCV infection was really pronounced. Annie came from poverty, and because of the virus, and remained under threat of it until her death. Annie's internal dialogue of not feeling good enough or cut out for a political career was worse than the loss of earnings resulting from her HCV infection, and the loss of her career that she so loved was probably the number-one regret for my mother.
39. The Infected Blood Inquiry's Rule Nine document asks me to "please describe, in as much detail as you feel able to give, the impact on you - physically, mentally and emotionally - and on your private, family and social life." I grew up on income support, and Annie's HCV infection impacted my own life in every way I can measure, but on this I will only say a little as I want the focus of this testimony to be Annie. I will say, however, that I was my mother's only living child and she was my only living parent and we were very close. What happened to her has altered my life in ways that go beyond my ability to grasp, across too many metrics to count. Annie never got to live a life in which she was not infected and slowly killed by HCV, and so I will never know what shape my life would have taken in the absence of our all-defining trauma.
40. I believe that the manner in which we face the suffering and injustice that we encounter in our lives is one of the core traits that determine who we are and who we become; for this and many other reasons I can say that I am very proud of my mother, and that I learned so much from the dignity and tenacity

with which she faced injustice, suffering and death. I would also like to say this: full recognition, apology and admission of the wrongdoing and obstruction committed by this government will help me to feel some closure, and to feel that my mother's most fervent wishes were finally, belatedly, honoured.

41. Although I was part of her support network for many years, during the last year of my mother's life I was my mother's full-time live-in carer and had to give up work. I watched my only parent go through torture and die as a result of her HCV infection, which she contracted through no fault of her own.

42. My mother was infected before I was born so it is hard to imagine what my life would have been if my she had never been infected. It has coloured nearly every period and aspect of my life. I do however believe that I've done well with the hand I have been dealt and have found a lot of equanimity and solace in my academic interests. As a younger man I was very angry and pent up towards the government and I do still tend towards an anti-establishment view; I suppose this is almost inevitable, having seen up close the harm inflicted through wilful negligence and political malfeasance.

43. Annie felt a great deal of stigma from health professionals and social services, and was often labelled as a drug addict or an alcoholic by them.

44. Her neighbours never raised an eyelid about my mother's deteriorating health and the stigma she suffered issued primarily from the medical profession. She became another one of those confined to a bed in a council flat, forgotten by society save for the network of friends and peers who had also been infected and effected by this scandal.

Section 6. Treatment/Care/Support

45. Nowhere was the alienation felt more sharply than in her dealings with Social Services, in her attempts to access the welfare she needed to survive. Aggressive, belittling, displaying zero compassion and constantly treated her as if she were on the scam: my mother's experiences of trying to access

incapacity benefit and disability living allowance revealed a barbaric strategy of deliberately withholding benefits on the basis of specious sanctions, and impossible-to-meet demands for evidence and interview. Iain Duncan Smith's time at DWP was marked by aggressive attacks on society's most vulnerable, and his sanction culture constantly threatened to revoke my mother's literal lifeline on benefits.

46. My mother was treated by some truly dedicated and well-meaning medical professionals, in particular the incredible teams at Addenbrooke's Hospital and Royal London Hospital, and she never stopped singing their praises. But she was also met with suspicion, hostility and presumption by many other doctors who were supposed to be supporting her. Many accused her of making up and exaggerating symptoms and over-reporting pain; even more simply didn't take her or her condition seriously, talking over her head. One even opined, *on her medical record*, that she had probably contracted the virus from drug abuse, a fact my mother only discovered when she demanded access to her records.

47. At every turn, my mother felt outraged at this treatment and sought to set the record straight but it was an utterly tiring and Sisyphean task. In the final year of her life she was in incredible pain; having had to use pain killers for the past decade of her tolerance to them had grown significantly and, instead of factoring this side-effect into her treatment, her doctors refused to increase her medication.

48. Night-time in particular was agonising for her, when the pain was so bad it threatened her sanity; when reporting the need for a higher dose she was met with moralising and suspicion. It was not until the final few weeks of hospitalised palliative care, when medical staff could no longer miss the need for much higher levels of painkillers, that she was finally allowed some respite from the pain.

49. There was no integration between the liver specialist team and professionals from the wider health profession. Outside of the hepatology department, my

mother found that medical professionals were ignorant and prejudiced and found the onus to be on the patient to answer all of the questions.

50. Annie had difficulty accessing mental health support and depression treatment. There was not much secondary support offered, and the little support that was offered was actively bad.

51. I have never been offered any psychological support myself.

Section 7. Financial Assistance

52. The advent of the Skipton Fund had a direct and positive impact upon Annie when she was granted access to its annual payment of £14,749. (I'm afraid I do not have the details to hand of when she first received payment of the fund.) However, as a no-fault government payment scheme, Skipton had a dual place in my mother's life: it was both a lifeline and a constant reminder of the government's refusal to admit wrongdoing. In a similar way to the Irish Compensation Tribunal of 1995, and its decision to establish the Reparation Fund, it served to highlight the difference that admission of wrongdoing would make to her life and to her mental wellbeing. Yes, compensation was an important point of campaigning for my mum, but it was nothing compared to the admission of wrongdoing and apology that would have to accompany it.

53. Annie just wanted to see with her own eyes that what Lord Robert Winston described as the 'worst treatment disaster in the history of the NHS' could never happen again.

Section 8. Other issues

54. One reason for some of the disturbing attitudes that my mother encountered within the medical profession in this country is that they, along with the general public, were actively misled and kept in a state of ignorance by our government. The state has denied, obfuscated and obstructed any attempts to bring information relating to the infected blood scandal into the light of

scrutiny, and its decades-long efforts to ensure that key information should not be in the public domain had a direct and incredibly harmful effect upon the quality of my mother's life. The landscape of silence, discrimination, and alienation that she had to navigate was created by ministerial decision-making.

55. No government, healthcare or pharmaceutical entity in the UK has admitted any liability in the scandal, and no damages have been paid to those infected or affected. The ministerial papers of Lord Owen have been destroyed; key documents relating to blood products have been destroyed; records being examined by Lord Jenkins met the same fate, as did the Blood Transfusion Service's records in late 2005; there is a litany of missing records and eliminated medical histories. No officials have been prosecuted. No one has been held responsible. Successive governments have failed to even apologise or acknowledge the mendacity that has marked their response to the biggest scandal in our health service's history, and at every turn attempts at justice and truth have been curtailed.

56. My mother died less than a year after the 2015 Penrose Inquiry concluded, and its tone and recommendations left her feeling demoralised and abject. Even for someone who had become painfully familiar with denial and whitewashing, Penrose left my mother speechless. To understand it, and its wider place in regard to a strategy of blame avoidance, I feel we only really need to understand one thing: that *inaction is a form of action*. The Penrose Inquiry followed a well-established tradition in the British government of using initial public inquiries to stall for time. They have repeatedly been used to create both distance and a veneer of accountability between crimes of governance and their public reckoning. Normally, in cases such as Bloody Sunday or Hillsborough, the effect is to cool outrage and make eventual revelations a matter seemingly only of historical concern to the public, and of direct concern only for a decreasing few. Here, with the infected blood scandal, it was a particularly pernicious tactic, as the greater the delay, the less victims there were left to receive closure, apology, admission and damages. There are very few left today; every four days there is one less.

This Machiavellian strategy of inaction-as-action has reaped particularly rich rewards for the government, and a particularly bitter harvest of injustice for its victims.

57. As the whole world has recently been made aware, an epidemic is both a medical and a social occurrence. HCV often means a slow death, and its victims are often forced to retreat to their beds for years before they die. Its victims disappear gradually, before they actually pass away, and so they are missed in a different way, too, by their friends, colleagues and society at large. HCV and the infected blood scandal *should* have stirred a wide social moment of outrage, similar to that which accompanied the HIV epidemic. But HCV sufferers, and infected blood victims, have not been afforded the outrage or cultural memory that would normally accompany such tragedies. Because of government handling, people like my mother may perhaps never receive that legacy. The scope of this scandal is so wide, but for my mother it was best understood as a double injustice: on the scale of lived experience for her and her peers, and on the greater scale of an erasure from our culture memory of suffering and inequity. There has been no reckoning and so there can be no learning. I am not my mother, I do not have the encyclopaedic understanding of the issue that she had, nor her command of the details, people or stories that make up this scandal. I have tried to represent her perspective here to the best of my limited abilities, so that she might have some voice in this Inquiry, which she worked so hard for, and hoped for so fervently, as a means for her experience to drive change. She didn't want to be forgotten; not because of ego, but because for her to be forgotten would also mean the smothering of injustice that distorted her life so completely.

58. I would like to close my testimony with a question to the Inquiry: If there had *not* been a series of government mistakes, and so if ministers had *not* sought to conceal the truth, *how would the lives of its many victims differed?* I think it beyond obvious that the welfare state's and medical community's support of them would have been unrecognisably improved. Therefore it is my deeply held belief that, no matter how politically inexpedient, this Inquiry *must* reckon with no one but two grave injustices. Firstly the negligent infection of

countless victims with HIV and HCV, and secondly the toll taken upon their lives as they sought to survive in a society kept ignorant of their predicament in the name of petty political capital.

Statement of Truth

I believe



that the facts stated in this witness statement are true.

Signed

Dated 15 September 2021