Witness Name: Karen Gray
Statement No. WITN4686001
Exhibits: Nil
Date: 20/10/2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF KAREN GRAY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 22 September 2020.

I, Karen Gray, will say as follows: -

Section 1. Introduction

1. My name is Karen Gray. My date of birth is GRO-C 1970, and my address is known to the Inquiry. I give this statement in my capacity as a Social Worker specialising in Haemophilia.

2. I am also Co-founder and an associate member of the Haemophilia Social Workers Association UK, as well as being an associate of the Haemophilia Nurses Association and a member of Haemnet.

3. I intend to speak about my professional experience as a Haemophilia Specialist Social worker at Newcastle Royal Victoria Infirmary Comprehensive Care Centre. I hold a Diploma in Social Work, awarded by Northumbria University in 1998. Below is a summary of my relevant employment history in chronological order:

    1996 – 1998: Barnado's Northeast - centre worker/project worker
    1998 – 1999: Darlington Children's Services - social worker

2000 – 2002: North Tyneside Children's Services - social worker

2002 – 2003: Barnado's (Sungate Project) - social worker/project worker

2003 – 2008: Barnado's Orchard Bereavement and Loss Team - children's bereavement worker

2008 – 2011: Barnado's Byker Sands/Northeast - senior practitioner

2011 – 2020: Newcastle Haemophilia Comprehensive Care Centre, RVI Hospital Newcastle – specialist haemophilia social worker

4. I co-founded Haemophilia Social Workers Association (UK) in 2017 with fellow Haemophilia Specialist Social workers. I served as the Association's chair between September 2019 and September 2020. I will go into further detail on the nature of this organisation and its establishment in Section 3, below.

5. I can confirm I have not provided evidence to any previous inquiries, nor have I been involved in any civil or criminal litigation relating to the infection of recipients of blood products. I have however provided emotional and advocacy support to patients whilst they have given statements to the Inquiry, either directly or through the solicitor's firm Collins.

Section 2. Role as a Haemophilia Social Worker

6. The role I have held that is of most direct relevance to the Inquiry's terms of reference, is my most recent position; Haemophilia Specialist Social Worker at The Newcastle Haemophilia Comprehensive Care Centre ("the Centre"), employed through Newcastle City Council funded by Newcastle Haemophilia comprehensive Care Centre. I started this position in 2011 as a member of the multidisciplinary Care team. I

provided psychosocial support to patients with non-malignant bleeding disorders at Newcastle Royal Victoria Infirmary. This was with adults and with children and their families, a cradle to grave service. These could include relationships, family dynamics, employment/training, life transitions, housing, and finance. Emotional and psychological wellbeing for adults and parents of children with a bleeding disorder. This not being an exhaustive list. A very large proportion of my work in this role was with patients infected with hepatitis C (HCV) and/or HIV via their treatment with blood products such as Factor VIII. I was responsible for the assessment of patient's psychosocial needs as new and existing patients came under the care of the Centre. I got to know them, assessed the support they required and alongside health professionals on the team, provided support to obtain best health outcomes.

7. For example, if a patient was having difficulty adhering to their treatment plan e.g., prophylaxis, I would engage with the individual and explore barriers to their management of treatment; this could be financial, family or any manner of psychosocial issue. This was also supporting and exploring complex issues derived from the huge impact of diagnosis and related infections. Needs were identified and a creative psychosocial plan developed. When possible, I would be present at patients' appointments to facilitate timely support. I was supported in providing welfare rights advice by a Welfare Rights Officer assigned to the Centre from Newcastle City Council. Skills and models of Social Work practice I implemented included Solution Focussed Therapy, Person Centred Therapy techniques, Active Listening. Also, with Children and Families, Non Directive Play therapy techniques, Family Group counselling techniques and the implementation of the Signs of Safety model. All work advised by current and relevant legislation.

8. Clinics attended; multidisciplinary clinics, patient regular clinical reviews and all appropriate appointments for all or any Haemophilia Centre/Haematology Unit patient's adult and paediatric (non-malignant).

Also, joint clinics between Haemophilia consultant and Lead Consultant in HIV/HepC.

9. Patients were referred to me via discussion within the weekly multi-Disciplinary team meeting, other professional meeting/discussion, clinics, correspondence, or direct self-referral from patients. During clinics there was an open-door service where patients could approach me directly.

10. The support provided to patients was often very complex. It is my understanding a Specialist social worker has been in post in Newcastle Haemophilia Comprehensive care centre since 1987. The post being created in response to the need for support for those infected by HIV/ AIDS. Currently funding for post comes from the Haemophilia Comprehensive Care Centre budget. I provided a service to adults, children, their families and carers affected by non-malignant bleeding disorders, HIV and/or HepC. I did not engage with any individuals infected by means other than blood products, such as recipients of whole blood transfusions.

11. The Haemophilia Specialist Social Worker post was an evolving role I had freedom to develop in response to the needs of its service users. Not to a concrete job description or service level agreement.

12. At the commencement of my post, I visited and learned about the organisations available or tasked to offer support to infected and affected patients and their families. Also, where there were gaps in necessary support for my service users. These included The Hepatitis C Trust, The Skipton Fund, The Macfarlane Trust and Caxton Fiundation. More latterly England Infected Blood Support Scheme.

13. I carried out one to one home visits, providing a tailor-made package of support. This would include where appropriate provisions for family members and loved ones of the infected individual. I was able to make

direct referrals to external services for example Charitable organisations, mental health teams, psychological resources, local community or authority resources without having to go through a service-user's GP.

14. My responsibilities within the Newcastle Haemophilia Comprehensive Care Centre crossed fifteen different local authorities' boundaries. It was necessary to have an awareness of the differing policies and protocols (interpretations of legislation e.g., Care Act, Children and Families act) of these authorities. This could mean disparity in level of support area to area.

15. I did work with patients infected with hepatitis B (HBV). However, as with all patients regardless of their diagnosis I worked within a psychosocial model of practise not a medical model. It was not my practise speak about the individual's specific medical issue unless they chose to do so. This was firstly because I am not qualified to do so. Secondly our work together offered an opportunity to discuss wellbeing in a non-medical way that still promoted good global health.

16. In terms of the counselling and psychological support offered to infected patients with Haemophilia, I believe Newcastle was progressive from the start. The Newcastle Centre has prioritised psychosocial support from when the need was identified in the 1980's and has consistently provided this service to today.

17. Through positive and meaningful engagement with patients, also using tools such as 'screening of psychological and emotional wellbeing questionnaires' It was possible to assess when a referral to a more specialist service was required, for example Health Psychology. Some patients appreciated just a safe and confidential space and opportunity to discuss their feelings and experiences, 'emotional maintenance'. It was striking the very clear commonality in themes that patients would discuss.

18. Approximately three years ago, a designated Psychologist was assigned to the Centre. She had one day a week dedicated to Haemophilia patients. Funding for private Counselling through the English Infected Blood Support Scheme (EIBSS) was also available. About one year ago (pre pandemic) senior management of EIBSS came to visit me. We discussed their service and how I had experienced accessing it from the patient's perspective as I have advocated for their 'members'. We also shared professional knowledge. From this discussion some procedures of EIBSS were changed.

19. Confidentiality within the work between social worker and the patient was paramount. I was part of the multi-disciplinary team, but it was not necessary or right for the content of psychosocial sessions to be shared. With mutual professional respect to my colleagues, I would work to the goals of improving outcomes and care for the patient. I would share information that was relevant, and consent was given or guide change through advice without sharing detail.

20. Over the course of my time at the Newcastle Centre, the issue of vCJD came up on two occasions I can recall. Both concerned patients raising the issue with me after receiving a letter notifying them, they may have been exposed to vCJD. This caused fear. A patient I work with who has a lot of stomach bleeds and has regular colonoscopies. He has designated equipment for his use only because of the vCJD risk. He did share with me that he worried people would judge him unkindly for this. I state that I have no professional knowledge of vCJD and its effects and this condition has never been part of my work. I have never had discussions with any other member of the team regarding this.

21. Recently there has been discussion of an annual 'psychological and emotional wellbeing screening questionnaire'. They have proved to be successful on recent trials. I am unaware of how this will go forward. If a patient that is not already known to me was in need of support it would be a team member responsible for sharing information or concern with

me or discuss it in team meeting. There is no formal structure for making patients aware that there is a Social Work service available to them. I cannot speak to what it was like before I worked there, but I believe the support available to the patients at the Centre was of a high standard. It concerns me at times that there is only 22 hours of Social Work per week allocated to the Centre.

22. Whilst in my position at the Newcastle Centre, I worked alongside the following medical professionals whose names and positions I include in the event they are helpful to the inquiry's investigations:

    - Dr Kate Talks, Lead Consultant
    - Dr John Hanley, Adult Consultant
    - Dr Bridget Greystoke, Adult Consultant
    - Dr Tina Biss, Paediatric Haematology Consultant
    - Dr Matthaeus Schmitt, Consultant Infectious diseases
    - Julie Vowels, Nurse Specialist & Team Lead
    - David Hopper, Physiotherapist

Section 3. Haemophilia Social Workers Association

23. In 2016, I met a fellow Haemophilia Specialist Social Worker at a HNA meeting. It was from there we began discussing the need for a community of practise or organisation that would bring together Haemophilia social workers in the UK.

24. In 2017, we formally founded the Haemophilia Social Workers Association UK (HSWA). A constitution for the organisation has been drafted. The stated aims of the Association; are to promote equality of service across haemophilia centres. Raise awareness of psychosocial need. Provide peer support to one another. Promote and provide evidence of fact that provision of specialist psychosocial support at Haemophilia Care Centres provide good health economics. I served as the vice-chair between 2018 and 2019, and I was the chair from September 2019 to September 2020. Now my tenure as chair has come

to an end, I am an associate member of the Association. All membership of the association is voluntary. No financial support is provided from any source. Most work is caried out during personal time.

25. Due to the very specific nature of the Association and our membership, we are a small organisation, currently comprise of six core members; We have a member from Manchester, Leeds, Sheffield and Newcastle. Two members job share in Cardiff and a member in Northern Ireland. I believe there are social workers in Birmingham and London, but are not currently involved with the Association. There are no social workers in Haemophilia currently in Scotland.

Section 4. Impact on people infected and affected

26. My feeling is I could talk for ten years about the impact of infection on those I have worked with over the past decade. The impact of being diagnosed with virus like HIV or HCV were so extreme it is hard to put them into words. I will try my best to illustrate the extent of the impact on the Centre's patients by using examples shared with me from my time there, but it is very difficult to convey the totality of the impact.

27. I would say that dealing with the effects of HCV treatment was the lion's share of my work. The largest cohort of my case load could be described as middle-aged men, most of whom had been infected/co infected with the virus when they were considerably younger. I cannot give example of discussion with any doctor I worked with about the long-term mental impact of HCV and its treatment. The men I worked with described suffered tremendously with numerous mental health issues during their treatment for HepC and long-term post treatment for example, anxiety, agoraphobia, depression, lack of confidence and low self-esteem, overwhelming fatigue.

28. In addition to these challenges, the stigma associated with the infection lead to constant effort to hide diagnosis from others. It was reported to me multiple times that 'family, friends and colleagues have asked if they

were going through chemotherapy or trying to conceal the fact they were dying of cancer'. The element of secrecy about status within my case load was almost uniform. I have found it very rare to come across an individual who had been infected whose family knew the full extent of their condition. I have reported to my manager during my 'Work Supervision' that there have been times that when writing up my reflective notes, I have felt that the themes being reported to me had such strong commonality I could literally just replace the name at the top of the page. Over a period of years, I worked intensively supporting two men from the centre who were first cousins. Their families were close and lived in the same community. Both men had been infected with HepC and had undergone treatment to clear infection several years ago. Neither told the other of their infection or experience. So great was their fear of judgement and harm to the family, that they missed out on what could have been a huge support to each other. The burden of living with the secret was truly tremendous. A sense of great loneliness was reported to me by many I worked with.

29. Many people may think that having started this job in 2011, a lot of the stigma around HIV and HepC infection would have dissipated. My experience is that this is not the case. The infamous HIV adverts, featuring the images of tombstones, coincided with the start of my social work career, so I have always been aware of the stigma. Thirty to forty years later, being involved directly, I myself was shocked to see the level of stigma still around.

30. Recently a patient discussed this matter with me; 18 months ago, he suffered a bad nosebleed. He was advised to attend his local A&E department. He felt obliged to inform the nurse/health care assistant he was still HCV-antibody positive. At this point she dropped the tray she was holding and ran from the room, loudly stating he should have told her this sooner as he could have infected her. He is in fact PCR negative. This is current. Lack of education leads to ignorance which is just as stigmatising as it's always been. He did not want to make a complaint. It

is my experience that there is a lack of willingness ‘to make a fuss’ and risk negative repercussions, no matter how bad the treatment.

31. It is common for patients to not actively seek out the help and support they would benefit from and are entitled to due to fear ‘being found out’. Also, that the general health care professionals would not understand the route of their infection the way Haemophilia services would. GP’s, pharmacist, nurses and others were all people living in their community. They would be terrified that if they went to see them for support, their secret would get out. Myself and my service users had an agreed code that if I saw them out in the community, I would only speak to them if they initiated it so that they did not have to explain our acquaintance.

32. The experience of one of my patients really illustrates the wider impact of the stigma associated with Haemophilia and its link to HIV and AIDS. GRO-A lived in a small pit village, where everyone knows everyone. His family were known to have haemophilia. In the late 1980’s the stigma of association alone, began to affect his family’s life in the village. His children stopped being invited to classmate’s birthday parties and so on. He moved his family to get away from this. Later his wife died. He himself who had multiple health issues. He was left in an unfamiliar place, with no links to his community, no relatives nearby and no feeling of being at home.

33. Several my service users state they received no advice about living with HIV or HepC in the early days or they have no recollection of it if they were. I can recall an instance of patients reporting; they found out about their infection from their GP who assumed they knew. More than one patient had to ask for clarification from his consultant of his status when a doctor or nurse mentioned a detail that raised his concern. They had assumed that as it showed in the medical notes the patient himself knew of the infection. However, they had never been directly told.

34. My experience of working with men who are undergoing treatment for HepC are that it can have an utterly debilitating impact. The strong side effects of earlier HepC treatments were so powerfully negative that the treatment was stopped or not repeated if necessary, so was un-successful in clearing infection. For the most part the conversations I had about this were with predominantly married men with mortgages or rent to cover and families to provide for. People who could not afford to be on long-term sick leave. Living with Haemophilia has meant that work is often precarious at the best of times. The effects of HCV treatment made it so much worse. I have been told of work within an office job with a bucket next to them so they can be sick. Worries of running off the road whilst driving due to acute fatigue. Many deciding not to tell family members they are having treatment as their condition was secret. Whether they told their family or not, it was usually impossible to hide the effects such as mood swings, changes in personality and depression. Together with the physical side effects of looking ill and losing weight. It was reported to me by a gentleman that he had an emotional time during treatment as his friends and family believed he had cancer, was on chemotherapy treatment and was keeping it from them.

35. I carried out a very intensive piece of practical support work with a young man in his 30's and his wife during his treatment period. GRO-A had been infected with HepC when he was only a few weeks old. He really struggled with his mental health during treatment, mood swings and very low mood and lethargy. This put great strain on his relationship with his wife who was caring for their young children. He was unable to carry out his self-employed work due to it being very physical. I carried out numerous, regular home visits to help the family talk through their difficulties and find solutions. I signposted and referred to mental health services. Referred to community family services for mum and children. As well as securing all benefits entitled. At one point due to the low income and increase in heating bills as GRO-A was very cold all the time, I did an extensive internet search for charities that offered financial

support to patients. I was successful enough to secure a charity grant to pay the families gas Bill.

36. GRO-A reported that after 10 years plus post treatment, he still suffered mental health issues. His life was ruled by anxiety and depression directly linked to the HepC treatment. He was unable to work or even go out in his community without his wife. After a long period of building engagement and trust I was able to help GRO-A with a respite break for him and his wife to the countryside funded by Caxton Foundation.

37. Financial difficulties were common in infected/affected patients. Living with Haemophilia and infection/co-infection often had a huge impact on educational attainment. Qualifications are not always a reflection of ability. I saw cases were the impacts of being infected prevented those who may have otherwise attended and completed university, from taking that step. I have been told by more than one man I worked with; they had chosen a certain career path on the basis of their infection. Not wanting to commit to one that will challenge them or be unmanageable alongside managing their condition. When they were in a job, there was anxiety around colleagues finding out about their health conditions. The longer they were in one position, the more they would have to 'lie' about their life and avoid questions about their personal situation. Whether or not this would have happened or not the fear of potential stigmatising attitudes was enough to cause mental health issues.

38. I have heard the heart-breaking stories of a number, not one or two, who have deliberately denied themselves romantic relationships or a meaningful career as they have believed it not possible due to their infection. One man told me that he was told at a young age, by his doctor, that it was not possible for him to have a physical relationship with a woman. However misguided, this advice has stuck with him. He has never moved on from it and he has never had a romantic long-term relationship. He is now 57 years old.

39. Many patients have told me that they have been denied mortgages unless they were linked to a partner or relative. It would appear life insurance has been extremely problematic in the past and has restricted many infected people. The need for additional financial support would appear obvious. However, the welfare system was/is filled with so many obstacles that some patients would rather struggle financially than go through the process of claiming benefits. The questions asked are intrusive and, once again, there is that fear of disclosing your HIV or HCV status. Just like the GP surgery, the local benefits office is staffed by people from the local community. Advice is, there is no requirement to disclose their infection. However, it is asked what medication are prescribed, which could give away their HIV/HCV status.

40. I have worked with a number of cases where all benefits were in place. The individuals were also in receipt of the appropriate and entitled funds from Skipton and/or Macfarlane and more latterly EIBSS. The gentlemen were then contacted by DWP, interviewed under caution and accused of benefit fraud as they had not disclosed their income from the above-mentioned agencies. The money from these funds does not need to be disclosed to the welfare system and does not affect eligibility for benefits. Proof of this has had to be provided to the DWP before the investigation is stopped. This situation proved to be so traumatic that more than one refused to claim is benefit entitlement. The lack of understanding and appreciation for the impact of policy/procedure was devastating for some I worked with.

41. One of my most recently cases paints a picture of the devastating effects of being infected by contaminated blood. [redacted] has severe Haemophilia A. He was diagnosed with HIV when he was 18 and then HCV sometime later. He described the day he was told he had HIV vividly to me. Who he was with, the weather, what he wore, the smell in the room. His brother, also haemophiliac, died of AIDS. He is extremely bright and has multiple university degrees. He has never committed to one long term career as he worried, he would let people down if he died shortly after

taking up a job. He has gone through several different treatment regimens for both infections, including Interferon treatment for his HCV. The effects of this medication led to the end of a valued relationship as he wanted to free his partners from the horrendous impact of the treatment on him. He will say that he has been told all his life he only has a couple of years left to live. Until quite recently. He now understands that his HIV treatment is effective, and his viral load is undetectable. He has cleared HepC. He is now struggling with the fact he *IS NOT* going to die in two years. He has spent his whole adult life as if on the brink of death like his brother. He now has a completely blank canvas, and he had no idea what to do with it. He describes himself as a shadow of the man he was before his treatment for HCV. He is now struggling to face the prospect of a longer life than he expected to lead. It is unbelievable sad to see how devastating the impact of his infection has been. GRO-A is now receiving counselling.

42. While working with the children and their families even today, the historic impact of contaminated blood product has an ongoing legacy. I worked with a number of mothers who have lost their fathers, or other family members to AIDS as children themselves. This has had far reaching effects on them and how they feel about their own sons Haemophilia.

Section 5. Trusts and Schemes established to provide financial support

43. When I joined the team at Newcastle in 2011 extensive work had already been carried out to ensure that all relevant patients, they were able to contact, had been registered with MacFarland Trust and Skipton Foundation. The Caxton Foundation was just coming into being as I joined the team. I made sure I had a good knowledge of their aims, policies and criteria. Throughout my work I supported members to ensure they were receiving all payments they were entitled to and supported their applications for one off grants for financial hardship, home adaptations or respite breaks. I advocated and spoke on behalf of member to the agencies many many times. Men or families, known as

members to the agency, I worked with found the process frustrating, belittling and stressful.

44. Late 2019, early 2020 EIBSS took over from both Macfarlane Trust and Skipton/Caxton. EIBSS introduced a scheme known as The Special Category Mechanism. The application for this scheme, which provided ongoing payments for individuals infected with HepC from contaminated blood products, ask the applicant 'if they believe their Hep C or its treatment has led to ongoing mental health problems or fatigue. They can also add additional information to describe the extent of the impact and how long they have been experiencing symptoms'. This was an extremely difficult and challenging time in my career. The trauma this document caused the patients I worked with and ones I had never worked with before was unbelievable. Day after day for many months I supported the completion of SCM forms. As I opened my room door after ending an intense one to one session with one gentleman, another was waiting in the waiting room. The sessions usually lasting hours. This was not just support in completing an application. It required the applicant to look at the experiences of their life that had coursed them huge pain. Many emotionally broke down. My referral rate for therapeutic work quadrupled. Taking on board this level of increased work, and this level of trauma was incredibly difficult. I sort counselling for myself via occupational health services.

45. People who became applicants for SCM told me they found the process incredible intrusive, frustrating, worrying and stressful. Many stated to me that they would not claim at all if I had not supported them. It appeared no consideration to the impact of stigma and fear was shown to infected/affected individual or their family. GRO-A told me he had not told his adult stepchildren with whom he lived with, of his status. Proof of their income was required for his application. He made EIBSS aware of this situation, but they offered no help. It was very frustrating to me as a professional to see a scheme that was devised to help was so unhelpful.

46. GRO-A said this of EIBSS to me during a one to one appointment with me; “It’s just paperwork and criteria to them. To us, it’s our lives

Section 6. Effect on clinical staff

47. I cannot claim to have any knowledge of how the policies and practices of the Centre changed in response to the specific risks posed by HIV and hepatitis. Having begun my work at the Centre in 2011, I believe the risk to clinical staff was widely understood and these policies were already well-established when I took up the position.

48. I have never been formally trained on the risk to me. Knowledge of the conditions themselves and risk comes with experience. I would trust my colleagues to tell me if there were specific circumstances that would increase the risk to me relating to infection.

49. I have never been approached with a formal complaint about patient safety. An integral part of my job would be to listen to patients’ feelings towards the Centre and its staff. I have never had a case were a patient has wanted to lodge a formal complaint against a member of staff. Similarly, I have never felt the need to make such a complaint.

50. The work I have undertaken with infected people has had a huge impact on me. There would be something wrong with me if it did not have an impact. It is utterly heart-breaking. If I had not been self-aware and actively surrounded myself with supportive people, I could not have done the job. Professionally, it has made me more passionate in wanting to help. I feel it is very important for the social worker in this role to have support. This is why it is one of the key aims of HSWA. The work needs to continue.

51. At times it has been possible to forget the impact of my work had on me and my family. I have a very mild bleeding disorder myself. Not long after the public announcement of the Inquiry, I must have been talking about

it a lot at home and focussing on news reports. My son asked my husband if I was dying. You have to remember others often do not quite appreciate the extent of what you do and how much it affects you.

52. Many patients reported very positive memories of Peter Jones, historic consultant. It is the case now that a number who had this view, now doubt there historic explanations of what has happened to them and questioning what had happened to their own body in the past under the centres care. This has changed since reading their requested medical notes to inform the enquiry.

Section 7. Other Issues

53. In my interview today, in my mind's eye, I have sat with the faces of so many people I have worked with around the table with me. Some are still around and well, but many have passed away. There are so many people who have been so tragically affected. I will remember each of them.

54. In October 2020 I left my post at The Haemophilia Centre after almost ten years. This was for personal reasons. It has been a complete privilege to work with the people attending Newcastle Comprehensive care centre. I would like to thank each and every one of them for allowing me to get to know them.

Statement of Truth

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

Signed ___GRO-C___(signed Electronically)

Dated ___20/10/2022________________________