Witness Name: Margaret Jean Lovie
Statement No: WITN4090001
Dated: 24th June 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MARGARET JEAN LOVIE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 200 dated 15 April 2021.

I, Margaret Jean Lovie, will say as follows: -

Section 1: Introduction

1. **Please set out your name, address, date of birth and professional qualifications.**

    1.1. My date of birth is GRO-C 1942 and my address is GRO-C GRO-C.

2. **Please set out your employment history as a social worker, including the positions you have held, the dates that you held these positions, the haemophilia centres and other organisations in which you held these positions and your role and responsibilities in these positions.**

    Professional Qualifications

    2.1. 1961-1964 - B.A. in Social Studies, Newcastle University (Faculty of Economics and Social Studies).

    2.2. 1964-1965 - Certificate in Applied Social Work, Newcastle University. Placements in Child Care and Medical Social Work.

2.3. November 1965 - Membership of the Institute of Medical Social Workers, Bedford Sq. London and later transferred to membership of the British Association of Social Workers which remained until 2008.

Employment Record

2.4. 1965 - 1968: Medical Social Work Dept, Sunderland and Ryhope General Hospitals, also community focused in Sunderland and Durham.

2.4.1. Task - Geriatric Care. Asst., Care planning and Provision: support and care of the dying and their families.

2.5. 1968 -1970: Medical Social Work Dept., Royal Victoria Infirmary, Newcastle Upon Tyne. Medical Specialities - Arterial Surgery, General Medicine and Gynaecology, within multidisciplinary teams. Small pilot scheme - patient service opinion.

2.5.1. Task - Asst, Care planning, Support, Service provision.

2.6. Joseph Rowntree Memorial Fund, York. Outreach worker. 80 families visited to assess family needs related to children with long term varied disabilities.

2.6.1. Task - Asst. leading to the identification of needs to meet a number of family requirements - equipment, holidays, family activities- house alterations, that were outside statutory provision.

2.7. 1976 - 1989: Medical Social Worker attached to the Newcastle Haemophilia Reference Centre, Royal Victoria Infirmary, Newcastle Upon Tyne. Task - Provision of a Social Care Programme within a multi-disciplinary team required for people with Haemophilia and related Haemostatic Disorders. Of the 1984 patient cohort - 76 diagnosed with HIV and three sexual partners.

2.7.1. Task-Initial post part time in 1976 to focus on young children and their parents.

2.7.1.1. To identify and assess the family social circumstances to aid treatment and to support the adjustment to the diagnosis.

2.7.1.2. To promote the Centre/Home link and address the practical and emotional needs of families presented with the management of haemophilia and a possible transfer to home therapy.

2.7.1.3. To work as part of the Multi-Disciplinary Team for the welfare of the family and child.

2.7.1.4. From 1979, the post gradually became full time by 1983/4 to accommodate all ages, the full patient population.

2.7.2. Amended Task prior to HIV/AIDS. Social Needs and Circumstances Asst.

2.7.2.1. Care planning and Provision including practical care, for Benefits, practical items from the DSS and from other sources for example, Loan Equipment etc.

2.7.2.2. Provision of listening, reflective skills - Selected counselling and support through 1-to-1 work, group work, written materials. Focal point within the Centre for social care community liaison and services within the Centre's catchment area. Assistance with general policy making within the Centre and beyond.

2.7.2.3. Role in haemophilia social care training and later HIV/AIDS locally, regionally and nationally.

2.7.2.4. Contribution to lobbying on behalf of PWH and their families to Government Departments, Service Provider Agencies, for patient resources and Policy changes.

2.7.2.5. Contact with the Haemophilia Society nationally and locally and with BASW and its SIG.

2.7.3. When HIV/AIDS were added:

2.7.3.1. Understanding of HIV/AIDS and of those additional factors associated with HIV/AIDS care;

2.7.3.2. Risk reduction and the promotion of sexual health within the Centre and into the Community;

2.7.3.3. The supporting of patients and families including those non-infected;

2.7.3.4. Recognition of the needs of all age groups HIV infected in the Centre.

2.7.4. These are a list of tasks reflective of the formal Job Description.

2.8. 1990 - 2004: HIV Services Development Officer, and then HIV and Sexual Health Manager, SSD, Newcastle City Council.

2.9. Additional Training

2.9.1. Sept 1985 HIV/AIDS Course, St Mary's Hospital, London.

2.9.2. Nov 1985 Meeting/ Training, Terrence Higgins Trust, London.

3. **Please set out your membership, past or present, of any committees, groups, associations, societies or working parties relevant to the Inquiry's Terms of Reference including the dates of your membership and the nature of your involvement.**

3.1. National Haemophilia Society 1976 - 1990 Member (See Section 6)

3.2. British Association of Social Workers Special Interest Group 1979 - 1990 Committee Member - Membership Secretary 1979 - mid 1980s (See Section 6).

3.3. Haemophilia Nurses Association - non-member but links via the SIG for information exchange, shared learning, and at conferences.

3.4. 1987 Membership of the DMO's Working Group, Newcastle Upon Tyne- Health Education and AIDS.

3.5. Haemophilia Society Submission to an All-Party Meeting, House of Commons, Nov 5th 1987, for monies for PWH and their families. Social Care needs and costings presented.

3.6. 1987 Member of the Social Work Inspectorate Working Group to look at Policy and Practice for the PSS. Chair- Mr Maurice Phillips, Deputy Chief Inspector SSI. Topic - AIDS, Policy and Practice Guidelines for the PSS. Particular focus on Haemophilia and confidentiality and need to know. The total Group's work contributed to the 1988 Circular on Confidentiality and Personal Information for the PSS and helped lead to HIV/AIDS Local Authority Guidance published later for Adult Care and also Children.

4. Please confirm whether you have provided any evidence to, 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 and/or variant Creutzfeldt-Jakob disease ("vCJD") in blood and blood products. If so, please provide details of your involvement and copies of any statements that you made.

4.1. I confirm I have not provided any evidence to, or been involved in any other inquiries, investigations, criminal or civil litigation.

Section 2 – Your role as a Haemophilia social worker

5. Please provide details of your role(s) within the Newcastle Haemophilia Centre ("the Centre") and how this fitted into the wider organisation of haemophilia care. Please provide the names of any significant and/or senior staff members who were working in the Centre at the time.

5.1. The role was one of full-time social worker within the Northern Regional Haemophilia Centre based in the Royal Victoria Infirmary, Newcastle ("RVI"). My remit covered those patients and their families attending the Centre inclusive of those on Home Therapy or admitted to Ward 13 for Adults and to Ward 8 for Children at the same Hospital. Home visits were done as required. The role included training, advocacy on behalf of those with haemophilia and later HIV/AIDS and writing to raise awareness on key social care issues. Please see Q2.7.1 to 2.7.4. above for more information on the work role. (A part time social worker had worked before 1980 in the Centre with adolescent boys and young men on matters such as career planning but left before 1979.)

5.2. Opened in 1974, the Newcastle Centre Outpatient facility by the 1980s was compactly located in one Unit in the RVI. It provided medical services (Dr P Jones: Dr P. Hamilton), a Nursing Services Team (Clinical Nurse Specialist, Mrs M. Fearns), Physiotherapy (Snr. Physiotherapist, the late Mrs B. Buzzard), Welfare Rights Service SSD, (the late Mr M. Leates), Unit Secretaries (Mrs. L. Mc Bride and Mrs M. Davies), Social Worker, SSD. (Mrs J. Lovie).

5.3. The close proximity together of the aspects of the Service greatly facilitated formal and informal joint working and provided patients with an Outpatient "one stop" resource. PWH who came for an arranged consultation would often speak to other staff sharing points of concern and interest. There were four Associated Centres in Whitehaven, Carlisle, Sunderland and on Teesside with the Home Therapy Programme run from Newcastle. The Liver and Hepatitis Clinics were also run from the RVI. The Reference Centre covered the Northern Region. The team met weekly and medical diagnoses were given by medical staff in the privacy of the Medical Consulting Room. All colleagues should be acknowledged for their willingness to work collaboratively but particular mention should be made of the Haemophilia Centre Nursing Team, with its daily, constant overview task in the Centre alongside the medical staff.

6. Please explain (if you know) how your role as a social worker at the Centre was funded, and how the role came to be created.

6.1. I am not able to fully clarify how my role was created and funded. My understanding was that some of the hospital social work posts in the RVI were jointly funded out of Health Authority monies and Local Authority ("LA") hospital allocated social work funding and some by Charities. Haemophilia social work was, in 1989 in some areas, including Newcastle, part-funded for a period out of the LA 1989 AIDS Support Grant paid to LAs by Central Government.

7. What particular responsibilities did you have as a social worker at the Centre?

7.1. Please see Questions 2.7.1 – 2.7.4 and 8.

8. **What kind of support, advice, information or assistance did you provide to patients in your capacity as a social worker at the Centre? Please describe, in particular, the support, advice, information and/or assistance that you provided to patients who had been infected with HIV, HCV and/or HBV.**

8.1. The information set out below, includes prior to 1984, so providing background information for later comparison with the workload, under HIV/AIDS. Examples include:

8.1.1. A Centre run Conference in 1980 in Newcastle covering Haemophilia treatment changes and implications for care. I spoke about helping families adjust to haemophilia, as a chronic disability with an emphasis on the child within the family, as I can recall. It was open to all professionals and over 150 attended.

8.1.2. Around 1977, a monthly Mothers Group was set up, who met at the RVI. The mothers brought their preschool children. The Group met with staff regularly and by sharing their experiences were more confident to address the haemophilia from many aspects and less isolated. In 1980 the Group wrote the 'Children's Haemophilia Book' illustrated by Dick Bruna, which was shared with the Haemophilia Society and widely circulated. The Group also produced a short paper on its work with selected circulation. The Group was social work lead and well supported by other Centre colleagues. It closed in 1990.

8.1.3. In 1983, a weekend Residential Conference was held in Newcastle at Graham House, National Coal Board premises and run by the Centre and local Haemophilia Society with National Society attendance. There were lectures, group work sessions etc and full, constructive patient feedback on the Centre Service and how it might be improved further.

8.1.4. Once into HIV/AIDS, the needs of staff were addressed to be able to work effectively. The work immediately refocused and was Director led on policy and practice covering confidentiality, consent to test, consent to share, no press comment unless by the Director, the protection of self and others and safe record keeping. All this was alongside access to ongoing up to date HIV information and was overall a basic set of tools for working in and out of the Centre. Testing for HIV was offered to 68 Centre and Haematology staff, all negative as reported in the BMJ in Sept 1985. This was to prove very helpful when training as a way of proving that safe, steady working methods, even where HIV was present but unknown, would ensure working safety. Transmission risks were covered for staff safety and reassurance.

8.1.5. See AIDS and Haemophilia morbidity and mortality in a well-defined population. P. Jones et al BJM Sept 1985

8.2. The specific HIV/AIDS social work task was divided into two parts:

8.2.1. Needs of people with HIV/AIDS known to the Centre and their families.

8.2.2. Needs from outside, the public and care agencies and their workers. All had information needs and sought advice from the Centre because the HIV experience was as new for managers as for staff, for quite a long period.

8.2.3. Also, negotiation of the interface between people with HIV and the services they might or did need.

8.3. For patients and partners:

8.3.1. There was the issue of pre and post-test counselling, the sharing of information with family and so many questions leading to the need for personalised information and advice.

8.3.2. This led to a series of contacts about relationship issues, coping with fear, stigma, shock and gradually grieving, replanning, rearrangement to try to keep fit, as well as frustration and in some instances anger, with the likelihood of facing the real possibility of serious illness and dying.

8.3.3. For example "will I die?", "how will I look?", "whom must I tell?", "I want to be in charge", "what can be done?", "shall I make a Will?", "will my family be safe?", "how will they cope looking after me with both the haemophilia and HIV?", "do I have to tell my employer?", "how can I pay for the added costs for bedding, added travel to hospital, extra heating and washing, clothes with my weight loss…", "what of relationships, what to say and intimacy?" were the type of questions that emerged.

8.3.4. These identified issues were addressed across the team with direction as to suitability, leaving patient choice as to whom they spoke within skill limits which included the Social Worker.

8.4. For Services:

8.4.1. "Am I safe?", "What are people's needs if I visit?", "I know no one with HIV.", "whom can I tell about my work?", "I want advice such as Guidance and Policies and supportive Managers to be ready to help and able to respond to HIV prevention also".

8.4.2. For people with HIV/AIDS, it was necessary from a social work perspective in the Centre, to contact seniors at the head of organisations as to how information would be used and stored before referrals were made. Social work referral letters were copied to patients if they wished them, so that they knew what had been said.

8.5. Under information and advice, a training programme was instigated. I recall many sessions with especially L.A, SSD and DSS (now DWP) staff in groupings of up to 20 to ensure their help would be there and also to address public attitudes to HIV/AIDS when PWH were reporting discrimination, isolation and vulnerability. These services once trained could also become messengers about the real HIV, at work and elsewhere.

8.6. Under support and assistance, work examples are:

8.6.1. The revamping of the Mothers Group. The Group Members decided to go **on** meeting. Some had sons with HIV. It continued until around 1990, the Group providing mutual support for haemophilia and a conduit for

Centre information. By 1990 the diversity within the Group became too great to sustain, as some were coping with HIV ill children. In the interim years, it was possible via the Group to pick up on the Women's own health issues which increased, for referral back to the Director and Primary care.

8.6.2. Extensive work with the DSS by Mr Leates, with social work input which included form filling and Benefit Appeals. Support was also given to the Haemophilia Society in its campaign for the extension of Attendance Allowance to PWH over the age of 12 which was ultimately successful. Medical support letters were always provided by the Centre Director, where applicable. In later 1988, the introduction of Income Support impacted on some single payment areas.

8.6.3. Provision of a six-month Training Course for the Northern Haemophilia Society Committee to set up a telephone help line for those wanting to talk with others coping with the Haemophilia/HIV experience, somewhere outside of the Centre and HIV and Haemophilia aware. There was strict vetting by an independent psychologist for suitability. The line was not used extensively but there was increased recognition and use of the Group for information, the newsletters helpful conduits from people to people with haemophilia and often HIV. Later, the Group with its added confidence, openly raised the issue of recompense with the Centre which provided support and led to the Group's selected link with a Newcastle Solicitor specialising in disability and rights. The Group also contacted the Haemophilia Society and set up a continuous link on that matter. It is important to record the strength and commitment of the local Haemophilia Society to its members.

8.6.4. Questionnaire Survey of young people – In 1987/8, the Centre was involved in a Questionnaire Survey of 355 young people in the City aged 16-19. The questionnaire covered perceptions, current behaviours and knowledge about HIV prevention and care including relationship negotiations, with participants from Barnardo's, a Youth Training Scheme, Education (schools), the SSD Care system and from the Centre. There were acceptable-to-high levels of information about infection transmission and protection but 60% would not share a flat with someone with HIV and 25% would not share a desk/workplace. There was a gap between information, emotions and fears through having not met anyone specifically with HIV/AIDS, reinforced at times by negative press presentation. The information from the questionnaires was then incorporated into future training or teaching by the agencies involved to try and address those concerns and fears.

9. To what extent, if at all, was counselling and/or psychological support provided at the Centre to people who had been infected with HIV, HCV and/or HBV, and to people who were affected by the infection of a partner or family member? What was your role, if any, in the provision of such support?

9.1. Counselling and Psychological support were in place before HIV/AIDS. PWH and their families had a direct telephone line and open access to the Centre and Wards 8 and 13 at all times, even when the Centre was closed. Different Centre staff were able to offer support in their own areas and on many occasions to assist widely, whilst respecting specialist skills. Child Psychiatry, Psychology, Psychiatry and Drug and Alcohol Services were available. The Northern Haemophilia Group provided events, support and information.

9.2. These options were carried forward into HIV/AIDS to which were added:

9.2.1. Referral to HIV/AIDS Specific Psychology Services based in the City hospitals.

9.2.2. Referral after 1987 to an HIV/AIDS Community Centre in the City, the Team Leader an experienced Psychologist.

9.2.3. Availability of a befriending and support Scheme provided for those 12-16 with HIV and their families coming to the Centre, by trainee priests from the Ushaw College Seminary near Durham. This included visits to the Seminary grounds and facilities and was very successful. The Director was the establishing link with the College and led from the Centre perspective.

9.2.4. The setting up by the Centre Social Worker of a Bereavement Group that met monthly for women, wives and partners of men who had died from Haemophilia and HIV. Their loss was not limited to their partner but also a way of life for some people, for whom haemophilia had long been present. The women produced a paper setting out their experiences which was shared.

9.2.5. Assistance from the RVI multi-faith Chaplaincy and local URC Ministers, especially around the time of death and later. Links were also established with sympathetic funeral directors.

9.2.6. Emerging other local Voluntary Sector HIV/AIDS Support Groups and also Mesmac North-East, were also patient available.

9.2.7. Centre staff, the Clinical Nurse Specialist and/or Social Worker, attended funerals by invitation in specific circumstances and follow up appointments were provided by Medical Staff and support to families by all staff. Some relatives bereaved were also HIV infected, or carriers of the haemophilia with difficult decisions to make.

9.3. For more on the social work role, please see above in Q8.

10. To what extent, if at all, was counselling and/or psychological support provided at the Centre to people who were informed that they might have been exposed to vCJD? What was your role, if any, in the provision of such support?

10.1. I am unable to answer as I had no involvement with vCJD notification.

11. In your view, were the arrangements at the Centre for i) social work support; ii). counselling; and iii) psychological support adequate for the needs of those who had been infected with HIV, HCV and/or HBV as a result of treatment with blood products (or for the needs of their families)?

11.1. This question requests both a professional and a subjective opinion. Real effort was made to provide these services in-house and to refer and link up patients elsewhere.

11.2. As ever there were time constraints and challenges and complexities meeting the needs of people, especially for some of those living greater distances from the Centre. The coming into post of local HIV Service Coordinators with haemophilia knowledge in counties such as Cumbria and Northumberland was very useful.

12. **Please set out what you can recall about Dr Peter Jones; his approach to the treatment of those with haemophilia; the circumstances in which patients learnt that they had been infected with HIV, HCV and/or HBV; the arrangements for the care and the treatment of those infected at the Centre; and the policies or practices at the Haemophilia Centre under Dr Peter Jones insofar as relevant to the Inquiry's Terms of Reference.**

12.1. Dr Jones brought to the Newcastle Centre not only his haemophilia skills but his wealth of experience as a Consultant Paediatrician. His aim was to treat and care and to help people find opportunity in daily living, a quality of life and this was reflected in all his work. One of his first steps with HIV/AIDS in the way of Policy and Guidance was to prepare the Centre for the work to come, as set out elsewhere in Q2.8.

12.2. Patients and their partners received their results from the medical staff in the privacy of a Consulting room. Dr Jones' awareness of the fears and isolation of patients were addressed directly and through his willingness to educate and share his knowledge of HIV/AIDS in the public domain. His overall commitment to his work and support as Director to staff was of the highest order.

13. **Please set out what you can recall about any other doctor who worked in the Centre during your tenure; including their approach to the treatment of those with haemophilia; the circumstances in which patients learnt that they had been infected with HIV, HCV and/or HBV; the arrangements for the care and the treatment of those infected at the Centre; and the policies or practices at the Haemophilia Centre under their care insofar as relevant to the Inquiry's Terms of Reference.**

13.1. Dr Hamilton was a welcome addition to the Centre Team in 1979 to address Liver Disease and Hepatitis amongst the haemophilia population. He provided regular Clinics and also medical cover in Dr Jones' absence. He was a Multi-Disciplinary Team member. I had left the Centre before this work expanded further, so I cannot comment additionally.

SECTION 3: Impact on people infected and affected

14. Please describe, as fully as you can, the impact, on those infected and affected, of infection with HIV, Hepatitis C and/or Hepatitis B from blood products and what you can recall about the impact on them of the treatments for those infections.

14.1. After earlier progress, the arrival of HIV/AIDS could only be described as catastrophic. PWH and their families and those close to them through many social contacts had begun to lead fuller lives with an extended sense of achievement, possibilities and with longer life expectancy. Many had come from families where in the family network there had been a number of deaths from unstoppable bleeding and days spent in hospital away from those they cared about, irregular schooling, difficulties finding work and living with added pain from damaged joints.

14.2. Home therapy and more concentrated treatments had brought a different outlook with greater freedom, away from hospitals and the restrictions of illness. This was not to say that the haemophilia did not have to be managed, but rather in different ways that would lead hopefully to greater security, the possibility of wider relationship choices and community engagement. HIV/AIDS was to change this profoundly, certainly for many more seriously affected haemophiliacs. For those non infected there were added anxieties and issues too about haemophilia treatments and public safety, because they were known to have a bleeding disorder.

14.3. Regarding treatments my points are observational – profound fatigue, loss of weight, difficulty eating, the possible need for intense nursing care and a hope that the increasing understanding of HIV/AIDS would lead to more meaningful treatments in time.

15. In responding to question 14 please include in particular your knowledge of the following matters:

a. The impact on the quality of life of people who were infected and affected;

b. The impact on the relationships, private and family life of people who were infected and affected;

c. The impact on the ability of people who were infected and affected to live their life fully as a member of society;

d. The impact on ability of people who were infected and affected to access education, to work and earn money, to obtain insurance and to accrue a pension;

e. The stigma and/or discrimination faced by people who were infected and affected;

f. Any difficulties encountered by people who were infected and affected in obtaining financial support from the trusts and funds established to provide financial support (i.e. the Macfarlane Trust, Caxton Foundation, Eileen Trust, Skipton Fund and MFET) and/or from the current infected blood support schemes (EIBSS, SIBSS, WIBSS or the Infected Blood Payment Scheme for Northern Ireland);

g. Any difficulties encountered by people who were infected and affected in obtaining assistance from the welfare benefits system.

15.1. A - E) After a reduced likelihood of dying from bleeding episodes and living with incapacitated joints as in previous generations, the patient population was again presented with medical uncertainty and the real possibility of dying prematurely with no immediately clear picture of HIV disease progression in the mid-1980s period. There was concern amongst some patients how others they knew were progressing, HIV/AIDS was to affect close partners also, through perceived and actual infection risk, a changing intimacy and by bringing added care tasks into a relationship as well as a foreseeably different future. Families were often living with secrets to protect their youngsters and to help those who felt guilty passing on the affecting gene. There was loss of membership, companionship and status within communities. Financial impact was inevitable. Many patients had not been able to gain insurance in the past and had had relatively little time to accumulate monies. Access to education depended on health and required educational guidance which was provided by the Government and help from the Centre Director about safety based on good procedures not named HIV status. Some schools and colleges needed particular reassurance from the Centre Director and were visited by other Centre staff. Stigma and discrimination were present usually based on misinformation, fear and prejudice. There were patients welcomed into local pubs where they had been known for years but reported incidents requiring action where there had been poison pen letters, burning items in a letter box and “AIDS in here” painted on a house wall in large letters.

15.2. F) I am unable to comment as I left the Centre in 1989 as the Trusts were introduced, some yet to be launched, as I understood.

15.3. G) The Centre was fortunate in having Mr Martin Leates who was attached to a large City SSD Welfare Rights Service. He was conversant with both haemophilia and HIV/AIDS. Patients attending the Centre in and out of the City were offered Benefit Checks and medical support from the Director, which helped them to access appropriate benefits. Help was given also to obtain DSS single payments for items listed earlier and below, some affected by the later introduction of Income Support. Social work time also was given to this task through sharing information and helping to complete and trace financial applications. Patient funding came from Statutory sources, local Charitable sources and the Haemophilia Society’s Benevolent Fund accessed monthly via Mr David Watters prior to the Trusts.

15.4. Diets for those with HIV who were healthy and another for those with progressive illness were produced by a Senior Dietitian at the RVI, costing out at £22.00 and £32.50 weekly. Via a number of Appeal attendances by Centre staff, the DSS regionally issued instructions to pay on application. This information was circulated to the Haemophilia Society, Terrence Higgins Trust and others. Help with applications for funeral costs was also provided.

15.5. It was often possible at the start to meet the local levels of need from the payments made by the DSS, assisted by the training undertaken, but it was recognised this was an interim step for as costings rose, longer term funding needed to be seriously found to address the increase in the severity of the illness.

Section 4: Trusts and Schemes established to provide financial support

16. Were patients at the Centre provided (whether by you or others) with any information about the organisations (as listed in paragraph 15 f above) that had been established to provide financial support? If so, what information?

16.1. Historically, steps had been taken prior to HIV/AIDS to place information on the Centre's Notice Board and in newsletters. Leaflets and notes, many from the Haemophilia Society, were distributed and guidance given through one-to-one patient contact with Centre Staff leading to introductions to specialists as required. I cannot be Trust specific. See Q 15.2F above.

17. Were patients at the Centre provided (whether by you or others) with any assistance in making applications to these organisations? If so, what kind of assistance?

17.1. The task of assisting as much as possible was in place before the Trusts arrived. For the Trusts, I was not involved and therefore cannot comment.

18. Did the Centre provide (whether through you or others), to these organisations, information about those applying and/or information in support of applications?

18.1 It was generally customary to assist with applications for financial aid and across a range of resources. I have no information or information here related to the Trusts.

19. Please describe any involvement or dealings that you had with any of the Trusts and Schemes and answer the following questions (to the extent that you are able to):

   a. **What was the application process like for those infected or affected?**
   b. **Were the criteria for the provision of financial support transparent and accessible?**
   c. **Did the Trusts and Schemes unnecessarily require repeat applications to be made?**

d. Was sufficient practical support and assistance given to applicants to make applications?

e. What if any observations do you have about the decision-making processes of the Trust or Scheme when considering applications for financial support?

f. How were applicants treated during the application and decision-making process?

g. Were decisions made in an efficient and timely manner?

h. Were applications decided in a consistent way or were there differences in the way applicants were treated?

i. Were adequate reasons given when applications were refused?

19.1. I have no experience or information related to these points.

Section 5 - Effect on Clinical Staff

20. If you haven't already answered further above, how did the Centre's practices change over time to reflect the risk that HIV, HBV, HCV and vCJD infections posed to clinical staff?

20.1. Please see Q8 above. vCJD was explained but I had no part in it.

21. What was the Centre's protocol for reporting concerns or complaints about staff and/or patient safety? Did you ever report any concerns or complaints? If yes, who did you report these to?

21.1. Issues related to staff safety covering transmission were immediately addressed by the Director and then risk management generally updated as necessary. Points could be raised within the Centre with the Director, supported by the Clinical Specialist Nurse for direct resolution: there were also for local social workers via Newcastle SSD, set procedures and staff line management systems.

21.2. Equally, concerns related to partner and patient safety, such as transmission risks, mental state, or incidents about stigmatisation etc, were dealt with as soon as reported, to and from within the Centre and if from outside, preferably with patient knowledge.

22. What impact did treating haemophilia patients who subsequently contracted infections from their treatment have on you both personally and professionally?

22.1. Professionally, new learning, a reconsideration of people's needs and service requirements and a major increase in caseload. An expansion of the social work task to include more community training, assistance with benefits, new group work and consideration of policies and guidance, as well as more 1 to 1 work. There was also the deep sadness about what was happening to the patient grouping.

Section 6: The Haemophilia and Related Haemostatic Disorders Special Interest Group

23. The Inquiry is aware that the Haemophilia and Related Haemostatic Disorders Special Interest Group ("SIG") was set up in 1979, as referenced in HSOC0002853. Please confirm whether you were part of the group when it began and provide answers to the following:

- **a. What was the reason for the creation of the SIG?**
- **b. What was the purpose of the SIG, and what goals did it intend to achieve?**
- **c. How were you involved in the SIG? Please provide details of any set roles or positions if applicable.**

23.1. A & B) I was a member from 1979 to 1990. A social work information and support network was initiated by Mrs V. Stopford appointed as Social Worker to the Haemophilia Society in 1974. This was encapsulated and crystalised in 1979 into a more formal entity. I can confirm the 1979 objectives, as reflected in the tasks listed in **HSOC0002853**. The first objective rightly emphasises the Centre worker and Area based worker collaboration and information and experience exchange. The forum provided an opportunity also for exchange between social work staff in Centres. It was essentially to address the social care provided to people with Haemophilia and their families through greater shared understanding and consideration of old and new ways of working in response to their haemophilia in a changing treatment situation. This was to be shared with others working in the haemophilia area and guided by the general patient experience.

23.2. C) I was involved in the SIG as a participating member, Committee member and from 1979 to the mid-1980s was Membership Secretary responsible for keeping the members list up to date. As a Committee member, I shared in the planning of meetings, production of reports and spoke at some events and shared in lobbying as asked and agreed.

24. When the SIG was established, were you involved or associated with the British Association of Social Workers ("BASW") and / or the Haemophilia Society? Please detail your involvement.

24.1. I was a member of both the Haemophilia Society and registered professionally with BASW.

25. Please set out how you came to be involved with the SIG.

25.1. As stated above, I was already a member of the emerging link between social workers and interested others, so it was a natural step to join the SIG.

26. What was the Haemophilia Society's involvement with the SIG? What role, if any, did they play in the SIG?

26.1. The Haemophilia Society's involvement was continuous and valued via Mr David Watters and with support from the Rev Alan Tanner. This covered information exchange, shared lobbying for resources, and legislative change for patient benefit, support at events and to pick up on the patient voice Regular information booklets from the Society were distributed widely.

27. What was the BASW's involvement with the SIG? What role, if any, did they play in the SIG?

27.1. BASW's involvement provided a professional base for the SIG and a route to share needs and concerns specific to the Haemophilia population under BASW's commitment to illness and disability. The SIG was placed under the auspices of Mr David Swaysland, Acting General Secretary of BASW, responsible for all the SIGs.

27.2. The late Mrs Elizabeth Wincott was appointed joint link worker to the SIG, BASW and the Haemophilia Society bringing her experience as a social worker at the Mount Sinai Haemophilia Centre in New York. It was Mrs Wincott who presented a Haemophilia Social Work job description, for the SIG, jointly worked, to Task Force 1 of the World Federation of Haemophilia in 1982 which secured a Social Work Group within the World Federation structure.

27.3. BASW agreed to pay for Report and Conference information publishing and the Haemophilia Society, the postage. The late Mrs Riva Miller, social worker and counsellor at the Royal Free Hospital, was appointed as a committed Chair, in 1979 to the mid-1980s, when Mrs Fran Foy from the Birmingham Centre continued the task. Mrs Miller was also Newsletter Editor.

28. Please set out details of the work you undertook as part of the SIG.

28.1. As a Committee member, there would be shared planning for two larger meetings a year, one certainly in full Conference format, the shared writing of some occasional papers or short reports, newsletters and a contribution to Policy writing especially later with HIV/AIDS. There was the sharing of new difficulties and joint learning. It was about professional understanding and I was part of this.

28.2. By 1985, the SIG had nine Committee members and a Study Day was held in June, the theme 'AIDS, the facts' with a large attendance of SIG and non-SIG members. It set out how Centres and Social workers could respond. David Watters spoke also. Concern was expressed about caseload sizes and the need for more social workers.

28.3. The siting of Conferences in different Reference Centre catchment areas, making it possible to draw in local area social workers and other interested staff, was crucial. People were able to meet and hear speakers from their nearby Centre led by the Director, so meeting a SIG requirement to outreach.

28.4. I recall a Report **'AIDS and Haemophilia'** produced jointly in 1985 which covered Patient needs, and in a second section, Service needs. There were recommendations for moving forward for social care and references. It was circulated to the Centre Directors, for their staff, Directors of Social Services, BASW, the SSI, the Haemophilia Society, the Nurses Group Chair and other HIV Organizations such as the Terrence Higgins Trust, as well of course to SIG members also. A positive response from the Social Services Inspectorate especially, was received.

29. On 13 September 1982 you presented a report on behalf of the SIG at a meeting of Haemophilia Centre Directors and offered to support Directors who entered into negotiations for greater provision of Social Services (See CBLA0001619)

- **a. Did any Directors accept your offer of support, and if so, who?**
- **b. Were additional resources provided to Social Care as a result of the SIG's assistance?**
- **c. The report to the Directors also noted the publication of a SIG newsletter. To whom was the SIG's newsletter disseminated and what topics did it cover?**

29.1. With reference to the above document **CBLA0001619,** I am unable to recall the response, or if it led to any added social work time. The Newsletters provided information on legislative changes in benefits to PWH and their families, and often focused on one topic, e.g., employment, family living with Haemophilia to address an issue in detail. This was of course prior to HIV/AIDS and later included the HIV/AIDS dimension. It was circulated to Members and interested parties.

30. On 10 June 1983, you and Riva Miller gave a workshop in Birmingham about the "role of the Social Worker in a Haemophilia Centre" (See HSOC0002814)

- **a. Please detail, as far as you are able, if there were any concerns raised or discussions regarding HIV, infected blood and blood products and how to handle these issues.**
- **b. Who attended this workshop?**

30.1. As seen in the Paper for the Workshop **HSOC0002814** there was no mention of HIV/AIDS. I would say that HIV/AIDS as a topic began to make its way into the SIG in 1984.

30.2. Attendees at the Birmingham Meeting would have been Centre staff, local services staff as referred to above, with added social workers in the SIG and likely from Reference Centres from around the country.

31. Did the focus of the SIG change with the knowledge of infected blood products and if so, how? What issues did you identify arising in relation to infected blood and blood products, and what was the SIG's response to the issues outlined in question 15 above?

31.1. To the best of my recollection, the Group never discussed blood products, their production, source etc but rather the focus of work changed very substantially to accommodate the impact of HIV/AIDS on daily living. It was also necessary to maintain an overview on haemophilia and other bleeding disorders, which was the continuing core condition. A sizeable percentage of patients did not have HIV/AIDS but still had very real social care needs to be met. The SIG turned round its balance of work to cover all of the above but with a necessary major focus on the concerns raised by HIV/AIDS. The work undertaken was reflected in the Discussion Paper referred to above, which in a way was a summary of work in 1984 and 1985.

32. Please describe, in as much detail as you are able, the support that the SIG offered and provided to Haemophilia Society members who were infected with HIV, HBV and/or HCV through blood or blood products.

32.1. The SIG itself as an entity did not provide direct services to members of the Haemophilia Society as I am aware. A social work service was provided via the Centres individually or via specific Centre projects. Patients did not attend SIG meetings unless they were invited as a speaker.

33. On 28 June 1985, you wrote to Baroness Trumpington (See DHSC0003689_054), as a representative of the SIG, expressing concern about the lack of resources available for Social Work time. Did you receive a response to this letter? If so, please provide a copy of any response and/or outline your recollection of the

content of the response. Were more resources made available to you as a result of this request?

33.1. My letter to Baroness Trumpington in June 1985 **DHSC0003689_054** summarised the situation for Haemophilia Social Care on behalf of the SIG and reflected Member opinion.

33.2. A letter received back from Baroness Trumpington personally to the SIG had also been sent to Mr David Swaysland Deputy General Secretary at BASW, the content implying that BASW had written in a similar vein. After such a time it is impossible to recall word by word what was written without a copy, but because the letter was important to the SIG, I can give a general flavour.

33.3. The letter stated that there was no new specific funding for social work posts for people with AIDS, from Central Government. No mention was made of haemophilia specifically. Local Authorities individually were to look to their presently available local resources, whilst sensitive to changing needs. Baroness Trumpington had met with representatives of the Haemophilia Reference Centres Group. A Supra Regional Services Advisory Group was considering Health Authority funding.

33.4. Regarding adding Haemophilia Social Work resources specifically, in Newcastle, post 1985, a welcome part time Haemophilia Social Work post was added to the Centre Team for a limited period, which I think would have been in approximately 1987/8. This post was replaced in approximately 1988/9 by a full-time social worker raising the total social worker staffing level in the Centre to two full time posts. The City separately provided a social work service attached to its Infectious Diseases and GUM Units and set up Mesmac North-East.

34. On 7 December 1988, you wrote to Dr Christopher Ludlam at the Royal Infirmary Edinburgh (See LOTH0000006_024), requesting he complete a questionnaire intended to establish a picture of the provision of social care services within the United Kingdom in light of the information about blood and blood products being infected with HIV.

a. How widely was this questionnaire disseminated?

b. **What conclusions were you able to draw from the responses to this questionnaire?**

c. **Were the conclusions published? If so, where were they published?**

d. **In light of the conclusions, did the SIG seek to make any recommendations? If so, what were they and to whom were they made?**

e. **Were any such recommendations acted upon? Please provide as much detail as you are able.**

34.1. A) With reference to my letter to Dr Ludlam **LOTH0000006_024**, 52 Questionnaires were distributed to Local Authority Principal Social Workers/ Managers responsible for health-related social work and letters sent to relevant Haemophilia Treatment Centre Directors based on a 50% coded sample of listed Centres held by the Haemophilia Society.

34.2. B) Conclusions: 35 Centres were providing a social work service and around 7 were planning service provision subject to available funding, some with expectations based on the DoH L.A Circular ("LAC 89i") announced in Spring 1989. (Of the 52 Questionnaires sent out, 36 were returned and of the 16 non returners, information on 4 was provided in other ways). Service provision had increased since 1984 in part, funded out of Health Authority HIV monies and/or out of L.A budgets faced as reported with frozen posts and under pressure from other patient groupings. (The Questionnaire was sent out prior to the Circular announcement and referred to in replies.) The new L.A HIV Support Grant (Circular LAC 89(i)) announced in April 1989 was short term and whilst welcome would not easily address the longer-term stability and planning of Haemophilia Social care services, the costings of which needed to be mainlined. Time given to those with Haemophilia and non-HIV infected had been affected by the HIV focus.

34.3. C) The results were made available in Report format. I cannot recall distribution but assume it was sent to the BASW SIG Committee, BASW, Haemophilia Society and shared with the Treatment Centre Directors.

34.4. D) Recommendations: The Haemophilia Society, BASW, Medical Directors, and Local Authorities were asked in their discussions with the DoH AIDS Unit and Regional Social Services Inspectorate to highlight the dependency of this service on short term funding. Transfer of funding to mainline LA budgets was crucial for service maintenance if specialised HIV funding were withdrawn. The geographical diversity of treatment centres presented particular service funding and delivery issues for haemophilia social care. Where posts were funded from Health sources it was crucial that the posts were managed by Local Authority Social Services to professionally monitor and support those staff. In larger Centres especially, caseload sizes should be carefully monitored. For new social workers coming into post, specific SIG training days should be arranged by the SIG with Haemophilia Society and BASW support; the social work needs of those attending smaller Centres should be further researched. Possibilities included the appointment of a worker in certain regions to work across a number of smaller Centres, or the inclusion in the job descriptions of the larger Treatment Centre social workers, a stated requirement to contribute to more tangible support and joint working networks, to relevant Area and smaller Centre social work staff.

34.5. E) I am unable to add information here. The Questionnaire as I recall was short, aimed at establishing social work service presence. The paper title was: ''The availability of a Social Work Service in Haemophilia Care." - Results of a Survey conducted in Spring 1989 for the Haemophilia SIG and Haemophilia Society, by the Newcastle Haemophilia Reference Centre .

By the time the Report was forwarded, I had left the Haemophilia Centre and had no further input or feed-back on the Report.

35. Please provide information detailing your professional relationship with other UK Haemophilia Centre Directors.

35.1. My links to the other Centre Directors were via Conferences but not major, rather with their Centre social workers.

Section 7: Other issues

36. If you have had, at any time, any significant discussions or conversations or interactions with senior clinicians at the Centre, about any of the matters set out in paragraphs 5 to 34 above or in the Inquiry's Terms of Reference, please

provide (to the extent that you are able to) details of those discussions or conversations or interactions.

36.1. I confirm I had no discussion whatsoever with senior clinicians at the Centre about the matters set out above.

37. Please provide, in as much detail as you are able to, information about any other issues associated with your work at the Haemophilia Centre that may be relevant to the Inquiry's Terms of Reference.

37.1. May I end by acknowledging the courage, fighting spirit, sadness and complexities faced by people with Haemophilia and HIV coming to the Newcastle Centre during my spell there as a staff member.

Statement of Truth

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

Signed GRO-C

Dated 24th June 2022