Witness Name: Mary Dykes
Statement No.: WITN3619001
Exhibits: WITN3619002 - 005
Dated:

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MARY DYKES

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 9 September 2019.

I, Mary Dykes, will say as follows: -

Section 1. Introduction

1. My name is Mary Dykes. My date of birth is GRO-C 1948 and my address is known to the Inquiry.

2. I intend to speak from memory about my work as a Social Worker to the Haemophilia Unit of the University Hospital of Wales in Cardiff (UHW); patients' lives before and after the introduction of concentrates; and my role in the establishment and growth of 'The Birchgrove Group'.

3. At this point, I do not feel that I require legal representation and I am happy to provide a written statement to the Inquiry.

Qualifications and employment history

4. Following a degree in sociology 1967-70, I was employed as a social work assistant by the Hospital Management Committee for St Ann's Hospital, in the London Borough of Haringey.

5. Following the Seebohm Report in 1973, medical social workers were transferred to the Social Services Department of Local Authorities, nationally.

6. From 1973 to 1974, I was seconded to doa postgraduate qualifying course at the London School of Economics. I completed it in 1974with a Diploma in Applied Social Work Studies.

7. From 1974 to 1977, I worked as a Social Worker based at the UHW in Cardiff. I worked in several units, including the Haemophilia Reference Centre covering adults and children.

8. From 1978 to 1986 I worked in various roles within the health setting, but not directly with haemophilia patients.

9. From January 1987 to October 1992, I was a part time Senior Social Worker exclusivelyon the Haemophilia Reference Centre. The role was funded by the Welsh Office to offer support to those infected by HIV, their families and to the worried-well attending the centre.

10. In October 1992 I took up full time employment when I became a single parent. I worked for South Glamorgan County Council Social Services Department as a Senior Social Work Practitioner in community-based teams for the physically disabled.

11. In 1996, in the same middle management gradeof SeniorSocial Work Practitioner, I returned to the UHW.

12. In 2003, I took an Advanced Award in Social Work and an MSc in the Management of Human Services, both from the University of Wales College, Newport.

13. In 2006 I moved into County Hall in a Health Liaison role.

14. I retired in 2011.

Membership of committees or groups

15. Since 1970, I have been a member of the British Association of Social Workers (BASW).

16. I joined the BASW Special Interest Group for Haemophilia and Haemostatic Disorders in 1974. The Special Interest Group covered patients with haemophilia (deficient in factor 8), patients with Christmas disease (deficient in factor 9), and patients with von Willebrand disease. This group was UK-wide and we attended the Haemophilia Centre Directors' Meetings at their invitation. I was actively involved in the group between 1974 and 1977, and then again between 1987 and 1992.

17. I was also a member of the local group of the Haemophilia Society (now known as 'Haemophilia Wales').

18. I facilitated the setting up of what became known as 'The Birchgrove Group' in 1987 and remained actively involved with it until I left the role in 1992. I remained interested in the group's work until I retired in 2011. Please see the attached transcript of my presentation for The Birchgrove Group Woodland Grove opening on 23 May 2004, which sets out what this role entailed (**ExhibitWITN3619002**).

Evidence to other inquiries, investigations, criminal or civil litigation

19. I have had no involvement in other inquiries, investigations, criminal or civil litigation in relation to Human Immunodeficiency Virus ("HIV"), hepatitis B virus ('HBV') or hepatitis C virus ('HCV') infections in blood and blood products.

Section 2: My role as a Haemophilia Social Worker

20. The social work role was dependent on what the patient needed and requested help with, taking into account any relevant legal framework and concerns voiced by other professionals in the multidisciplinary team to provide comprehensive care for the patients and their families. I provided practical

help (for example by assisting patients to claim state benefits), financial help (for example by finding assistance from charitable sources) and emotional help. The role also involved facilitating referrals to, or liaising with, other professionals within the Haemophilia Reference Centre, schools, psychologists, psychiatry, employment services (particularly the Disablement Resettlement Officers (DRO)), counselling, occupational therapy, housing services, and any other service that might improve the quality of life for those experiencing difficulties or disability as a result of their medical condition.

21. When I was at the UHW in Cardiff from 1974 to 1977, there were approximately 350 registered patients in the whole of Wales not counting those living in the north Wales coastal towns who were served by Regional Hospitals in NW England. If a person with haemophilia needed comprehensive care, they would go to a Reference Centre in the few Regional Hospitals spread over the UK rather than to a local haematology centre in a general hospital. We had one patient from North Wales who chose to stay registered with the Cardiff Centre.

22. With the introduction of concentrates in the 1970s, my role when I joined the unit was to support patients - both adults and children - to go onto 'home treatment'. I am not sure when concentrates became available, however by the time I joined the team at UHW in 1974they were alreadybeginning to be introduced to most patients.

23. Home treatment meant patients could give themselves concentrates the moment they felt a bleed. Parents learned to give the intravenous injections to their children and became expert at it, thus reducing the fear of needles that some children had suffered from while receiving cryoprecipitate. I remember seeing one dose of cryoprecipitate being administered to a child. It was a shock to see the volume of cryoprecipitate in the syringe that had to be injected intravenously into a small child who, like many other children, had a fear of needles. The concentrates (which mostly came from America but in small amounts from Britain - too small to meet all UK patients' needs) came in small glass containers and were ready for use. They just had to be stored in a

refrigerator. The introduction of concentrates was a major advance, and meant that patients were able to lead a more normal, pain-free life.

24. The introduction of concentrates and home treatment also meant that some of my earliest work at UHW was helping families to find funding for fridges, so that they could keep the concentrates at home. I provided further assistance by approaching the national Haemophilia Society for pagers; there were no mobile phones then.Prior to the introduction of concentrates, patients with severe haemophilia had not gone to school. It was therefore important that schools could easily contact a parent if they were worried that a child had suffered a bleed while in their care. I met with parents who were learning how to give intravenous injections, and lent a vein for them to practise on. Many patients previously had to travel miles to the hospital in order to get treatment, and as many people did not have cars back then, home treatment reduced this burden. Concentrates transformed haemophilia from being a life limiting and life shortening condition, and was the first very effective treatment available world-wide in countries that could afford to use it. It was lifesaving and life enhancing, and reduced the acute pain experienced by many.

My recollection of Professor Arthur Bloom

25. I first met Professor Bloom in 1974 when I joined the UHW team. Professor Bloom had just brought the Haemophilia Reference Centreup to the newly opened UHW (officially opened in 1971)from Cardiff Royal Infirmary. UHW must have opened up gradually over a period of time, because I remember that when I first started working on the unit, Professor Bloom would travel between the Infirmary and the UHW to treat patients who still arrived there.

26. Professor Bloom worked in an open multidisciplinary way with all the staff at the Haemophilia Reference Centreand with the members of the local Haemophilia Society. When I first started working at UHW, I really did not know much about haemophilia, so Professor Bloom encouraged me to attend a Haemophilia Society meeting (of which I believe he was a member) where I met many of his patients and their families. Further, in 1976, Professor Bloom asked several of us working in the unit to speak to the Welsh Paediatric

Society (jointly with a Haemophilia Reference CentreSister), about children with haemophilia and the role of the Social Worker in the care of young people with haemophilia.

27. Professor Bloom was fatherly and holistic in his care for patients. He ensured that his patients had the best possible treatment, for example by running a regular joint clinic with an orthopaedic specialist to protect joints damaged by internal bleeding. I remember learning from Professor Bloom that delay in treatmentcould result in damage to jointsandconsequently permanent disability. Professor Bloom had been in contact with local ambulance services so that patients could be brought directly to the Haemophilia Reference Centreand avoid long and painful delays while GPs organised transport. There was also a specialist service run by a dentist who was aware of all the problems haemophilia patients haveand based in the Dental Hospital in UHW for patients whose clotting factors were so low that they needed special cover while they had dental work done. Professor Bloom was always happy to write supporting letters when I explained a need. Later in the 1980s, when The Birchgrove Group needed financial support, he suggested that I wrote to the British drug company that made concentrates for help. This they were happy to do- I think that the drug company was devastated that their concentrates ended up giving patients viral problems.

28. The haemophilia patientswere like a band of brothers; the older ones looked after the younger patients and they were a very cohesive group. I remember that they would tell me about the days before treatment existed at all, or some of the older and less effective treatments, like blood transfusions, DDAVP and snake venom. Life was boring for the patients, and because many of them lived very far away, they could not just go home and pop back the next day for more treatment. Instead, they would have treatment and then just wait around on the ward for their next treatment. Professor Bloom allowed them to go off the ward for a break but if they were not back on time he would go and fetch them. I truly believe that if someone came into the ward needing him in the middle of the night, Professor Bloom would have wanted the ward to call him at home and let him know. Professor Bloom was someone who was really

good to work with, and cared deeply about all his patients.He had known many all their lives.

29. In terms of Professor Bloom's policies and practices, he took a needs-based approach. For example, in the 1980s I remember asking him whether I ought to put my sons on fluoride medication to protect their teeth and he said that he did not really agree with taking anything that was not essential. His ethos, I think, was that the minimum amount of intervention was the best thing. He would do everything he could to save lives and he was a good doctor in terms of his Hippocratic oath.

30. I am guessing that at some point before 1985 when a blood test for HIV was introduced, Professor Bloom and other consultants around the world became concerned that, as HIV (back then it was called HTLV-III) was causing sickness in the gay community in California and amongst injecting drug users, it may be transmitted through blood and bodily fluids and thus blood products. The invention of a test certainly could not have happened overnight. I am certain it was for this reason that Professor Bloomkept thelimited supplies of British concentrates for young children who had not been treated with concentrates; he was taking a calculated guess that the British product was safer than the imported product. In Britain, no one is paid when they give blood; it is a gift relationship. However, in America it is bought and sold in a commercial relationship, and it was therefore felt that this might increase the risks of infection as vulnerable people in need of money were giving blood, and by doing so could infect whole batches of concentrate. I understood that 22,000 pints were pooled to produce a batch of concentrate and just 1 infected pint would contaminate the whole of that batch unbeknown to the manufacturers. Sadly, using British products didn't protect all children, as we now know.

31. The genetic nature of Haemophilia and the Christmas disease (deficiency of blood-clotting factor 9) meant that blood samples were routinely stored for future genetic counselling purposes, so that descendants could be told what the risk of passing on the gene was. It also meant that once the test for HIV

was available, Professor Bloom was able to test samples of stored blood and discover when his patients had converted from being HIV negative to HIV positive. The earliest case of one of our patients becoming HIV positive (of which I am aware) was 1978. I remember being shocked because it meant that by the time the blood was tested in 1985 the patient had already lived with the virus for 7 years. At that time we were treating a lot of AIDS-related infections, and I guess they were testing these stored samples because they were concerned as to whether patients who had been HIV positive for longer were more vulnerable to AIDS-related infections and therefore in need of closer monitoring.

32. One day at the UHW, Professor Bloom and I were talking about work. He was stressed and said that patients sometimes misunderstood the medical advice he was giving them. For example, he had been counselling one man about HIV and the risks to his partner, and the man's response was that it would not be a problem because his wife had been sterilised. Professor Bloom immediately realised that the man had misunderstood what he was saying about the risk of bodily fluids. He emphasized the need to listen very carefully to the patient to ensure that they had understood any advice given to them, and said that if I felt they had misunderstood any aspect of this advice, I should urge them to go and speak to him. I think that not taking things on board when you are shocked is a recognised issue in medicine, because sometimes people get the wrong end of the stick or jump to conclusions- when you are shocked or frightened you don't always listen as well as you usually do.

33. I was not present for the counselling of people being informed of their HIV status because that had happened in 1985 before I returned to the unit. The only time that I was present was in the late 1980s, when a partner of a haemophilia patient with HIV was told that they too had contracted the virus. I think that this was the only partner we had who was infected with HIV. The implications of how to share such information has informed current practice.

34. The Inquiry needs to hear about when recombinant treatment was developed. This was manufactured in a laboratory without the use of human blood. I think that guinea pig cells were used instead, because I remember Professor Bloomsaying this at a Haemophilia Society meeting, and a few patients werelaughing and saying 'We are going to turn into guinea pigs!' This was a huge advance because omitting human blood meant that there was no risk of human viruses being transmitted. Recombinant factor was available in small amounts before I left in 1992, but I don't know exactly when it was first introduced. As before, Professor Bloomtried to protect the children by keeping the small amounts that were available of recombinant factors for those that had not been previously treated with concentrates.

35. In some ways it is hard to have a true perspective on the issues without understanding how limited the treatments for haemophilia were before concentrates came along. Men and boys with the severest form of haemophilia had none or only 1%-2% of normal clotting factors 8 or 9, and could bleed spontaneously without any apparent reason - turning over in bed might be enough. They spent long weeks in hospital in pain, being treated with snake venom or something called DDAVP, or cryoprecipitate - none of which came in a form that could be given quickly or at home. One man had grown up high in a mining valley and rather than see his son suffer acute pain his dad would carry him up the mountain to dangle an ankle joint in the icy mountain stream to numb the acute pain and hope it would stem the bleeding.

36. Professor Bloom was so devastated by the tragedy that I believe it precipitated his untimely death. I feel that Professor Bloomfelt responsible, even though he was just in charge theHaemophilia Reference Centreand what happened was not anyone's fault. Nobody knew that three viruses (HIV, HCV, vCJD) would appear out of nowhere- they were new to the world, not just the UK. He was devastated because his patients had become like his colleagues, and he had known and cared for many of them all their lives. He was invited to The Birchgrove Group meetings and did attend one. While he was glad the meetings offered the emotional, self-help support the men needed and always did what he could to support the group's aims, he did not attend another one

because he found it so painful. He did, however, come to a few of the social events.

37. I keep mulling things over, especially after hearing that Cardiff Haemophilia Reference Centrestaff had received abusive phone calls since the recent adverse publicity. It resulted in the removal of Professor Bloom's name and bust to ensure staff safety.This was a huge shock and is so sad. I think that the Cardiff members of The Birchgrove Group would have been upset that his name and bust had to be taken down, because it was their idea and they had fundraised for it after Professor Bloom's death in 1992.

38. This whole thing has been painful and I am sure it is based on amisunderstanding.I recollect that the men of The Birchgrove Group never blamed Professor Bloomin any way – they knew that it was nobody's fault. I always thought that theywere asking for acknowledgement, not someone to blame. They never directed any of their anger at Professor Bloom or any staff in the Haemophilia Reference Centre.

Part time Senior Social Worker at the UWH Haemophilia Reference Centre (1987)

39. I do not know exactly how my role as Senior Social Worker came to be created or how the funding by the Welsh Office was secured. I have no doubt Professor Bloom would have been one of the negotiators. There was always some service offered to the Haemophilia Reference Centre on a part-time basis, as shown by my role in 1974 to 1977 which was funded by South Glamorgan Local Authority.

40. In the part time Social Worker role I undertook from 1987, I was not required to give any account of myself to anyone in the Welsh Office, but Professor Bloom may have liaised in this respect. When I joined, there was already another part time Social Worker providing a service to the Haemophilia Reference Centre, whose role was still funded by the Local Authority. Together with my post, our roles made up one full time post.

41. We were very busy at the Haemophilia Reference Centre, so when my colleague moved on to Child Guidance Services (I think that was sometime in late 1987) my part time hours were totally insufficient and a further part time post was established. The Welsh Office, at the request of Professor Bloom, funded this. The new part time Social Worker arrived in September 1988 and we formed one full time post. We tended to split the list of patients alphabetically. Despite this, I still saw many of my colleague's patients because they already knew me and would wait to see me. Many of my responsibilities were the same as in 1974, but the biggest difference was that I facilitated the establishment of The Birchgrove Group in 1987.

Numbers and role of Haemophilia Social Workers across the UK

42. In terms of the number and role of Haemophilia Social Workers across the UK and how this developed over time, I don't know if anyone could answer this question- I cannot. It would be necessary to contact each individual Haemophilia Reference Centre.

Counselling and/or psychological support

43. The men of The Birchgrove Group did not want counselling and I think they would have been horrified if I had suggested that. Professional psychological counselling can be quite challenging and I think they felt that they had experienced enough challenges in their life already. Instead, they wanted to deal with their needs by being part of a self-help group with others in the same position.

44. Professor Bloom secured the support of a Consultant Psychiatrist to offer some hours a week to the patients of theHaemophilia Reference Centre. This psychiatrist and other professionals were invited to The Birchgrove Group Meetings when this was requested by the group members. For example, we had a GP come to discuss how he looked after his immune system when life was very stressful. We also had a Professor of Medicine at UHW come to talk, who said that his approach to medical counselling had changed from the paternal style to a more collaborative approach with patients, and that this was one of the few positives in the global challenge of HIV.

45. We had an early member of the MacFarlane Trust Committee attend a Birchgrove Group meeting, who struggled with the anger of the members. These feelings of anger arose out of their predicament and the idea of having to ask for help from the Trust. It felt humiliating and as though they were being doled out charity. It made them feel uncomfortable knowing that they had to ask for the money and that there was a possibility of their applications being refused. Although they may have targeted some of their anger towards the gay community in California in the beginning, this was only because they thought that this was where AIDS had started. However, their anger subsided and they soon came to view those men as victims too. They invited staff from the Sexual Health Clinic in the Cardiff Royal Infirmary to some Birchgrove Group meetings. These staff members were well regarded, as were some from the Cardiff AIDS Helpline and other related voluntary groups.

46. My colleague, the other part time Social Worker (who has now passed away), set up a parents and partners group alongside The Birchgrove Group. The two groups had social events together, for example summer barbeques. Later this second group included the bereaved. If the wives, partners or family members of infected patients wanted professional counselling or complementary therapies, such as reflexology, this would be something we could facilitate. Often these were funded by the MacFarlane Trust.

47. Professor Bloom also found funding for myself and my colleague to have some individual counselling about how the caseload was impacting on us as individuals because it was such a weighty subject. The Health Authority staff were always treated like they could and should cope with everything – nowadays first responders and paramedics get help with traumatic events, but back then it was not a known thing for Health Authority staff to ask for help. Professor Bloom cared for his staff.

48. Currently I know that there are two part time Social Workers on the unit funded by the Welsh Office. The current centre Director values social work support for

his patients and was so concerned about the depletion of Social Workers within the hospital that they have now been transferred to become employed under the terms and conditions of Cardiff Health Authority, so that their jobs cannot be taken away from them. Local Authorities are under enormous financial pressures. There are fewer patients with HIV now, and the remaining ones are on more successful treatment. I therefore suspect that the Social Workers on the unit are probably more involved in the other viruses and doing the usual job of supporting people with long-term conditions, or supporting children who are newly diagnosed with haemophilia. Aside from this, I have no other knowledge about the present position of counselling and/or psychological support to people who are infected or affected, because I am now retired.

Section 3: Impact on people infected and affected

Impact of the infection from blood products and treatment of the infection

49. The impact and the treatment of the infection are very hard to answer.

50. In 1987, I understood 55 of those registered at Cardiff Haemophilia Reference Centrehad had treatment with concentrates that, unbeknown to anyone, had been infected by HIV. Not all had the most severe level of haemophilia, though mostly this was the case. Some had been extremely unlucky and had road traffic accidents or needed surgery that required treatment cover with concentrates. It was the patients themselves that shared this information with me and I was not familiar with all 55, although eventually the majority of them joined The Birchgrove Group. Just a few chose not to be in touch.

51. In terms of the mental and physical effects of being infected with HIV through the use of blood products, I experienced this most while I worked with The Birchgrove Group. We met in a pub, and in the group was a space where the men could relax and be with others in the same boat. They could joke, but also share their fears and nightmares. I remember one man saying that he would have nightmares where he was trapped in a body bag and flames were melting the plastic over his face. The men had all sorts of nightmares and it

was totally understandable. That was the benefit of the group- they could share these things with each other, because they wouldn't tell their wives or partners so as to not upset them. When I saw the men individually they would also share these fears with me. I had one family - a couple- where the man found it difficult to talk to his wife about his experiences and problems, so I would go and do regular home visits once a month to help them communicate. I did not do anything magical, but having me there helped them to talk to each other. I saw them recently and they joked that I was to blame for them still being together.

52. All of the men had issues. A lot of the older men with haemophilia did not have wives or partners and felt that haemophilia had limited their life opportunities because they didn't have families, didn't go to school and were not literate due to the lack of an education, and couldn't work. For those who were married or who had partners, it was a constant worry that they might infect their partner. Some of the men who wanted children felt that they couldn't because of the risk of passing the infection on (and were therefore very interested when sperm washing became available). It just influenced every aspect of their lives.

53. In terms of treatment, when patients were put on AZT - an antiviral HIV treatment that had to be taken routinely throughout the day - I remember them finding this very tough because they were constantly reminded of their HIV status and it felt like they could not escape it. I think they managed to find electrical pillboxes that could be set to go off with a buzz at set times of the day so that they could take their tablet and then put it aside again.

<u>Ability to live life fully as a member of society</u>

54. Severe haemophiliacs and those with antibodies to treatment were unable to enjoy a full life in the way that others without the condition do. They needed to be careful where they went on holiday- near enough to a haemophilia treatment centre so that Professor Bloom could ensure they had access to care if needed. Many did not have careers unless they were educated to a level where could take up a relatively sedentary occupation. Many had missed schooling and spent long periods as in-patients in hospital, which limited their

opportunities. Ironically, the concentrates and home treatment had initially offered them freedom from these restrictions.

55. At the beginning the concentrates were so effective that, for a while, they were used to prevent bleeds before they occurred (prophylactically). Prophylactic treatment allowed haemophiliacs to do things that they were never are able to do before; although they were never encouraged to do things like contact sports, they could live life more fully. When Professor Bloom realised that there might be a risk of viral transmission, the idea of using the treatment prophylactically was discouraged and the patients were advised to only use it when they really needed it, like when they had a nasty bleed and risked great pain or permanent disability. When the HIV test was introduced in 1985 and people were informed of their HIV status, this freedom was ironically snatched away and other burdens were imposed.

The quality of life of people who were infected and affected

56. In the 1980s, the Haemophilia Society thought that if they started to include things about HIV in their magazine it would worry their readers. Instead, the magazine saw fit to keep information about HIV in a supplement to the regular magazine so that it could be easily discarded if not relevant to those receiving it. The men of The Birchgrove Group were distressed about this and it felt like an added insult that their own society was just slipping information about HIV through the back door. I do not think that this was intended to be hurtful, but rather there was no guidance on how to deal with the situation at the time- no one knew any better and what the best course of action was to follow. I do not know when the Haemophilia Society changed this practice and their name. Clearly Haemophilia Wales have addressed this concern.

57. The stigma of being HIV positive was the reason why most chose not to inform their family, friends, employers (if they were working) or associates. HIV was a problem for already stigmatised groups, namely drug users and gay men. The general public were frightened, and being shunned made things worse for infected individuals. Many of our patients who were infected with HIV felt

insulted, angry, affronted and distressed by the TV adverts with gravestones falling, icebergs looming and wording like 'Fatal Attraction' being used. Such was the fear that if they did tell loved ones they then had the added burden of needing to support them. It was a reason why The Birchgrove Group was born - a self-help group where members could relax, share nightmares but also indulge in black humour.

58. One of the blessings but sometimes challenges of Wales is that communities are very close knit. When the MacFarlane Trust was set up and individuals received grants, neighbours, would ask ‘Are you involved in this?’ or ‘Where did all that money come from?’ Receiving grants could be a bit of a double-edged sword.

59. I too was shunned socially at times. I remember people asking me what I did for a living and the moment I told them what my role was they no longer wanted to know me- they were scared they would catch AIDS if they sat next to me. I learnt not to say what I did in social settings, because it would turn into a long conversation about the risks of HIV. These experiences were just a little taster of how members of The Birchgrove Group would have constantly felt if they ever discussed their condition with anyone.

60. I remember hearing about someone who called the Cardiff AIDS Helpline to ask whether they could catch AIDS if they went ice-skating and there was a bit of dried blood on the inside of hired skates from a burst blister. I myself had been asked questions like ‘If the pub doesn’t clean their glasses enough or if I use a dishwasher with cutlery used by an infected person, can I get HIV?’ The fear was just rife in the public.

61. I am in touch with my colleague (and friend) who already covered the Cardiff Haemophilia Reference Centre on a part time basis when I returned to take up the first Welsh Office funded post in January 1987. She told me she felt sure the unit was transparent in its communications with patients. The outside world was a different matter. All staff were very aware of the interest, the fear and the stigma surrounding HIV. It made staff very careful about confidentiality in

all conversations beyond the unit. Awful things happened, such as funerals taking place without a body in the casket. Another example was in June 1991, when our hospital chaplain sent a memo about the managers of a crematorium in GRO-D who wanted the body of an AIDs patient to be disposed of in a rather insensitive way (**ExhibitsWITN3619003** and **WITN3619004**). People were very frightened. My former colleague was sent to St Mary's Hospital in Paddington for training in what the implications of HIV and its treatment were and she believes the nurses were too. At that time St Mary's led the way in terms of experience and knowledge

62. Incidents regarding funerals may have been the reason why Professor Bloom had discussions with the Cardiff Coroner, however I am not sure if HIV was a notifiable disease, in which case this would be the reason for the discussions. However between 1987 and 1988 there just happened to be no deaths at Cardiff Haemophilia Reference Centredue to HIV.

63. My first experience of HIV-related deaths was in 1989. I remember that from this point onwards, when HIV positive patients passed away I would take their widows/partner to the Coroners Court (situated in Cardiff Central Police Station) before accompanying them to the Registry Office to register the death. I think the purpose of this may have been to ensure that the full details and facts were known, but also because I would have known the family and the person who died, so helping the family with all the paperwork after the death was part of my ongoing support. I think families were worried about experiencing stigma or a negative reaction from the Registrars or Undertakers. We ended up working with a sympathetic undertaking service for some years before people felt safe to go to the local undertakers. Clearly 1991 was too soon to use local services in light of the incident at the crematorium in GRO-D in June 1991.

64. In terms of hepatitis C, up until 1992 I do not remember it being referred to as such- it was referred to as non-A non-B hepatitis. I think that hepatitis A is bacterial while hepatitis B is a viral infection of the liver that you can be vaccinated against. I assume that non-A non-B hepatitis was called this at that

time because there was no scientific blood test to say exactly what it was, only that it was neither hepatitis A nor hepatitis B. I think that the TV HIV adverts really increased the fear and stigma and there has not been the same level of advertising for hepatitis C- I don't know why. Perhaps like many aspects of these new viruses it was those with HIV who had to lead the way and suffer before lessons were learned about how things could be done better.

65. I remember Professor Bloom telling me that despite all of the advertising about HIV that was happening at the time, hepatitis, whether A, B or C, was many times more infectious than HIV. A lot of people would have had a blood transfusion during a time when there were possible risks of viral hepatitis transmission, but maybe the authorities realised that the HIV adverts of the icebergs and tombstones had just made the stigma so much worse, and decided not to repeat this for hepatitis. Hearing about the number of people infected with hepatitis during the Inquiry's Oral Hearings, and how the NHS has or has not dealt with it, is alarming.

Relationships, and private and family life

66. In terms of the impact on relationships, and private and family life, this is an impossible question to answer succinctly, because people had many different responsibilities and were in different stages of their lives. Some were married but then terrified of infecting their loved one, some were unmarried and felt they now never would be, some wanted a family and HIV risks would deny them this joy. It impacted every area of their lives.

Access to education, work, insurance and pension

67. For the severest haemophiliacs it must have been like going back to the 1950s and 1960s when access to education and employment for some was impossible. People with infections had to tread carefully when so much fear and misunderstanding about HIV existed. I remember an older patient telling me that he had had no schooling at all- in fact, this may have been common. I am not sure when home tuition became available in Local Education Areas. I only heard about one child who was rejected bya school. For those with a

career it was the stress of colleagues asking blatantly whether they were infected.

68. On the other hand, even after the tragedy of the transmitted viruses, the introduction of concentrates appeared to have extended the life of a few men who had a condition that denied them the chance to grow old. The eldest man I knew of in 1987 was 55 years old. Recently, men with haemophilia have reached their 70s. It freed men to take on a variety of employment, so referrals were made to our Disablement Resettlement Officer (employed by what became known as the Careers Service). The Disablement Resettlement Officer had a room in the Social Work department and had haemophilia himself, so was fully aware of patients' needs. He was able to refer patients to organisations such as Remploy, which offered employment with the understanding that patients may be unable to maintain as good an attendance record because of their health problems or disabilities.

69. Getting insurance had always been an issue for haemophilia patients. Insurance for a holiday was always difficult to obtain and the Haemophilia Society had tried to provide support on this, but it was nonetheless a major undertaking to go on holiday if you had haemophilia. This problem just got worse with HIV. Many haemophilia patients had never been employed, so never received occupational pensions.

Financial support from the Trusts and Schemes, EIBSS, and the welfare benefits system

70. I don't know much about EIBSS. However, I know that many in The Birchgrove Group felt angry about having to go 'cap in hand' to the MacFarlane Trust. They each received a lump sum depending on whether they had dependents or not. Children received a lower amount than adults without dependants. They were called ex gratia payments and no one appeared to want to hear how 'swept away under the carpet' this made patients feel who were infected with HIV through blood and blood products.

71. The sharing of information within The Birchgrove Group meetings and my own efforts meant we learned which MacFarlane grant applications were likely to be successful and which weren't. We ensured that we passed this information along to help people understand what might make their applications successful.

72. In relation to welfare and benefits, we approached various charities on behalf of our patients, or helped them with applications to other grants and benefits. A lot of state grants and benefits are interrelated, so if you get one this opens up entitlement to others. We tried to solve problems in different ways, so if they were not entitled to one kind of grant or benefit, we would try to find out if they were entitled to something else.

73. Furthermore, some state benefits are means tested and some are not. If acquiring financial assistance from the trusts or funds resulted in the loss of state benefits this was of no help to the applicant and actually made things worse.

Section 4: Trusts and Schemes

74. There was no eligibility testing for support schemes implemented at the Haemophilia Reference Centre - if we could assist in any way, we did.

75. I don't think that the government took any steps to advertise the existence of trusts and schemes. I think that it was more likely that the haemophilia centres took steps to ensure that patients were aware of the schemes and trusts they were entitled to. I have never seen any government issued posters advertising the trusts and schemes. We knew what existed - this was a benefit of being part of the BASW Special Interest Group - and we were able to spread this knowledge to other social workers at those meetings. We aimed to get as much help as we could for our patients. I do not think that the government would have seen it as their role at the time to ensure that everyone was informed of allentitlements. Although the government is more proactive these days in ensuring people are aware of their medical entitlements (for example

the flu jab), financial entitlement tends to be advertised more by other organisations and charities.

76. I cannot remember if I helped patients to make applications to the Macfarlane Trust beyond letting them know what was likely to be successful. We were allowed to help and certainly would have if patients asked us to, however I cannot specifically remember filling out a form. I just remember people being upset at having to approach the Macfarlane Trust as though it was charity, when actually the money had been set aside specifically for them as an ex gratia payment.

77. I never saw the trusts and schemes advertising their existence, nor do I have any knowledge if this was something they did. Maybe this was due to the stigma and fear. I guess that as Professor MacFarlane (deceased) was a well-respected Haemophilia Reference Centre Director, it was via the Treatment and Reference Centres that those eligible were informed. Professor Macfarlane was the senior centre Director who the Trust was named after, in recognition for all his work in relation to the advancement of haemophilia treatment.

78. I do not know about the level of take up of the support schemes within the Haemophilia Reference Centres. It would be necessary to ask each scheme individually.

79. As to whether more should have been done to ensure that the support schemes reached people who were infected and affected, I don't know. However, from attending some of the sessions in Cardiff I am aware that having access to a Haemophilia Reference Centre ensured people had access to a comprehensive service when others had no service at all. This was because staff at the centre would ensure that patients knew about services and if, for example, someone saw a patient who did not know about a particular service or entitlement, they would tell that patient about it or come and see me to let me know the individual was not claiming support.

80. In terms of the accessibility and transparency of the application and decision making process, I don't know whether the criteria against which applications were determined were publicly available and accessible, or whether the trusts and schemes unnecessarily required repeat applications to be made- this would be for the MacFarlane Trust and other trusts to answer. I am sure that the Macfarlane Trust tried to be fair, and maybe they had to be strict with the application process to make sure that funds were available to give support to people as they aged. I understood no haemophiliac was infected via concentrates after 1985.

81. In Cardiff, social work support for patients of the Haemophilia Centre has always available to help them make applications to trusts and schemes.

82. As to the fairness and accuracy of the application and decision-making process, I cannot answer this, as I do not know. The issue is that so many peoples' situations were so different.

83. In relation to the extent to which haemophilia centres were required to advance applications on behalf of infected and affected patients and whether this remains the case, this needs to be answered by my successors. When I was in the role, we always would have advanced applications to the Macfarlane Trust.

84. As to my views on the current system, in terms of the application, decision-making processes and the payments made, I can't say because I don't have any experience as I am retired.

Section 5: Your role within The Birchgrove Group

85. My role is set out in my talk at the opening of The Birchgrove Group Woodland Grove on 23 May 2004. Please see the attached transcript of my speech for theopening held on 23 May 2004(**Exhibit WITN3619002**) - the video is also available to the Inquiry.

86. The Birchgrove Group began when three men who I knew from my work in the 1970s approached me as soon as I returned in 1987 and explained that they wanted to set up a self-help group as they had been infected by HIV and knew others were. As mentioned above, the haemophilia patients had always been a cohesive group, so I was not surprised when they approached me about this. I acted as their facilitator. They did not want to be organised or counselled- it was their group and they were in control.

87. Initially their plan had been to talk to other patients in the waiting room to find people who were infected with HIV and interested in becoming part of it. I was appointed to work with all those haemophiliacs infected with the HIV virus, but at the beginning I had not been told which of our patients were HIV-positive. I spoke to Professor Bloom, who agreed that I could write an introductory letter to the 55 who had been infected, so as to tell them about The Birchgrove Group and invite them to hear more about it or come to a meeting. He sent it out to all those haemophiliacs infected by concentrates and registered with the Haemophilia Reference Centre. I also offered them the option of having individual home visits, or to let me know if they did not want to hear from me at all. My speech at The Birchgrove Group Woodland Grove opening sets out the contact options we offered (**Exhibit WITN3619002**). This is how the group grew at the beginning.

88. The Birchgrove Group were also looking for acknowledgement that infected blood had affected so many people across the UK and the world- I remember Lord Robert Winston saying that this was the biggest tragedy in the history of the NHS. So to many, the Macfarlane Trust felt like a way of downplaying everything instead of acknowledging the situation. I feel that the members of The Birchgrove Group, many of whom have since passed away, would have been delighted to know that this Inquiry is eventually redressing this and is finally acknowledging and listening to what happened, because this is all they wanted so many years ago.

89. Acknowledgment was the reason The Birchgrove Group planted a living forest of 1270 trees and a huge engraved stone marking the site- it was their own

way of acknowledging what had happened. A sound archive project at the British Library was another way of acknowledging the tragedy. It is called 'Unexpected Futures – Haemophilia and HIV Life History Project' by Sian Edwards- I have provided a copy of a Birchgrove Group magazine which mentions it (**Exhibit WITN36190005**).The sound archive project was led by the Brighton University and South Bank University with the active involvement of GRO-A who in 2004 was a patient/consultant for the NHS and chair of The Birchgrove Group. It was supported by the Heritage Lottery Fund. It can be found in the British Library Sound Archive under the following reference: *Edition No. 30 Winter 2003 of Playback*. Some people who took part in this were also present at The Birchgrove Group Woodland Groveopening and members could choose to put their thoughts down for the historical records with the British Library.

Section 6: Other Issues

90. The scale of the stigma of being HIV positive cannot be overestimated in the 80s and 90s. Nowadays, rugby players and others can be more open about living with HIV and make TV programmes explaining how difficult it is for them. This was not the case back then.

91. The advances in medical treatment for HIV are amazing. I recently bumped into one of the patients who had just been a little lad when I first started seeing him, and at some point before 1985 he had been infected with HIV. He showed me pictures of his sons, and it made me so happy to see him all these years later, and to see how well he has done.

92. Similarly, it is amazing to know how far treatment for haemophilia has come. The next stage of treatment for haemophilia is apparently nothing to do with concentrates or recombinant factors, but rather a subcutaneousinjection that binds other clotting factors together to stop a bleed. It is hard to believe how quickly the science has progressed. Some people with haemophilia might still be alive, who in their youth had to beon bed rest with acute pain prior to the introduction of concentrates, and in their life time have witnessed all of these advances.

93. I think it possible that Professor Bloom died because of his stressful job. This was his life's work and he was made a Professor due to recognition from his peers for all that he had done.

Statement of Truth

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

Signed _Mary Dykes_

Dated _14th April 2020__