Witness Name: June Ward
Statement No.: WITN4056001
Exhibits: WITN4056002
Dated: 20/04/2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JUNE WARD

I, June Ward, will say as follows: -

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

   June Ward

   GRO-C

   DOB: GRO-C 1963

   Registered General Nurse
   Bachelor of Science- Nursing
   Non- Medical Prescriber
   Essentials Haemophilia Care

2. **Please set out your employment history as a nurse, including the positions you have held, the dates that you held these positions, the haemophilia Centre's and other organizations in which you held these positions and your role and responsibilities in these positions.**

CURRENT POST:

Jan-2020-Present	Colorectal Nurse Specialist	Support Specialist Nurses / department to collect, collate and report Surgical Site Infection Audit	NHS Tayside Colorectal Nurse Team Ward 9/10 Ninewells Hospital

Past posts

Jan1995-June 2018	Haemophilia & Anti-coagulant Nurse Specialist Band 7	Lead Nurse responsible for providing specialist-nursing care to patients and families affected by inherited bleeding disorders throughout Tayside & North East Fife. Provision of care in both adult and paediatric departments. Provide and facilitate home treatment programs, treat & prevent acute bleeding. Provide education, information, offer expert practical support to patients / families, emotional support and financial advice when appropriate. Liaise with multi disciplinary teams and other haemophilia centres, national groups to provide, maintain and enhance patient centred care.	NHS Tayside Haemophilia Centre Haematology Department Ninewells Hospital
1985-1995	Senior staff nurse	Senior staff nurse coordinating high standards of comprehensive nursing care and ward management within acute medical wards, intensive /coronary care/ infectious diseases (included HIV/ Total Parenteral Nutrition units) /infected orthopaedics	NHS Tayside Kings Cross Hospital & Ninewells Hospital Dundee
1984-1985	Staff nurse	Providing and leading a high standard of Nursing care within Acute Respiratory Medicine	NHS Tayside Kings Cross Hospital Dundee
1981-1984	Student Nurse	Comprehensive Registered General Nurse Training	Dundee Hospitals
1980-1981	Auxiliary Nurse	Acute Medicine/ stroke unit, offering basic care and assisting the wider nursing & medical team	Ninewells Hospital, Dundee

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 (which can be found on the Inquiry's website at www.infectedbloodinquiry.org.uk), including the dates of your membership and the nature of your involvement

Haemophilia Nurses' Association/ RCN	1995- 2018	Active member
Scottish & Northern Ireland Nurse Group	1995-2018	Active Member, Share chair
Haemophilia Society	1995- present	Member
Haemophilia Alliance	2004- 2006	Active Member Nurse Rep
Scottish Inherited Bleeding Disorders Network	date of conception	Nurse Representative in mid 2000's-2018

4. **Please confirm whether you have provided any evidence or been involved in any other inquiries, investigations, criminal or civil litigation in relation to human immunodeficiency virus ("HIV") and/or hepatitis B virus ("HBV") and/or hepatitis C virus ("HCV") infections and/or variant Creutzfeldt-Jakob disease ("vCJD") in blood and/or blood products. If you have, please provide details of your involvement and copies of any statements that you made.**

Yes. See attached Penrose Inquiry Statement. This is the only report I have submitted.

Section 2: The haemophilia centre at Ninewells Hospital, Dundee. ("the Centre")

5. **Please provide details of your role within the Centre, including the dates when you worked there, your responsibilities and, if you can remember, names of significant or senior staff members who were working there at the time.**

In this statement I have attempted to answer all of the questions asked of me accurately and to the best of my recollection. However, as it is over 25 years since I took up my post as haemophilia nurse, it is of course possible that my memory of the events described has been affected by the passage of time. My statement covers the period of my employment from 1995 until I retired in June 2018. I was not in post during the emergence of HIV/HCV in the 1980s. My role summary and responsibilities have previously been outlined in my Penrose Statement and in question 2 (past posts 1995-2018). Other significant / senior medical staff throughout my post included: Dr Philip Cachia, Dr Rosalie Wilkie, Dr John Dillon, Dr Margaret Peebles and Dr Ron Kerr. As I became a more experienced Haemophilia Nurse I worked at an advanced practice level.

6. **Please explain the hierarchy and dynamics at the Centre, identifying in particular who was responsible for (a) decisions as to the selection and purchase of blood products, (b) decisions as to use of blood products (including factor VIII and IX concentrates) for patients' treatment and (c) decisions as to what information to provide to patients about treatment, testing and/or diagnosis.**

Dundee Haemophilia Centre had, and remains to have, one Haemophilia Director. There had been one Haemophilia Specialist Nurse from 1995 until Autumn 2017. In 2017 as part of succession planning the nurse post was split between adults and paediatrics. In my time as Haemophilia Specialist Nurse, the Haemophilia Director post was held by Dr (now Professor) Philip Cachia until he left to take up post as Post Graduate Dean around 2003/2004. The post was then filled by Dr Ron Kerr, Consultant Haematologist who remains in post. The paediatric patients were cared for by Dr Rosalie Wilkie, until her retirement in early 2000's, then by Dr Margaret Peebles until present day. Dr John Dillon was appointed as Consultant Gastroenterologist in late 1990's and I am aware he remains in post. The adult service liaised with Dr Dillon who advised the haemophilia team on aspects of care around hepatitis C. This liaison

work by all teams included team meetings, combined clinics, educational / information sessions for both staff and patients. The Haemophilia Director was at the lead of haemophilia care however, this was always a democratic and shared process utilising the experts required e.g. if there was a paediatric problem this was referred to the Paediatric Consultant, hepatitis C to gastroenterologist, musculoskeletal problems to departmental or community physiotherapy or an Orthopaedic Surgeon, dental problems to the dentists or oral –maxillofacial team. The team, since I commenced, offered patient centred comprehensive care.

a) decisions as to use of blood products (including factor VIII and IX concentrates)

From memory in the mid to late 1990's procurement of blood products initially was organised by The Scottish Haemophilia Directors who had worked hard to gain agreement from all health boards to set up a National consortium to purchase Recombinant FVIII & IX. The goals of this was not only to share risk throughout health boards of the cost of treatment/products particularly when inhibitor patients may present, but also to have improved bargaining power to try and drive down cost. This collaboration allowed an improved Scotland wide recording and reporting system to be set up regarding patient factor use, batch numbers, procurement systems and national contracts to be agreed and instigated. It was important to have information on product use in order to predict future use and maintain accurate records. Some other products were included in this system and to my knowledge the Scottish Haemophilia Directors (Dr Cachia representing our centre) liaised directly with NHS Scotland Procurement and later with NSD to set, negotiate and purchase products all of which were recommended by UKHCDO treatment guidelines. Over many years this system developed and allowed an organised system to introduce and roll out recombinant products for all throughout the mid-late 1990's. As a Scottish Haemophilia Centre we were part of this system with our Comprehensive Centre being Edinburgh

and part of the East Coast Reporting system. This system allowed stock to be held in our centre and we would prescribe directly to our patients both for acute bleeds and home treatment. At all times if there where alternatives to using human derived products e.g. use of DDAVP, this was always considered to minimise patient exposure to plasma derived products due to the past risk and unknown pathogens. In more recent years a similar system was adopted but as a UK wide system and national contracts. Medical, nursing and national procurement representatives worked together to organise these contracts which also allowed home delivery to patients to be rolled out. Initially within our Centre the Director, Consultant Paediatrician or Specialist Registrars would prescribe factor concentrates. When I completed my non-medical prescribing I also took over this role from 2007.

b) decisions as to use of blood products (including factor VIII and IX concentrates) for patients' treatment

Decisions regarding blood product choice were made in accordance with UKHCDO treatment guidelines, national contracts and clinical need. As a prescriber consideration of proven safety profiles, viral profiles, inhibitor rates, guarantee of supply, patient ease and preference to use were required to make choices of products. Every effort was made to avoid 'switching' products and if at all possible to give out recurrent batches to patients for home treatment or to cover surgery.

(c) decisions as to what information to provide to patients about treatment, testing and/or diagnosis.

See previous Penrose statement which gives a good summary of care, clinic and routine practice within the centre in the early years which continued throughout my posting. In my opinion, our Centre and team practiced in an open, honest and professional manner at all times. Our

patients' care and wellbeing was at the centre of all decisions. We included the patients/families at organised appointments to discuss individual cases. In addition, we offered home visits, patient group meetings to share information, share changes in treatment, developments in practice, home delivery and any factor which would influence their care or treatment. Routine tests and specialist tests would be fully discussed with patients outlining the reasons why they were required, risks/benefits and need for treatments. At all times the patients were offered all currently known and relevant information so they could make an informed choice. We had sourced many patient information sheets primarily through the Haemophilia Society, British Liver Trust and World Haemophilia Organisation. These outlined expected standards of haemophilia care and treatments, routine and special tests, information about disease process, recombinant and other treatments, hepatitis C, HIV, genetics and arthritis. These were offered to patients after consultation to assist in sharing information and giving patients a source of written information to take home with them so that they may be more informed. From around 2000, when the Centre moved to the west block of the hospital, there were information leaflets freely available within the waiting area of the Centre. After receiving information in clinic, some patients chose not to take leaflets. Usually they would prefer to have further verbal conversation/follow up by phone or face to face appointments. Whatever they wished we tried to facilitate.

As treatments and tests evolved, particularly in relation to recombinant or new treatment choices, this was relayed to patients in a similar format usually within clinic, but also at home visit, by letter or by phone whichever was most suitable to patients or their family. Over the 2000's in relation to HCV, specific tests, treatment and information we routinely offered more combined appointments with the gastroenterology team who led on the information regarding HCV treatment options, success rates and organised the patients' prescriptions.

Section 3: Knowledge of risk

7. **What was the Centre's approach and the approach of senior clinicians at the Centre[1] to the use of blood products (in particular factor VIII and IX concentrates)?**

   To use FVIII & IX where appropriate for acute bleeding, provide prophylaxis to reduce musculoskeletal problems thus enhance patients socio-economic wellbeing and reduce admission to hospital. All products were used in keeping with national guidelines and appropriate clinical need.

   How did this change or develop over time?

   This practice was adopted throughout my posting.

8. **What were the Centre's approach and the approach of senior clinicians at the Centre to home treatment and to prophylactic treatment for patients with bleeding disorders?**

   As explained previously in my Penrose statement, initially there was little or no organised home treatment or prophylaxis for children prior to 1995. Some adults were using home treatment but more on an on demand basis. The senior clinicians have always driven and supported prophylaxis. The benefits were to reduce acute life-threatening bleeding,

reduce musculoskeletal complications and pain, reduce admission to hospital and to improve patient autonomy. Health and well-being was a key driver within our team. Each patient had differing needs in relation to prophylaxis and we tried to tailor treatment to the specific needs of the patients.

How did this change or develop over time?

Only when there was national shortage of product in late 1990's was this changed to conserve treatment for emergency use and to maintain children on prophylaxis.

9. **What was the Centre's approach and the approach of senior clinicians at the Centre to the use of factor concentrates for children with bleeding disorders?**

Senior clinicians always followed UKHCDO treatment guidelines to guide prophylaxis within our Centre. However, individuals, particularly children, do require deviance from guidance to meet the child and family's needs. Recombinant or use of non- plasma derived products were always chosen over a plasma derived products if possible and if appropriate.

How did this change or develop over time?

When new generations or long-acting products became available all of the team were keen to provide our patients with access to these.

10. **Do you recall any policies or standard operating procedures (written or otherwise) relating to the use of blood products being in place? If so, please describe what they were and whether they changed or developed over time.**

Our local treatment guidelines were based on the UKHCDO treatment guidelines, outlining treatment dose and choice of products. We used standard operating procedures for obtaining factor products and to

record products. These were used both in paediatric and adult services. These were changed and adapted over time to accommodate changes and developments in treatments, practical facilities e.g. location of fridges etc. In addition, there were clear written treatment and expected response guidance sheets for individual patients within their medical and nursing notes. Also most severe haemophilia patients/parents were provided with a hand held response sheet /letter to present to any known A&E facility should that be required.

11. **What was your general understanding as to the risks of infection associated with the use of blood and blood products?**

Using pooled plasma products or any human derived product had greater risks than using recombinant products. Avoidance or reducing exposure to blood or blood products was desirable.

What was the source of your understanding?

Scientific papers, UKHCDO guidelines, WFH, papers, attendance at conferences, haemophilia nursing course.

Were you provided with any information or training, whether at the Centre or elsewhere, about the risks of infection and if so when?

Yes, conferences, courses.

How did your understanding develop over time?

My knowledge grew and my understanding of donor selection, why products were heat treated, viral inactivation, screened and batches recorded was clear. As new products are available the lessons learnt from past generations to continue to provide safe, effective and sustainable products is required. I understood that recombinant products with the

least addition of human or animal protein will reduce the risk of exposure to infective agents as will virus removal and inactivation processes.

How did your knowledge affect your nursing practice?

I understood the need to be aware of these risks to enquire about product safety profiles and source. To share information with patients and ensure they had information about the products they were using. To avoid using any human derived products if possible.

12. **What was your understanding as to the risks of the transmission of hepatitis (including Hepatitis B and Non A Non B Hepatitis/Hepatitis C) from blood and blood products?**

Always a risk if using any human derived blood product. Risks reduced by donor & batch screening, viral inactivation steps.

What was the source of your understanding?

Scientific papers mostly, conferences and study days.

When did you first become aware that hepatitis could be transmitted by blood or blood products?

January 1995 when I commenced my post as a haemophilia nurse.

Were you provided with any information or training, whether at the Centre or elsewhere, about the risks of the transmission of hepatitis and if so when?

From 1995 onwards within in-house tutorials, attendance at conferences, study days and reading scientific papers.

How did your understanding develop over time?

My knowledge grew and my understanding of donor selection, why products were heat treated, viral inactivation, screened and batches recorded. As new products are available the lessons learnt from past generations were implemented to provide safe, effective and sustainable treatments. I understood that recombinant products with the least addition of human or animal protein will reduce the risk of exposure to infective agents and the need for virus removal and inactivation processes.

How did your knowledge affect your nursing practice?

I understood the need to be aware of these risks and to enquire about product safety profiles and source. To share information with patients and ensure they had information about the products they were using. To avoid using any human derived products if possible. I had knowledge about the disease process of HCV and how it may affect my patients. I understood why it was important to offer screening tests to monitor for HCV complications so early detection and treatment may be offered. I understood patients' fears and concerns and tried to provide them with practical support, information and emotional support as they required. Some patients asked for more formal psychological support which we organised through our departmental psychology support service. However, this was little used.

13. **What was your understanding as to the risks of the transmission of HIV from blood and blood products?**

What was the source of your understanding?
When did you first become aware that HIV could be transmitted by blood or blood products?

Were you provided with any information or training, whether at the Centre or elsewhere, about the risks of the transmission of HIV and if so when?
How did your understanding develop over time? How did your knowledge affect your nursing practice?

My answers would be the same as for question 12. However, in addition we had only one patient who had HIV who was looked after by the Edinburgh CC. He died shortly after I commenced in post.

14. **What was your understanding of the relative risks of infection from (a) the use of commercially supplied blood products and (b) the use of NHS blood and blood products? How did your understanding change or develop over time?**

Since my employment in 1995 all NHS and commercial products had viral inactivation steps added thus rendered as safe as could be. Therefore, same risk for both.

15. **Was any training or advice provided (and if so, what training or advice) to clinical staff at the Centre in relation to advising patients of the risks of infection associated with the use of blood and blood products?**

I cannot recall any specific training. Our consultants were very experienced clinicians with many years' experience of sharing information/bad news with patients. I had undergone a generic counselling skills course and utilised my own experience and knowledge when advising patients of any information. Generic and ongoing training throughout my nursing training and post registration education was used.

Who provided this training or advice?

Counselling course - Dundee College Dundee College of Nursing & Midwifery

Abertay University

Study Days/ Conferences

16. **Were any steps taken at or by the Centre to mitigate or reduce the risk of infection from the use of blood or blood products? If so, please detail what steps were taken and when.**

Adhered to good practice as outlined in UKHCDO guidelines.

Section 4: Testing, treatment and care of patients

17. **What information was provided to patients at the Centre about the risks of infection (generally and/or specifically in relation to hepatitis and/or HIV) associated with the use of blood and blood products, and by whom?**

For patients who were newly diagnosed and/or had never been treated they would usually meet with the consultant and myself. A full explanation of the disease, disease process, available treatments, risks, tests and expected care was discussed. For patients who were HCV positive I have explained how initially the testing and advice were given in my previous Penrose statement. Our Centre operated in an open and honest manner and we strived to inform our patients in all aspects of their care so that they could make informed decisions about disease process, tests and treatments.

18. **What information was provided to patients at the Centre about alternatives to treatment with factor concentrates, and by whom?**

We offered advice and information both verbally and written to treat minor bleeds, e.g. first aid techniques, use of tranexamic acid and DDAVP.

We offered physiotherapy and homeopathy to try and minimise factor concentrate need. Both medical & nursing staff undertook this.

19. What information was provided to patients at the Centre before they began home treatment, and by whom?

The practical issues of undertaking home treatment were discussed at clinic. To ensure patients/parents were competent to reconstitute and administer factor concentrate a number of factors were taken into account. The Scottish & NI Nurses group had devised a home treatment training pack which I particularly used within our Centre when commencing home treatment. This ensured there was a methodical approach to introducing home treatment and covered all aspects of home treatment from reconstitution, administration, safety, record keeping and attendance at clinic. It also recorded practical sessions with parents/child. When home delivery was introduced a complete pack requiring patients to read and signed consent had to be given by patient or parent to agree to comply with record keeping and attendance at clinic. This was primarily my role to ensure this was completed.

20. What was the Centre's approach and the approach of senior clinicians at the Centre to obtaining patient consent to treatment and to testing?

Consent was always sought when organising simple or more complex tests. Treatment options with risks and benefits were clearly explained no matter what treatment was being planned or offered. The consultation was recorded in the patient's notes and a letter to the patient's GP was sent.

What information would be provided to patients and by whom?

Full information of any tests or treatments was given by the appropriate member of staff.

To what extent were decisions about treatment and testing taken by the doctors rather than the patients? Did this change or develop over time and if so how?

Patients were always fully informed of treatments or changes to treatment and why these were necessary. This was always our usual practice since my employment in 1995.

21. **Was any training or advice or instruction provided to you at the Centre in relation to obtaining patient consent to treatment and to testing? If so, please describe the training, advice or instruction given.**

I cannot recall specific training or course. However, at my attendance at World Haemophilia conferences, HNA, other study days, nurse codes, this was frequently discussed. I can recall UKHCDO guidance, Haemophilia Alliance National Guidance then specific Scottish Guidance clearly giving instruction around consent, treatment, information, record keeping. We followed this guidance and adhered to good practice re consent to treatment or tests.

22. **Were you ever told to withhold information from a patient or patients about risks, or treatment, or testing, or diagnosis, or their condition? If so, by whom and in what circumstances?**

No- never.

23. **Was it customary to take blood samples from patients when they attended the Centre and for what purpose?**

Yes. To monitor their general health, monitor for any derangement and inhibitor development. Look for response to treatment that patients were undergoing.

What information was given to patients about the purposes for which blood samples were taken, and by whom?

Our patients were seen for their review consultation prior to blood tests being performed. Clear information about why tests were being undertaken was given by both medical and nursing staff throughout the consultation. For example, if we were taking liver function tests we explained that these were to monitor liver function in relation to their hepatitis C status. Patients were informed this was to assess and monitor for progression of liver disease. These tests were advised to be performed in local and national guidance for Hepatitis C patients. Prior to the actual venepuncture my routine practice was to speak with the patient as I took the sample, reminding and re-enforcing with the patient why the sample was being taken e.g. 'the yellow one is for your liver function tests that, as you know, we monitor 6 monthly'. This also gave the opportunity for our patient to ask other question we had not already answered throughout the consultation.

24. **What information would routinely be given to patients about liver function tests and the results of such tests?**

After a consultation our team would review all blood test results and share with patients as they wished. Some patients wished phone calls with feedback on all tests, most patients were happy to wait until their next clinic visit to get feedback of results. Some patients wished written results for their own records. Whatever system the patient wished we complied with. If there was a change or unexpected deviation in results we would routinely call patients and ask them to revisit for review, discuss and retest. Routinely at review appointments we always discussed previous blood test and scan results updating the patient on any changes and discussing what these changes may mean, answer any questions and plan or order more tests as required and with their consent. As mentioned previously, dependent on

what had changed we had patient information booklets that we could offer if patients wished more information. These were devised by the British Liver Trust and UK Haemophilia Society.

25. **Were patients informed if their blood was going to be tested for HIV, HBV and/or HCV and, if so, by whom?**

Yes, by both medical & nursing staff.

Did the approach to informing patients change over time?

No

26. **What was the practice at the Centre about informing patients of test results (whether positive or negative or inconclusive) for HIV, HBV and/or HCV?**

We generally arranged a return visit for results test. However, for some patients due to geography, mobility or work issues this was not practical and we would discuss with patient how they wished to receive test results usually by phone with a letter also.

Were patients informed of the test results promptly or were there delays in test results being communicated to them?

Informed promptly with no delays.

How, as a matter of usual practice, were they advised of their test results (e.g. by letter, or by telephone, or in person at a routine appointment or at a specific appointment) and by whom? What, if any, involvement did you have in informing patients of test results?

As explained above, usually at clinic visit or an agreed plan with patient. Initially by medical staff, but I undertook this role in their absence when I was an experienced haemophilia nurse.

27. What information or advice was provided to patients diagnosed with HIV, HBV and/or HCV regarding the management of their infection including the risks of infecting others?

As explained in Penrose statement.

How did this change or develop over time?

As knowledge and treatment options evolved this was fully shared with patients individually at routine review visits, organised patient group meetings and by the gastroenterology team as they also saw patients in relation to HCV tests and treatment.

28. What was the practice at the Centre as regards testing and/or providing information to the partners and/or family members of people known or suspected to be infected with HIV, HBV or HCV?

Patients who were known to be positive were encouraged to attend with wives and with long-term partners. We encouraged all our patients to discuss their status with their wives and long-term partners. We provided wives and partners with advice and gained consent for testing on request.

29. Was any form of counselling or psychological support made available to patients infected with HIV, HBV and/or HCV or to their families?

Yes

If so, please detail what support was available.

Some patients requested formal psychological support thus they were referred to clinical psychology. At the outset, when most of our patients were given diagnosis in the mid to late 1990's, there was no formal arrangement to have them routinely seen by a clinical psychologist for formal counselling. Most appeared to be content with the information and support offered by our team. Over many years some patients displayed varied levels of anxiety, fear and of other health concerns not always associated with HCV. The patients or family member were referred onto psychology with their agreement and consent. More recently patient groups and SNIBD group sought and secured funding for clinical psychology projects in Scotland. Prior to this although most centres could access psychology services they had had no onsite specific teams. This enabled a more speedy referral to psychology support. These practitioners were very knowledgeable of our patients' disorders and their needs. In my opinion this was a great advancement in psychological support for our patients and their families. This team offered appointments within the Centre and/or home visits.

30. Was any form of social work support made available at the Centre to patients infected with HIV, HBV and/or HCV or to their families?

Yes

If so, please detail what support was available.

As a HC we had no standalone social worker. In the late 1990's we had a designated social worker for haematology thus we were able to refer and access her advice and support for our patients. This service was cut and thus thereafter we would refer our patients to the general social work department when required. We also utilised the national Haemophilia Society Social workers and encouraged our patients to contact them as they

were very knowledgeable around all aspects of benefits/welfare rights available to our patients.

31. How was the care and treatment of patients diagnosed with HIV, HBV and/or HCV managed at the Centre?

In accordance with national guidance.

What treatment options were offered over the years to those diagnosed with HIV, HBV and/or HCV?

All treatment options available at the time were discussed and offered. These were set out in local and national guidelines which I believe the Inquiry has in their possession from previous expert witnesses.

What follow-up and/or ongoing monitoring was arranged?

Appropriate to patient needs and requirements. Usually 3- 6 monthly routine visits to Centre.

To what extent were patients at the Centre referred for specialist care elsewhere?

Patients were referred when specific needs were required, e.g. liver specialist, surgery.

How did any of this change or develop over time?

Liaison with HCV team improved and developed. Laterally most patients were seen independently by gastroenterology team to organise tests, commence treatment options and monitoring of complex cases.

32. **Do you recall patients diagnosed as HIV, HBV and/or HCV positive being treated differently to others? If so in what respects?**

No

What if any measures were implemented to address any risks of cross-infection?

No specific measures as we followed NHS Tayside guidance and protocols for high risk patients which advised universal precautions for all.

33. **To your knowledge, were clinical staff made aware of patients' infected status in relation to HIV, HBV and/or HCV?**

In keeping with high risk guidance of the time to ensure appropriate clinical waste be disposed of, the medical notes were highlighted as being high risk. Guidance has evolved and this is now recorded as alerts on the inside of patients' notes and on electronic systems.

34. **Please describe as fully as you can your involvement in the treatment and care of those who were infected with HIV, HBV and/or HCV.**

In our Centre there were no patients who were co-infected with HIV and HCV. There was one patient who, prior to my employment, had chosen to be looked after by Edinburgh and he died very early when I came to post in 1995.

As a specialist nurse I supported all inherited bleeding disorder patients who attended the Centre. There was a group who were infected with HCV. My role was to practically assist them to manage their bleeding disorder, review and monitor their blood results and refer to medical staff as required. I would offer information and facilitate educational sessions on all aspects of their care, treatments and tests. I acted as their advocate and provided a link to their consultant and on occasion acted as their voice at

national meetings. Specifically, in relation to HCV I would be present at clinics for any new or review appointments. I would assist to organise tests and obtain blood samples as required. In conjunction with the gastroenterology team we would organise prescriptions for treatment and I would demonstrate treatments and ensure patients understood their medication and how to self-inject treatments for HCV. I provided them access to the consultants responsible for their care.

and what you can recall about the impact of the infection(s), and/or of treatment for the infection(s), and/or of the stigma associated with the infection(s), upon them and upon their families over the years.

Patients had to cope with their bleeding disorder, arthritis and pain and also HCV, 3 chronic conditions. In my opinion the impact of being HCV positive did impact on all who were given this diagnosis. Most voiced a sense of fear, dread and uncertainty for the future. There was a general anger and some mistrust of the treatments particularly with plasma derived products. When recombinant products were made available this eased. Some patients had a bitter and prolonged mistrust of the NHS and the haemophilia care system. Some patients wanted to know all aspects of disease process whilst others wanted to shut out the information and dealt with the diagnosis by only speaking about it when they were in clinic then trying to forget about it when they left. They had to cope with their families and general public misunderstanding of their disease and lack of HCV knowledge of other healthcare professionals. This often caused further frustration and anger. It appeared that some marital relationships were certainly impacted with some couples separating and not coping with the strain of diagnosis. Some young men reported they had difficulty around who to tell, what to tell and when to tell. Some patients reported that they had difficulty getting life insurance, mortgages or travel insurance. In some cases, some patients reported using alcohol to cope with the diagnosis and living with HCV. Different people displayed

different coping mechanisms. Some patients and families were open about their feelings others wanted not to dwell on HCV and did not want that to define them. Some men experienced death of their brothers, cousins and friends from HCV which clearly impacted on their emotional wellbeing and impacted on their lives.

When treated with HCV treatments some coped with these well while others had an array of side-effects of fatigue mostly. From memory this was certainly present with all who underwent interferon treatments. The later treatments appeared more tolerable with fewer side effects.

Section 5: Research

35. **Please detail any knowledge you have of any research that may have taken place at the Centre including the names of clinicians who were involved in or leading the research.**

SNBTS LIBERATE Study – Dr Cachia
SNBTS DEFIX - Dr Cachia
JOINT Study - June Ward
As we were a small Haemophilia Centre we were usually not invited to take part in research studies.

36. **To your knowledge, were patients made aware of their being involved in research? What was the approach taken with regards to obtaining their consent to such involvement?**

Yes, patients were recruited, informed and consented to take part.

37. **What does the term 'PUPS', an acronym for a category of patients referred to as 'Previously Untreated Patients', mean to you?**

Previously Untreated Patients described patients never exposed to factor concentrates.

Was the term used at the Centre and if so by whom and in what respects?

Yes, when describing previously untreated patients.

Section 6: vCJD

38. Were you aware of the risks of transmission of vCJD associated with the use of blood and blood products?

Yes

If so, when and how did you become aware?

Late 1990's and then became more aware early 2000's

39. What was the process at the Centre for informing patients about possible exposure to vCJD?

As per the HPA and UKHCDO directive in early 2000's

When and how were patients told of possible exposure to vCJD?

HPA, in conjunction with UKHCDO and HNA, composed letters and information. All affected patients were contacted by letter in early 2000's.

40. What information was provided to patients about the risks of vCJD?

In the UK there was agreed patient information and letters sent by all Haemophilia Centres that had been devised by HPA, UKHCDO, HNA and I

believe Haemophilia Society. I understand the Inquiry has copies supplied of this information

41. What counselling, support and/or advice was offered to patients who were informed that they might have been exposed to vCJD?

Letters offered to patients clearly asked patients to contact the Centre if they wished appointments to discuss further which from memory most of our patients did. If a patient wished further counselling this could be arranged. The letters also stated to respond if they did not wish further information in the future.

Section 7: Effect on clinical staff

42. 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?

Our knowledge expanded but we practiced similarly to share our knowledge with our patients and their families at clinic review appointments and organised patient group meetings. Safety of patients was paramount. We followed local and national protocols with universal precautions applied to all.

43. **What was the Centre's protocol for reporting concerns or complaints about staff and/or patient safety?**

As per NHS Tayside Guidance.

Did you ever report any concerns or complaints?

Yes

If yes, who did you report these to?

NHS Tayside reporting systems laterally DATIX system and SBAR. All incidents were shared and reported to Centre Director and Nurse Manager. However, I cannot recall any reported in connection with HCV, HBV, HIV or vCJD

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

Personally I had, and continue to have, great sympathy and empathy for our patients and families who had to cope with their chronic disease and of course the uncertainty of HCV. After caring for men and their families for more than 20 years, when some had died of HCV, or related illnesses, it did affect me greatly. Emotionally I was greatly upset and felt very low at times as I knew how these men had loved and lived their life, they had families who relied on them and that their future was stolen from them. It is one of the reasons I retired from nursing. However, I always felt I had done my best for those patients and families and that gives me great comfort.

As I write this amidst the COVID 19 pandemic it reminds me of the fear and uncertainty that we now experience as individuals and as a society, this is probably very like the fear, anxiety and uncertainty the haemophilia men and their families had to endure over many years.

Professionally I kept up to date with the latest information about HCV so that I could advise them as best I could or refer them to experts if and when there was a deficit in my knowledge. Our team and the gastroenterology team worked well providing information, arranging timely required tests, monitoring and screening for progression of disease so that action or intervention could be taken speedily to improve outcomes. When treatments were made available we pushed for our haemophilia men to be offered these. Indeed, we achieved after a number

of years for all to be successfully treated and HCV negative. However, this was too late for some.

Section 8: Other Issues

45. Were you aware of any of the trusts or funds that were set up to provide financial assistance to people who had been infected (such as the Macfarlane Trust, the Eileen Trust, the Skipton Fund and the Caxton Foundation)?

Yes, all but the Eileen trust are familiar to me.

46. Were patients at the Centre provided with any information about these organizations or with any assistance to obtain financial support from them?

Yes

If so, what information and/or assistance was provided?

We referred and assisted all our eligible patients to apply for the Skipton Fund and some who were in financial difficulty to the Caxton Fund. We supplied contact information for both, assisted with applications and to complete forms

47. Please detail any involvement or dealings you had with any of these organizations.

Only to contact when required to get assistance for our patients

48. What were the retention policies of the Centre in regards to medical records during the time that you worked there?

As in keeping with NHS Tayside policies.

49. **Did the Centre, or any clinicians at the Centre, keep any separate records or files or information about patients who had been treated with factor concentrates and/or patients who had been infected with HIV, HBV and/or HCV?**

Not to my knowledge. We did have separate nursing records kept within the Centre to allow quick and speedy treatment for the patient's bleeding disorder, particularly useful for ward and on call staff.

50. **If you have had, at any time, any discussions or conversations or interactions with senior clinicians at the Centre about any of the matters set out in paragraphs 5 to 46 above, please provide (to the extent that you are able to) details of those discussions or conversations or interactions.**

I am aware that working documents, minutes of pertinent meetings and groups have been submitted to the Inquiry by the Centre. These contain and minute our joint discussions around topics.

51. **Please provide, in as much detail as you are able to, information about any other issues associated with your work at the Centre that may be relevant to the Inquiry's investigation. You will find the Inquiry's Terms of Reference and List of Issues on the Inquiry's website www.infectedbloodinquiry.org.uk t]. If you are in doubt as to whether or not to include something, do not hesitate to contact the Inquiry Team.**

Nothing further to add.

Please also identify any documents which you have that might be relevant to the Inquiry's Terms of Reference.

I have no access to any haemophilia documents and I understand the Centre has recently supplied all pertinent documents to the Inquiry Team.

Statement of Truth

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

Signed GRO-C

Dated 20/4/20