Witness Name: Juliet Swindells
Statement No.: WITN4123001
Exhibits: None
Dated: 25.2. 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JULIET SWINDELLS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13 August 2020.

I, Juliet Swindells, will say as follows: -

Section 1: Introduction

1. My name is Juliet Swindells and my home address is known to the Inquiry. My date of birth is GRO-C 1947. I am a professionally accredited social worker; at the time that I trained, the qualification was called a Certificate of Qualification in Social Work. It is the contemporary equivalent of a university degree in social work. In addition, I was a counsellor, registered and accredited by the British Association for Counselling and Psychotherapy (BACP). Finally, I also have an NVQ 4 in Management, that I obtained as part of a job that I recently held for an independent fostering agency. The structure of my written statement will follow the numbering of the questions in the above-mentioned Rule 9 request.

2. My work history, in chronological order, is as follows:

a. ***1971 – 1974***: Camden Social Services, Generic Social Worker. Working mainly with children and families.

b. ***1974 – 1975***: Buckinghamshire Social Services, Hospital based Social Worker. Also authorised as a Mental Health Welfare Officer.

c. ***1975 – 1984***: Birth of my three children; I did not work during this period.

d. ***1984 – 1986***: Kent Adult Education Service, Facilitator. Running a women's group for Ramsgate Probation Service.

e. **1986 – 1994**: Kent Social Services/Thanet Health Care Trust, Social Worker/Counsellor. Supporting patients and families of those with haemophilia and AIDS. Developed a specific service for supporting bereaved children and the families of those infected with HIV/AIDS via blood products.

f. ***1994 – 2002***: Self-employed, independent Social Worker. Providing counselling and training services to independent fostering agencies and schools.

g. ***2002 – 2008***: Futures For Children, Registered Manager. Managing a team of social workers and support staff, recruitment and training of foster carers, service development and planning.

h. ***2008 – present day***: Self-employed, independent Social Worker. Undertaking independent assessments and enquiries for a variety of fostering agencies, local councils. As part of my role I was a member of the National Steering group for Independent Fostering Agencies.

3. Where my employment history, above, states that I have undertaken 'independent enquiries', I have been contracted by a number of different agencies within the social work sector, in particular fostering and adoption agencies. This work includes undertaking independent assessments of prospective foster parents and adopters, evaluating potential foster

placements and reviewing such placements on behalf of fostering and adoption agencies.

4. When I took up the position that I held between 1986 and 1994, my primary employer was Kent Social Services. However, by the time that I left the role, the employer was Thanet Health Care Trust. At some point over the course of my employment, the organisation that officially employed me changed from the local authority to the health care trust.

5. The position that I held at Camden Social Services was much more general than my subsequent work. I was working here during the final part of my training and, at that time, we were encouraged to remain generic social workers, without particular areas of specialism. I, therefore, undertook the full range of responsibilities that come within the remit of social workers. It wasn't long before the benefit of social workers developing an area of expertise was recognised, allowing me to go on and work in the particular area of providing support to haemophiliacs and people with HIV/AIDS.

6. I was a member of BACP and as such was a registered and accredited practitioner, and I am registered with the British Association of Social Workers. Other than these bodies, I have not been a member of any committees, groups or societies relevant to the Inquiry's Terms of Reference.

7. I have not provided any evidence or been involved in any other inquiries, investigations, criminal or civil litigation in relation to Human Immunodeficiency Virus ("HIV") and/or hepatitis B Virus ("HBV") and/or Hepatitis C virus ("HCV") infections in blood and blood products.

Section 2: Your role as a Haemophilia Social Worker

8. Over the course of my employment with Kent Social Services/Thanet Health Care Trust, there was a shift in the attitude towards the role of social workers and what their primary purpose was. When I began my career, a central responsibility of ours was the provision of emotional support; we were expected to have a therapeutic relationship with our clients. However, today the role of the social worker is conceptualised as a functional one – we are

there to provide a service, not emotional support. However, this psychological and emotional support was an essential part of my role and I believe that this may be why the Trust took over the management of my position, as opposed to it being overseen by Kent Social Services, as it was initially. The position was based in the haemophilia centre at Margate Hospital and I was a staff member at the centre itself. However, I was not a haemophilia social worker and I did not have the same training that social workers who specialise in haemophilia care have. For example, I would not provide specific support and guidance regarding the management of haemophilia treatment itself there was a nurse to do this. Instead, I was specifically responsible for dealing with the counselling and support of haemophiliacs that had been infected with HIV/AIDS via blood products, initially at least.

9. As the HIV crisis grew, the service that the centre, and me in particular, provided to HIV positive haemophiliacs was extended to be available to any individual that was infected with HIV, regardless of the route of transmission. An HIV testing centre became a crucial element of the centre and was open to any member of the public that required an HIV test. Throughout my tenure at the centre, I worked closely with Dr Mark Winter, who was the centre's Director. I was also a colleague of Dr. David Lillicrap, who would step in for Dr Winter when the doctor was away. I will detail the exact responsibilities that I had in this position below, at paragraph 10.

10. The role was created as part of a direct response to the growing HIV crisis. It was a new position, formulated to specifically address the needs of those with haemophilia who were now testing positive to HIV. As previously stated, the remit of the role was subsequently extended to include providing support and counselling (as well as other services routinely offered by social workers) to all individuals that were HIV positive, not just haemophiliacs. The role was initially funded by Kent Social Services, before responsibility for it was handed over to Thanet Health Care Trust. There may have been a period of overlap, during which my position was jointly funded by both bodies, but I cannot specifically recall any more details regarding this.

11. I had a number of different responsibilities in my position at the Haemophilia Centre and I will summarise each of these individually. I will go into further detail on the advice, support and assistance that I provided in this role at paragraph 11.

    a. The provision of information and guidance to individuals infected with HIV/AIDS.

    b. Putting together packages of home support. This would be specifically focussed on the management of HIV/AIDS, rather than the treatment of haemophilia. It would include planning and arranging nursing and social services visits, carrying out home visits and the formulation of homecare plans.

    c. Providing counselling and advice, as well as mental health and emotional support, to HIV positive individuals.

    d. Looking after people who were terminally ill with HIV/AIDS. These were most often those that presented with the most need; it would involve end of life planning, bereavement counselling and psychological support.

    e. Providing bereavement counselling and mental health support to the parents and wider family of terminally ill children.

    f. Establishing, administering and overseeing the Centre's testing service; providing guidance and information to visitors before and after a test.

    g. Delivering talks and training to a wide variety of organisations, businesses and public bodies on topics such as 'Families and Bereavement' and 'HIV Education'. This was often undertaken at schools, hospitals in London or organisations such as the Women's Institute.

    h. Working closely with the Haemophilia Society to ensure that haemophiliacs with HIV/AIDS were provided with accurate and up to date advice.

12. One fundamental function of my role was the provision of advice and information to those infected with the virus, as well as to others, on the topic of HIV/AIDS. As stated previously, there was a drop-in HIV testing facility located at the centre, so I was often required to provide information and advice to individuals seeking a test. As very little was known about the virus, especially in the early years, I often found that a quick discussion with the patient could exclude the need for a test. People would come for a test as they believed they had been exposed to the virus by kissing or other non-penetrative sexual contact. They would often need information on safer sex practices or just reassurance that their sexual practices did not put them at risk. The information provided to HIV positive individuals could be health based, such as advice on the precautions necessary to prevent the spread of infection, or could include more general information on the support available to them, such as that from social services, healthcare bodies or the welfare system.

13. I was responsible for providing comprehensive information and guidance to the Centre's patients and was their first point of contact for any questions and concerns that they had about all aspects of their post-diagnosis life. The practical support that I provided was equally wide-ranging and would also include the family of HIV positive patients. As a number of our haemophiliac patients were children, or where children with terminally ill parents, I worked closely with parents to support the management of their child's healthcare needs and also the emotional needs of children facing bereavement and loss. I would often carry out home visits myself, providing care and support. The educational element of my role was also very important; I devised and delivered training, drafted literature and visited schools, hospitals and a wide variety of other places to educate and inform people on the risk, spread and management of HIV and AIDS.

14. Another crucial element of my role was the provision of counselling and psychological support to those infected with HIV/AIDS and members of their family. Patients would either be referred to me by the doctors working at the Centre, or they could request this kind of support from me directly. When

someone came into the Centre for an HIV test, I would provide counselling before and after the test was carried out. Pre-test counselling involved discussing risk factors and talking patients through the consequences of a positive test. If a test did come back positive, further counselling would be provided and I would register the new patient at the Centre, quickly followed by an appointment with the doctor. We tried to link the two as seamlessly as possible. I was also the person responsible for providing counselling and psychological support to all of the HIV positive patients being treated at the centre.

15. There was a big variation in the type of support needed. Of key importance was bereavement counselling – working with the families of those terminally ill with HIV and preparing them for the death of their loved ones. I developed a particular interest and specialism in this, setting up a service specifically geared towards the counselling of the families of HIV positive children. This was particularly crucial for the mothers of younger haemophiliacs. Many of the haemophiliac patients were on home treatment and this meant that their parents felt a sense of guilt when they became infected. Not only had they passed on the blood disorder genetically, but the treatment they had been administering to treat the disorder had now infected them with this deadly virus. Of course, I would also provide counselling and emotional support to patients themselves, helping them to come to terms with their illness and counselling them during their time at the centre. A lot of patients would be in denial about their HIV status and prognosis and would require counselling to accept the reality of their condition.

16. Many of our patients were non-haemophiliac homosexual men, who had often not discussed their sexuality with their family and friends. Some of these were even married with children. I would provide support to such individuals that focussed on how to disclose their HIV status to their relatives; counselling them on discussing their sexuality and providing continued emotional support as they broke the news to their partners, parents and friends. All of our patients would be going through great crises in their lives and we were there to support them. No referrals were made to external counselling bodies as far

as I can remember; I myself would provide all patients and their relatives with this type of support. I would only make further mental health referrals if the patient had a psychiatric illness. At some point, there was a discussion about having a psychiatrist attached to the unit, but this never materialised – I can't remember why though.

17. As stated above, I developed a specific service for supporting bereaved children and their families. A lot of my time was spent further developing the services that we could offer to children. Adult bereavement services were well established when I joined the Centre, but I devised specific provisions for children facing bereavement and terminal illness. We were initially at a loss as to how to deal with the number of children going through horrendously traumatic experiences. Dealing with bereavement is one thing, but counselling a child that is terminally ill or who has terminally ill parents requires a very different set of skills. St Christopher's Hospice in South London was leading the way in bereavement services at this time. Through research, I was finding a wealth of useful resources, such as workbooks by an American child psychologist, therapeutic games and ways of approaching difficult conversations. Drawing on these, we developed our own methods of working through trauma and bereavement.

18. This type of counselling would extend to all the family members of those infected. The service was not just focussed on the bereavement aspect, but also provided elements of support specific to HIV/AIDS. For example, we would give guidance to parents on how to explain the changing treatment that would be provided to their children. One minute, their child would just be getting their usual home treatment. The next, they are going into hospital again for treatment, with everyone wearing gloves and taking extreme precautions. It isn't easy to explain that to a child under the age of ten. We would be there to advise parents on how to discuss these issues. Finally, we would also carry out a lot of direct support arising from the consequences of HIV infection. For example, we would initiate the tricky conversation that needed to be had with a young patient's school. This was very difficult to get right and the risk of extreme stigma meant that it needed to be approached

sensitively from the very beginning. We developed a protocol whereby with agreement from the parents, a limited number of people at the school, usually just one or two, would be informed of the child's HIV status and educated on the consequences. We had to remain child-focussed at all times and consistently ask ourselves, 'what is best for this child?'

19. I have attended various training courses on bereavement and loss over the course of my career, but none of the courses were specifically related to HIV and AIDS. They were all more broadly related to counselling those who have lost loved ones or are affected by terminal illness.

20. Variant Creutzfeldt-Jakob disease (vCJD) was not something that my role was in any way concerned with.

21. On the whole, I do believe that the social work support and counselling provided at the centre was adequate for the needs of our patients and their families. Of course, there could always be more done to help individuals going through such horrific life experiences, but there is also always a limit to what can be done to minimise their trauma. Everyone employed by the Centre worked very hard and did everything possible to provide comprehensive care to the patients. I think the very existence of my role shows that there was support available to those infected with HIV via blood products, at the Margate centre at least. We were well linked up with other social services provisions and also the Haemophilia Society with whom I was in regular contact. One of their support workers would regularly visit the centre. The Centre was part of a much wider stream of support, encompassing healthcare, social services, education and welfare. We did our best to meet needs as they came along and I believe that we were fairly successful at doing so.

22. The Rule 9 request asks whether I worked with Dr Harold Sterndale. Whilst the name does ring a bell somewhere in the back of my mind, I did not work with him directly and cannot provide any comment on his practices. I did, however, work closely with Dr Mark Winter, so I will respond to question 17 with regards to Dr Winter instead. Mark Winter was a very good doctor; caring and sympathetic, with an intimate understanding of the tremendous impact

HIV had on the lives of his patients. He genuinely valued my role and saw it as an essential part of the package of care that we were providing. He was ultimately responsible for the practices employed at the centre, in collaboration with members of the local 'AIDS and HIV Steering Group'. I have nothing negative to say about any of these practices and believe that Dr Winter served as a highly effective leader for the centre. I vaguely recall him telling me that, under his predecessor, some of the haemophiliacs under the centre's care were informed of the HIV infection by post. I cannot be certain this recollection is accurate. However, throughout the period we worked together, Dr Winter and I always took responsibility for informing patients of their HIV status in person.

Section 3: Impact on people infected and affected

23. There is no generalised impact that can be said to be felt across the board amongst HIV/AIDS positive patients. Everybody deals with the impact of their diagnosis differently; finding their own way of coming to terms with their illness and handling the consequences of the infection. That said, for the vast majority, an acute sense of devastation follows their HIV diagnosis. I noticed that this is particularly acute when a patient's physical health begins to deteriorate. The observable breakdown in their physical state is usually accompanied by the realisation that very little can be done to treat the illness. Many of our patients found that denial was an effective way of coping with their infection. Until they are ready to face their mortality, you have to accept that. My job was to help people facing death and it was not my place to deny people any comfort they found for themselves, even if this was in denying the reality of their condition.

24. In addition to the above, there was a huge variety of incredibly onerous and wide-ranging impacts on HIV positive haemophiliacs and their families:

    a. Part of my role was to maximise the quality of life of HIV positive haemophiliacs. The life-limiting nature of the virus meant that it was important to ensure that the time left for infected individuals was as enjoyable as possible, with minimal pain and suffering. However, the inevitable impact on their mental state was often very difficult to manage and the emotional support and counselling was intended to improve quality of life by providing comfort and consolation.

b. The impact on affected people was also tremendous, as was the impact on their relationship with the infected individual. I remember, whilst on a women's retreat with the Haemophilia Society, speaking to a woman whose haemophiliac son was infected with HIV via his treatment. She told me that they would go out for the day, having lots of fun, and then this black cloud would appear and she would remember that she could never truly enjoy life again. This was the typical experience of family members, particularly for the parents of infected children. It just casts a pall over everything. There was so much being taken away from them. Older haemophiliacs also felt a monumental impact on their relationships, of course. For homosexual men there was often an extreme feeling of guilt amongst those that couldn't bear to tell their family, but they risked rejection by their loved ones if they did decide to inform them. Some did have sexual partners and we made sure that they were aware of the risk of transmission. I can remember one haemophiliac who did infect his wife with HIV. One or two went on to have children, who, fortunately, were not themselves infected.

c. Besides the obvious health impacts, many societal consequences prevented infected people from living their life fully as a member of society. A primary example of such difficulties is the barriers to obtaining financial products such as mortgages. It became a routine practice of ours, as part of the pre-test counselling, to ask whether people were planning on buying property or getting a mortgage, which would require life insurance. If they did, we would advise them to do so before getting tested and then return to be tested afterwards. Often, simply having had a test was enough to exclude someone from obtaining life insurance for a mortgage, regardless of the result. We at the centre did everything we possibly could to avoid these impacts on our patients and, failing this, supported them to overcome the issues they then faced.

d. In terms of education, I can't recall a specific example of a child's schooling being directly affected, other than the obvious health and psychological impacts. By and large, the reception from schools was supportive and they tried their best to create a caring and supportive environment for infected children. There was, however, a huge impact on adult patients' ability to find employment and earn a living. They would face a substantial dilemma over whether to inform their employers and this could cause a lot of difficulties with both guilt and isolation.

e. Stigma was, of course, an issue that we dealt with regularly. We would often talk to family members who were misinformed about the risk to themselves and were rejecting their infected relative on this basis. There was so much misunderstanding and misinformation, particularly in the earlier years of the AIDS crisis, that people were completely terrified of it and saw it as a plague that they would die from if they continued to associate with infected people. A routine part of our role was discussing the reality of the virus with people close to an infected individual and fighting the stigma that resulted from societal attitudes towards HIV/AIDS. Most of our patients did find at least one person already in their lives that they could discuss their infection with. We actively encouraged people to identify those in their lives that would be most sympathetic to their illness, slowly test the water with them and gradually grow their support circle. I found that people were generally pretty good at distinguishing between those they could trust and those that would stigmatise them.

f. We would refer all of our patients to any available financial support schemes and I would help them to complete any necessary application forms if the need arose. However, there were very few schemes set up specifically for those infected with HIV/AIDS at the time that I worked for the centre and it did not form a substantial part of my job.

g. Similarly, I had no specific training in the wider welfare system and helping them complete their applications for benefits was not directly within the remit of my role. However, we did ensure that they were made aware of any financial entitlements they were eligible for and I would have helped them complete a form if they asked. I cannot comment in any more detail if there were particular difficulties in obtaining benefits faced by HIV positive individuals.

Section 4: Trusts and Schemes established to provide financial support

25. As detailed at paragraph 19 (f) above, I have very little experience of the various trusts and schemes that were set up to compensate those infected via blood or blood products. I can't remember which schemes were set up at that point, but we would simply refer them to the relevant service and maybe assist them with the completion of an application. As stated earlier we were in regular contact with the Haemophilia Society so kept up to date with any relevant schemes, and this information would be passed on, therefore, I have nothing more to add with regards to the administration or practices of such trusts and schemes.

26. As above, paragraph 20.

27. As above, paragraph 20.

28. As above, paragraph 20.

Section 5: Effect on clinical staff

29. By the time I had taken up my position at the centre, most of the practices designed to protect clinical staff from the risk of infection were well established. In fact, I cannot recall any changes in the policies that were employed in this regard. It was known that the setting in which I was working posed a very low risk of transmission to members of staff and, by then, universal hygiene measures were in place and remained so for the duration of my tenure. When members of clinical staff were required to handle blood or blood products, they used gloves and all other necessary pieces of protective equipment.

30. I do not recall the protocol for reporting concerns or complaints about staff or patient safety, but this was not something that was a big issue at the centre.

Most of the patients, I believe, felt very well cared for and had a positive relationship with Dr Winter and all other members of staff, including myself. Over the course of my eight-year employment at the centre, I never felt the need to report any concerns or complaints of my own.

31. My experience of working at the Centre certainly had a considerable impact on me. It sounds strange, but I liked being involved in the challenges it presented and the difference we made in people's lives made the challenging aspects of the job worthwhile. That said, I do think that the pressure of being on the front-line of the fight against HIV/AIDS was at times overwhelming and that it took a while before I was able to take a step back and realise the true impact it was having on me. I was so involved every single day that I essentially didn't come up for air for about eight years. When I first started the job, under the management of Kent Social Services, I was able to go to senior social workers and managers for support. However, when my role moved to be under the remit of Thanet Healthcare Trust, this support ceased. There was a discussion about providing me with continued counselling and support. After a while in the job, Dr Winter recognised that we both needed some external support to cope with the trauma of our work. He arranged funding for us both to have monthly appointments at the Dover Counselling Centre, where we were counselled by Janet Johnson. The funding for this came from the hospital's AIDS budget and it was just Dr Winter and I that were provided with access to this service. I found it to be hugely beneficial and helped me to deal with the pressure that I was under.

32. I don't think the nature of my work was in any way detrimental to my family and personal life, certainly not in any specific sense, but the general impact of such a high-pressure job was apparent. I was exhausted a lot of the time and I got to the point where I would automatically decline any invitation to social events and gatherings etc. Initially I was anxious I might pose an infection risk to my children, but my fears were quickly allayed by training around the virus and how it is transmitted. Towards the end of my placement, my specialism in child bereavement meant that my remit was extended to include the families of any children in the intensive care unit of the Margate Hospital. There was

an incident involving the daughter of a hospital staff member. She died whilst in intensive care and the whole thing was handled badly. Dr Winter asked me to speak to family and, from then on, I took on responsibility for counselling all parents that had lost a child at the hospital. You only get one chance to get it right when someone dies in such tragic circumstances and I began to realise that this was the area I wanted to focus on. Eight years after I joined the centre, I made a conscious decision to leave the field of haemophilia and AIDS counselling and to widen the application of my expertise to support all parents and children that had suffered bereavement and loss.

Section 6: Other Issues

33. I worked closely with Dr Mark Winter for the whole period that I worked at the Centre and, therefore, had significant discussions and encounters with him on a regular basis. This means that I find it difficult to recall individual conversations that I had with him. However, there are two particular examples of discussions I had with Dr Winter that may be of interest to the Inquiry. The first, I have already mentioned; Dr Winter told me at some point that his predecessor was responsible for HIV positive haemophiliacs being informed of their diagnosis via the post. Secondly, I can remember having conversations with several senior colleagues, Dr Winter included, about the first treatment available to HIV sufferers – AZT. I can specifically remember Dr Winter emphasising the importance of informing our patients of the serious side effects of this treatment. Besides these two instances, I am unfortunately unable to recall the exact nature of significant discussions that I had with Dr Winter or other senior clinicians. It is over 25 years since I held this post.

34. There are a small number of additional points that I would like to draw to the Inquiry's attention; things that I believe may be relevant to the Terms of Reference, but do not fit specifically into the questions raised in the Rule 9 request:

    a. When I was employed by Kent Social Services, I was still technically within the Social Work Department and was able to draw upon the vast array of resources that were available there. This meant I could rely on the support of my colleagues for detailed information on benefits, such as attendance allowance, nursing support and other areas of social work. It also meant that there was a huge supply of literature that we could provide our patients with, containing all sorts of advice and guidance. In practice, I remained close to this unit when my role switched to being under the management of the Health Care Trust and so I was still able to draw upon these very helpful resources.

b. As far as I can recall, the blood samples that we took were tested for HIV at Margate Hospital and some of the records produced by the centre were also held there.

c. At the time that I worked for centre, there was very little treatment available to those suffering with HIV; a diagnosis of full-blown AIDS would usually mean that the patient would be dead within nine to twelve months. My time was mostly taken up with the care of such terminally ill patients. It was devastating for those living with haemophilia to receive a second blow like that and they needed a lot of psychological and emotional support.

d. There was no questionnaire employed in the testing centre. We would just rely on face to face conversations with people being tested, covering risk factors such as drug use and sexual activity.

e. I find it difficult to comment on the government's handling of the AIDS crisis and the infected blood scandal. I had a very enthusiastic group of people around me and we were so intent on easing the suffering of those infected that I don't think I ever stopped to think about who was to blame.

f. In the early years of my position at the centre, we established an AIDS helpline with the assistance of the hospital chaplain. This was manned by a wonderful team of volunteers, who took queries about the risk of infection from the public. As much as many people wanted to back away, a lot of people wanted to step forward and help out. There was a great willingness to offer help from ordinary people.

g. I myself was a member of the AIDS and HIV Steering Group that I have previously mentioned, as was the local Director of Public Health, the CEO of Margate Hospital and other healthcare professionals. The group was formed to make up for the lack of specific services for HIV/AIDS positive patients. Over time, the Steering Group grew to include members of other bodies that were set up to help people with the virus, as well as the hospital chaplain. It was a substantial committee in the end. One particularly notable organisation that was represented on the Group was the Thanet Association for the Terminally Ill, known as TATI. They really were a fantastic group; they provided a sort of 'hospice at home' service, giving end of life care for people within their homes. It was really inspiring to work with people so dedicated to helping others and a fantastic example of how a community can tackle a serious issue locally.

h. Organisations such as London Lighthouse, among others, were vital in the education campaigns that I myself learnt from. They focussed on making the educational materials they produced accessible and well presented, so that anyone and everyone could understand the information being conveyed. We learnt a lot from this; the ability to provide clear information was vital to dispel a lot of the confusion that surrounded HIV and AIDS. This misunderstanding even extended to health and nursing professionals. When organising home care packages, for example, it was fairly common in the early days that professionals wouldn't want to go into an infected person's home. As understanding of HIV developed over time and the education campaigns grew more accurate and wide-ranging, we did see a drop in the number of new infections.

i. Though I can't remember exactly, I have a rough idea of the numbers of patients we treated and supported at the centre. We had roughly 40 haemophiliacs, 33 of which were classified as severe. Four or five of these were under the age of sixteen, most were young adults and a few were from the older generations, a lot of whom had chronic joint damage. 26 of the 33 severe haemophiliacs we cared for were HIV positive and there were a small number of positive individuals in the moderate group.

There was roughly another 25 that were infected through unprotected sex, as well as a handful of drug users and one or two women from Central Africa. In total, therefore, we cared for about 50 HIV-positive people.

j. There is a possibility that some of my patients were co-infected with hepatitis C (or NANB, as it would have been known for a proportion of my time at the Centre) as well as HIV. However, this was not the focus of my job and I cannot recall specific instances of co-infection.

k. Something I learned over the course of my time at the Centre was the difficulties that arose from referring to those at risk of infection from anal intercourse as 'gay men'. It was far more complex than this and there were plenty of men who engaged in anal sex that did not consider themselves to be gay. We all needed to learn much more about people's sexuality and doing so helped us to understand the risk considerably.

l. A lot of the stigma that I encountered was only incidentally concerned with HIV/AIDS and would be more accurately characterised as homophobia. I would often encounter sentiments such as 'how can you treat the innocent victims as well as the guilty ones?' There were also some parents of haemophiliac boys that really resented the gay community and felt an anger towards them. I remember doing a talk on local radio with the mother of one of our young haemophiliacs. She had a lot of anger towards the gay community and saw them as the source of her son's infection. At the same time on the show there was a gay man, who approached the woman I was with, introduced himself and began chatting to her. I think it was the first time that she had actually seen the real-life, human side of gay people suffering with AIDS and had the opportunity to put a face to the gay community. It was a hugely healing moment for her, I think.

35. In 1992, I gave a talk to the biannual conference of the World Federation of Haemophilia (WFH) in Athens. Dr Winter was closely involved in the WFH and he put forward a paper that I had written on helping children and their families manage the psychological and emotional impact of bereavement. Mine was

selected for the 1992 conference and Dr Winter, myself and a few others from the centre went along. The purpose of the conference was to share knowledge and developments across disciplines. It was extremely useful for everyone in attendance. The audience I presented to was comprised of all sorts of people – clinicians, nurses, social workers, haemophiliac patients, researchers, biologists and so on.

36. My most notable publication is a paper, similar to that presented at the WHF conference, that was published in 1993 as part of a collection of papers called 'HIV Infection and Children in Need'. My contribution was titled 'Helping Children and Families to Cope with Bereavement.'

Statement of Truth

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

Signed GRO-C

Dated 23rd February 2021