Witness Name: Carol Anne Grayson
Statement No.: WITN1055207
Exhibits: WITN1055208-
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Dated: 4 February 2025

INFECTED BLOOD INQUIRY

FIFTH WRITTEN STATEMENT OF CAROL ANNE GRAYSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 January 2025.

I, Carol Anne Grayson, will say as follows:

1. My name is Carol Anne Grayson, and I set up campaign group Haemophilia North in 1994 with my late husband Peter Longstaff. We later renamed it Haemophilia Action UK to reflect the national remit with regard to the Contaminated Blood scandal. Newcastle, where I am based, had the worst death figures for haemophiliacs in the UK (after becoming infected with HIV and hepatitis viruses which decimated the group, however I continue to be active today including on compensation.

2. In 1996, I wrote to the Haemophilia Society calling for "compensation on a parity with Eire" a phrase I coined, and which became part of our campaign mantra along with the need for a public inquiry. I chose this scheme because it was the best I could find for infected haemophiliacs and other persons with inherited bleeding disorders internationally at that time and was specific to their needs in this regard. It was also inclusive of infected and affected partners, parents,

children, siblings and carers. Unfortunately, the Haemophilia Society chose to go for a "hardship fund" for several years until we pressured them to call for proper compensation. I have referred to the Eire model over many years and it helped influence our thinking when we wrote our own proposals for compensation.

3. My campaign colleague, independent campaigner, Colette Wintle and I, have tried where possible to continue to educate our wider haemophilia community, the Haemophilia Society, IBCA, the government and opposition parties, media, lawyers, other interested parties and the public on the impact of the Contaminated Blood scandal and the losses and needs of both infected and affected persons.

4. This was reflected in our written response to Sir Robert Francis on compensation proposals dated, 4th August 2021. I am including some relevant background recap as all was not going smoothly on compensation discussions before Sir Brian Langstaff published his report in May 2024. For us inclusion was an ongoing fight.

5. Our proposals were carefully thought out and are included in this statement as initially Colette and I were NOT included in meetings with Sir Robert Francis (prior to the Inquiry Report from Chair, Sir Brian Langstaff) until we kicked up a fuss and went to the media. We belatedly got a virtual meeting. Our compensation proposals are annexed hereto **(WITN1055208)**. We were not included in Sir Robert Francis' compensation study report which we complained about at the time. This was not a positive sign for us.

6. Colette and I were also prepared to meet Sir Jonathan Montgomery who was *"appointed as Chair of a group of clinical, legal and social care experts 'to give technical advice on compensation'"* where other campaigners had refused to meet him, but no one would facilitate that meeting for us.

7. We noted other campaign groups, even Terrence Higgins Trust that we emphasized did not speak for the majority of haemophiliacs and Jason Evans,

funded by THT, appeared to be both prioritized in meetings and included in Sir Robert Francis' initial report.

8. Other campaign groups and Haemophilia Action UK had previously raised many concerns over the behaviour of THT and did not consider them suitable to be involved in our fight for compensation. Angell and Ivor Caplin, Chair of Advisors to THT were strongly connected to the Labour Party and were not considered "independent" voices.

9. Since Sir Brian Langstaff's report was released, I have engaged with the media on compensation as part of our awarded *Bad Blood* campaign set up jointly with journalist Louella Houldcroft which began with the Newcastle *Journal* in 2000 and continues with journalist Samuel Volpe and sister paper the Newcastle *Chronicle* in 2025. Two examples of my Chronicle articles are exhibited **(WITN1055209).**

10. **NOT RELEVANT**

11. Colette and I have had to fight to attend meetings on compensation. Part of this is related to a "conflict of interest" regarding certain persons that have repeatedly plagiarized my work which is very traumatic for me and where we have requested separate meetings with government and IBCA to avoid these people and further traumatization.

12. Colette and I attended a meeting with John Glenn on compensation and we did feel more engaged and listened to at that meeting. I have exhibited my notes of this meeting **(WITN1055210).**

13. I attended a further virtual meeting with Sir Robert Francis and other campaigners on compensation. Colette couldn't get into the meeting because of technical issues and I had difficulty speaking through the same. Since then however, IBCA have improved on the technology side offering test runs with campaigners.

14. Colette and I did finally meet Sir Robert Francis and some of the IBCA team in Newcastle in person to discuss compensation. We were also supposed to meet David Foley. He then couldn't attend and we were not offered another date to meet him.

15. We raised issues in advance of that meeting regarding fraud, state benefits and pensions and the importance of protecting haemophiliacs and partners and carers receiving large compensation payouts and safeguarding privacy. Many of our older community in particular are reliant on state benefits though it could be some other family members may also be affected.

16. Colette and I will sometimes receive email updates with guidance and occasional phone calls from IBCA and the Cabinet Office. We have campaigned on the front line for decades, are close to retirement age and utterly worn out and burnt out from this experience. We are both finding the Compensation set up confusing in who has responsibilities for what. We had hoped the process would be a lot simpler and quicker. It feels as if we are waiting to die, in limbo, unable to make any progress in our lives and fearing as our health declines we may not ever get the compensation awards we deserve. It is not helped by the fact that we are also both WASPI women born in the 1950s and fighting pension injustice plus we are both on PIP and ESA and I am having to fight yet another appeal. Again, this is time consuming, frustrating and exhausting alongside monitoring the compensation guidelines and application process.

17. Our lawyers are very helpful, and we need them. They are important and valuable to us as they know our cases and the background to infections very well over several years now and most importantly, we trust them. They can explain difficult legal concepts and jargon and advise us regarding how and what we may be able to claim in compensation. However, we are worried that their role may be diminished due to the appointment of new case managers who don't know us or what we have experienced and are on a very steep learning curve in a very short space of time. It's important that our lawyers are funded adequately to continue to assist us on compensation issues. Our legal team provide support and a level of protection where there is existing "conflict of interest" they make life easier for us and we fear losing them.

18. I keep getting emails addressed to Haemophilia Action as opposed to Haemophilia Action UK, government and IBCA don't even use my correct name. My experience is that there appears to be a 2- tier system in practice regarding discussions on compensation. The newer and perhaps more "acceptable" groups of campaigners (in that they have far less lived experience of campaigning than the long-standing campaigners) are easily used and manipulated. Numerous new groups have emerged as the Infected Blood Inquiry began and their lack of campaign history (not going back decades) unfortunately sometimes compromises our chances of the best levels of compensation which is exactly why Colette and I feel they are chosen for engagement.

19. In the 1980s and 90s, the only campaign groups that existed were Birchgrove, Manor House Group (set up by the late Pete Mossman and Peter Hughes), Colette as an independent campaigner and Haemophilia Action UK.

20. Colette and I have now seen what a past Labour government stated about Colette and I in the early 2000s, top civil servants were watching us closely, the impact of our media campaigns, which politicians allied with us, our level of intelligence, how effective we were and working out how to manage us. We were never meant to see these internal government documents. Clearly from

the tone, Colette and I were a thorn in Labour's side, and they were keen to express in writing that we would never get an inquiry or a penny compensation. We are an embarrassment to government now. Several times we only found out about meetings on compensation by chance and at the last minute. We are a reminder of how badly Labour treated us since the 1990s. Some of those who ignored and abused us are now in high government positions with no accountability. One has even been approached regarding a potential criminal case and should not be involved due to her past position blocking us.

21. Trust is a major issue for Haemophilia Action UK, we have been let down so many times by figures in authority. How are Colette and I supposed to trust IBCA when they took on people such as Jason Evans as a "User Consultant" regarding compensation. In recent times he was funded by the Terrence Higgins Trust who do not speak for Haemophilia Action UK on compensation and still owe me thousands of pounds in back money after a mistake was made wrongly means testing the disability part of my monthly allowance. How can proper and fair compensation be calculated without true timelines of discovery of evidence?

22. Colette and I have no idea the names of the persons choosing the applicants to be compensated on Contaminated Blood or how they are chosen or what criteria is used, this is not transparency. There is a fear that those of us that have been outspoken over decades will be put at the back of the queue. Colette and I feel disengaged, disappointed and disillusioned and have concerns for all infected and affected people as to how we can know if the process of compensation is fair or not? It feels pointless contributing anymore as we don't feel heard or valued. The process feels unnecessarily confusing and the appointment of a plagiarist when we stand for truth and justice is deeply disturbing and we have now lost any trust we might have had.

23. The impact of the above on Haemophilia Action UK and my campaign colleague independent campaigner Colette Wintle is devastating. We fought for so long and now we are often the last to be heard. The process of compensation is undermining and difficult to follow. We notice our lawyers don't seem to be

updated as they should be, and we are often having to send them information they haven't received to keep them informed. We don't see why we need all these "case managers" when our lawyers can act for us, it feels like another unnecessary layer of bureaucracy. The stress of the process is exhausting to all infected and affected and as older women approaching retirement with multiple chronic health issues this is further impacting on both our health.

24. It feels pointless interacting with the Cabinet Office, it's more of the same misogyny and sidelining of female campaigners that we have had to deal with over several decades. I am struggling to write this statement. I am so disconnected and despairing. Thank goodness for the Infected Blood Inquiry Red Cross helpline that have listened and supported me. My complex PTSD is very problematic now and is impacting on my diabetes with the immense stress affecting my cortisone levels and trying to keep blood sugar levels stable is impossible.

25. Neither Haemophilia Action UK nor my campaign colleague Colette Wintle feel part of the IBCA and government compensation process. We just want it to be over so we can try to find some peace.

26. It feels as if every time we suggest an area that needs addressing, it is then used against us and declined.

27. We also note the employment of a Public Relations company to give a better look to the IBCA compensation process. This seems an unnecessary waste of money when the IBCA should be focussing on paying compensation to infected and affected people.

28. Again, it reminds me of when the Haemophilia Society wasted money employing Weber Shandwick early 2000s, a PR company that had worked for Blair's office whom we were fighting and appeared more keen on doing "damage limitation" for the Labour Party than supporting the rights of haemophiliacs and their call for a public inquiry and compensation.

29. I also lost trust when my confidentiality was breached. I was sent an email which included the addresses of those with whom I have a “conflict of interest” and they got mine. I had to point this out to IBCA. There was an apology, but the damage was already done.

30. The Government need to first address honestly the damage that was done by Labour to long standing campaigners within Haemophilia Action UK and Colette as an independent campaigner from the 1990s onwards that kept going for 3 decades to achieve justice for the haemophilia community. There has never been a direct apology to us related to the comments made about us in government files and blocking our evidence. We feel strongly this is affecting the compensation process and at times avoidance of contact and delaying sending information or us not receiving the same information or meetings as others.

31. Colette and I disagreed with having User Consultants due to a long history of “divide and conquer tactics” by government. IBCA need to stop promoting and funding plagiarists and disengage from the less ethical journalists putting out fake timelines of discovery of evidence in the media and instead, work from true timelines of discovery. I have been disturbed by some of the inaccurate reporting from journalists such as Caroline Wheeler and Cara McGoogan.

32. IBCA actually rang me to ask how I felt about User Consultants. I was furious regarding the appointments and told the caller so.

33. Confidentiality needs to be protected and safeguards put in place so that when compensation is granted, infected and affected are fully protected from false claims of fraud because government has failed to educate DWP adequately that this money cannot be taken into account regarding state and disability benefits, pension etc. We cannot have more traumatization of innocent people falsely accused of fraud.

34. We need honesty and to be heard by IBCA and government and action taken where possible to implement fair compensation proposals and address how females are often treated differently from males in the compensation process.

35. Making amends should also include putting an official history page regarding the documents Newcastle solicitors Blackett, Hart and Pratt returned to government in 2006 on my instructions with legal letters to the Dept of Health Legal Department to assist them. (Documents transferred to the National Archives at Kew). There should also be a link to my ESRC Michael Young awarded dissertation in the NA Kew plus a note (and letter) regarding the work done by Sir Patrick Jenkin and I in 2005 to save and protect whatever documents remained on Contaminated Blood and blood policy in all government archives. Andrew Dyer (NA Kew) informed us he was waiting for government to act in this regard. I was horrified to find government had gone against its commitment to me not to destroy further documents, but they had destroyed the legal letters of return (fortunately I kept my own copies). This trashing of key letters has enabled other campaigners and less ethical journalists to claim discovery of key and incriminating documents years after the event (that were discovered by me in several tranches in the late 1990s/early 2000s) and that were ignored by a Labour government who blocked me all the way. This has caused me huge distress. Please see reference to our Royal Television Society nominated best BBC Newsnight, April 2007, (of that year) where I was the researcher (many of my documents used) with Mags Gavan as Independent Documentary Film maker and Sue Watts as presenter. I have my emails to Andrew Dyer and the correspondence from my lawyers explaining the situation to him.

36. Compensation should include a system of quick access to physical and mental health assessments, investigations and treatment. This is just not happening and delays cost lives.

37. Compensation must be speeded up, infected and affected are running out of time age-wise and health-wise. Our lawyers need to be supported and financed

properly so they can continue to assist us regarding compensation, they are our safety net and lifeline.

Statement of Truth

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

GRO-C

Signed ____________________________

Dated _____18 February 2025__________

Table of exhibits:

Date	**Notes/ Description**	**Exhibit number**
06/08/2021	Haemophilia Action UK compensation proposals to Sir Robert Francis	WITN1055208
30/10/2024 26/01/2025	Articles for Newcastle Chronicle	WITN1055209
09/05/2024	Notes from meeting on compensation with John Glen	WITN1055210