Witness Name: Professor Gordon Lowe
Statement No.: WITN3496001
Exhibits: WITN3496002 - WITN3496012
Dated: 28th January 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF PROFESSOR GORDON LOWE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 28 June 2019.

I, Professor Gordon Lowe, will say as follows: -

Section 1: Introduction

1.1 My name is Professor Gordon Douglas Ogilvie Lowe.

1.2 My date of birth is GRO-C 1949.

My address is c/o Central Legal Office.

I hold the following qualifications: -

MB,ChB (with Honours)	1972 University of SaintAndrews
MRCP	UK1974
JCHMT Completion of Training in General (Internal) Medicine	1980
MD by Thesis (with Commendation)	1984 University of Dundee
FRCP (Edinburgh)	1986
FRCP (Glasgow)	1986
FRCP (London)	1989
FFPHM (Honorary)	2001
DSc by Thesis (Medicine)	2006 University of Glasgow

1.3 I have held the following University and Honorary NHS (Glasgow Royal Infirmary) positions: -

- Lecturer in Medicine, University of Glasgow Department of Medicine, Glasgow Royal Infirmary; and Honorary Senior Registrar in Medicine, Glasgow Royal Infirmary; January 1978 – September 1985. General (Internal) Medicine, with interests in thrombosis, haemostasis, and vascular medicine.

- Senior Lecturer in Medicine, University of Glasgow Department of Medicine, Glasgow Royal Infirmary (October 1985-1992), promoted Reader in Medicine (1992-1993), then Professor of Vascular Medicine (1993- September 2009); and Honorary Consultant Physician, Glasgow Royal Infirmary (October 1985-September 2009). Teaching, research and clinical practice in general medicine, thrombosis and haemostasis, and vascular medicine.

- West of Scotland Haemophilia and Thrombosis Centre, Glasgow Royal Infirmary; assisting Senior Lecturer and Honorary Consultant Physician Dr Charles Forbes (who was Co-Director, with Dr George McDonald, Consultant Haematologist) (October 1985- 1987);

- Co-Director (1988-September 2009) with Dr McDonald (1988-1990), liaising with Dr John Davidson, Consultant Haematologist with interest in haemostasis and thrombosis and who was in charge of Blood Bank, including ordering of blood products and recombinant clotting factor concentrates; and with Dr Isobel Walker, Consultant Haematologist with interest in haemostasis and thrombosis (including women and children at Glasgow Royal Maternity Hospital); then with Dr Walker as Co-Director, (1991-September 2009) who was also Honorary Professor of Perinatal Medicine; and also as Co-Director with Dr Campbell Tait, Consultant Haematologist with an interest in haemostasis and thrombosis (2000-September 2009). After Dr Davidson retired in 1996, Drs Walker and Tait were in charge of Blood Bank.

- Honorary Professor, Bioengineering Unit, University of Strathclyde; 1998-2009

- Emeritus Professor and Honorary Senior Research Fellow, Institute of Cardiovascular and Medical Sciences, University of Glasgow, October 2009-present.

1.4 I have been a member of the following committees or groups: -

- Scottish Society of Physicians, member 1979-
- British Society for Haematology, member 1980-; Scientific Advisor (1994-97); member, Working Party on Fibrinogen (1995-2001)
- British Society for Haemostasis and Thrombosis, member 1982; committee member 1987-92; President 1990-1991
- International Society for Thrombosis and Haemostasis, member 1982-; Vice-President 2001-2003; Senior Advisory Member (2003-); Investigator Recognition Award 2009
- Scientific Services Advisory Group, Scottish Home and Health Department, member 1987-88
- UK Haemophilia Centre Directors (then Doctors) Organisation (UKHCDO), member 1988-2009; organiser of Comprehensive Care Centre national audit 1992-2000
- Scotland and Northern Ireland Haemophilia Centre Directors Committee (SNIHCDC), member and Co-chair 1988-2009
- Scottish Home and Health Department, Scottish National Blood Transfusion Service, and SNIHCDC Annual meetings, and meetings of its Coagulation Factor Working Party, member 1988-2009
- Glasgow Royal Infirmary Stroke Service Development Group, chair 1993-97
- RCPE – Deputy Assessor 1993-98; Assessor and member of Council 1999-2003
- Health Sciences and Public Health Research Committee, Chief Scientist Office, Scottish Home and Health Department, member 1995-99
- Clinical Audit and Resources Group (CRAG), Scottish Office Home and Health Department, member (and member of its Clinical Outcomes Subcommittee) 1996-2002
- Scottish Intercollegiate Guidelines Network (SIGN), member of Council 1998-2003; Chair 2002-2005
- Clinical Outcomes Group, NHS Quality Improvement Scotland, member 2003-2008
- NHS Scotland Recombinant Coagulation Factor Working Party member, 1997-2002

Section 2: Responses to criticism of GRO-B

1. I am grateful to the Inquiry for affording me the opportunity of commenting on the criticisms made of me by Mrs GRO-B I have set out each criticism I have been asked to comment on and provided my response underneath. In preparing my responses, I have read Mr GRO-B 's case records of Glasgow Royal Infirmary, provided to me by its Records Department from 8 November 2019.

2. In 1986, Dr Anna Pettigrew, Clinical Assistant at the Haemophilia/Haematology Department at the Royal Hospital for Sick Children, Yorkhill, Glasgow referred Mr GRO-B to the Adult Haemophilia Centre, Glasgow Royal Infirmary for transfer of his haemophilia care.

3. Our Haemophilia Centre routinely sent all registered patients review appointments (six-monthly for patients with severe haemophilia, and annually for patients with milder haemophilia), in accordance with UK Haemophilia Directors' recommendations (Giangrande PLF. The management of Haemophilia, Christmas Disease and von Willebrand's Disease, p 201-226; and Jones P. Setting standards of care, p 456-480; both chapters in: Rizza CR, Lowe GDO, eds: Haemophilia & Other Inherited Bleeding Disorders. London: W B Saunders, 1997). There were several reasons for encouraging attendance at regular reviews, including keeping Centre records up to date (patient's current address and general practitioner address); reviewing their family history, general health; bleeding problems, treatment developments and options; and performing routine blood tests including testing of factor levels, presence of factor inhibitors, and transfusion transmitted infections (see Giangrande, and Jones, references above).

4. From 1986 to 1995, our centre sent regular review appointments to Mr GRO-B Unfortunately, he never attended any of these, despite reminders from Centre staff of their importance (WITN2288002; WITN3496002 1 – letter from Dr Lowe 25 Jan 1988; WITN3496003 – letter from Dr Lowe 13 October 1989; WITN3496004 – letter from Dr Walker 11 October 1991; WITN2288003), From 1993, review appointments and reminder letters were sent to registered patients by the newly-appointed Centre staff-Dr Elizabeth Kirke, Clinical Assistant, and Centre Secretary. Dr Kirke's main duties were reviewing patients at the Centre, and recruiting patients for Scotland-wide Clinical Trials of efficacy and safety of High Purity SNBTS concentrates.

5. The only occasion that Mr GRO-B attended the Haemophilia Centre between 1986 and November 1995 was on 14 September 1988, to report a very painful abscess on his buttock, requiring much paracetamol, with nausea, and requiring admission to a surgical ward for drainage under haemostatic cover (WITN3496005 – letter from Dr Murray, 5 October 1988). Routine blood tests were normal, including liver function tests. He was asked to return for review on 25 October 1988, when his abscess was found to be healed at the surgical outpatient clinic, but there is no record of his attendance that day at the Haemophilia Centre for review of his haemophilia.

   I should comment that non-attendance at review clinics was very common among other patients with mild severity haemophilia, perhaps understandably in view of infrequent bleeding or need for surgery, compared to patients with severe or moderately severe haemophilia.

6. At paragraph 9 of her statement, Mrs GRO-B states that she and Mr GRO-B were not given adequate information to understand and manage Mr GRO-B's infection. Mrs GRO-B also states that they were not told of Mr GRO-B's blood being tested for Hepatitis C nor had they provided their consent for this to occur.

   The case records include a letter from Dr Annielle Hung, Haematology Registrar, to Mr GRO-'s general practitioner on 27 November 1995, to report Mr GRO-B's review at the Haemophilia Centre Review clinic on 7 November 1995, and the results of blood tests performed at that visit (WITN228003). Her letter states: *"I informed* GRO-B *about his risk of previous infection and he was agreeable to being screened for HIV and Hepatitis B, C and A serology."* There is also a note attached to this letter from Haemophilia Sister Ishbel McDougall: *"Hep C testing discussed with patient and testing carried out on 7/11/95".*

   There is therefore no evidence in the case records to support Mrs GRO-B's statement that *"they were not told of Mr* GRO-B *s blood being tested for Hepatitis C nor had they provided their consent for this to occur."*

   The case records also include a letter from myself to Mr GRO-B's general practitioner on 7 December 1995, to report my review of Mr GRO-B at the Haemophilia Centre review clinic on 5 December 1995 (WITN2288006). My letter states: *"I explained to him that his HIV antibody test was negative, but that he is a carrier of the Hepatitis C virus; having both a positive antibody and positive Hepatitis C antigen by the PCR test.*

Liver function tests are still not available but we have repeated these at the clinic. As regards Hepatitis B, I see from his old notes that he was core antibody positive in 1988, suggestive of natural immunity. However, it was reasonable to proceed with a full course of Hepatitis B vaccination as his anti-HBS titre is zero – as noted by Dr Hung.

We are still waiting for his up-to-date Factor VIII levels. I gave him the Hepatitis C booklet produced for patient information by the Haemophilia Society and had a long discussion with him about the implications of carrying the Hepatitis C virus and the risk of possible liver disease. He was given advice about precautions with blood and body fluids and will discuss the implications with his wife. I have arranged to see them both in two weeks' time to answer any questions that they may have and offer testing to his wife should she wish it. He was advised to keep his alcohol consumption low. We will monitor his liver function tests and, in due course, refer him to Dr Morris, our consultant hepatologist for consideration of possible Interferon therapy.

His two daughters GRO-B *aged 13 and* GRO-B *aged 9 attended with him and we took blood to check their own Factor VIII levels."*

The case records also include –

- Note 19 December 1995 that Mr GRO-B and his wife did not attend the appointment with myself (for further discussion of Hepatitis C infection, answer any questions, and offer testing to his wife should she wish it). (WITN3496006).
- Letter from Dr Elizabeth Kirke, Clinical Assistant, Haemophilia Centre to Mr GRO-B s general practitioner on 14 February 1996, following her Clinic review of Mr GRO-B on 13 February 1996. She confirmed that the Centre had arranged for Mr GRO-B to see Dr. Morris to discuss the possibility of treatment of Hepatitis C infection with Interferon. She also reported the results of the Factor VIII levels of their two children, who were obligate carriers of haemophilia. (WITN3496007).
- Letter from Dr Morris to Mr GRO-B of 22 August, copied to his general practitioner, noting he had not attended two appointments at the Haemophilia Unit to discuss Hepatitis C infection. (WITN3496008)
- Letter from Dr Morris to general practitioner of 1 December 1996, following his meeting with Mr GRO-B and his wife on 4 November 1996. (WITN3496009). He noted no primary liver symptoms, excellent general health; and that his daughters and wife had been tested and all were negative for hepatitis C. He had detailed discussion with Mr GRO-B and his wife about the diagnosis of Hepatitis C, its

prognosis and therapies including side effects. A Doppler ultrasound of the liver and spleen (which were both normal in report of 15 November 1996) and pre Interferon screening bloods were arranged. Mr GRO-B was given an information booklet which would hopefully answer more of his questions.

- Letter from Dr Morris and Hepatitis C Specialist Nursing Sister Margaret Neilson to general practitioner of 21 February 1997, informing that Mr GRO-B had been prescribed Interferon for treatment of Hepatitis C. (WITN3496010)

There is therefore no evidence from the case records to support Mrs GRO-B's statement that "she and Mr GRO-B were not given adequate information to understand and manage Mr GRO-B's infection."

- Very shortly after Mr GRO-B was found to be a carrier of hepatitis C, I had a long discussion with him about its implications, risk of chronic liver disease, precautions with blood and body fluids (and need for discussion with his wife), and the importance of keeping alcohol consumption low. I gave him the Haemophilia Society information booklet on Hepatitis C for him to read and discuss with his wife; made an early appointment for further discussion with him and his wife (to include family testing for hepatitis C future monitoring of liver function) and referral to hepatologist Dr Morris for consideration of further investigations and antiviral (Interferon) treatment.

- Our management followed the recently-issued (December 1994) UK Guidelines on the Diagnosis and Management of Chronic Liver Disease in Haemophilia, issued by the UKHDCO Working Party on Chronic Liver Disease in Haemophilia (WITN3496011).

- Mr GRO-B and his wife eventually attended Dr Morris's clinic in November 1996, and were prescribed Interferon treatment in February 1997. Dr Morris and Sister Neilson, together with Haemophilia Sister Ishbel McDougall and Haemophilia Staff Nurse Elizabeth Little, established this Haemophilia/Hepatitis C Clinic in Glasgow Royal Infirmary in early 1996.

7. At paragraph 13 of her statement, Mrs GRO-B claims that while in a consultation with Mr GRO-B and myself, that there was no "long conversation" as suggested in my letter (exhibit WITN2288006).

- In my letter to Mr GRO-B s general practitioner of 7 December to report my review of Mr GRO-B at the Haemophilia Centre review clinic on 5 December 1995 (WITN2288006), I did indeed report a *"long conversation"* with him. This conversation followed my standard procedure for patients diagnosed to be carriers of Hepatitis C. I would plan that this would last about 30 minutes on average (finishing when the patient indicated that they had no further questions or issues to discuss), and it would follow guidance from UKHCDO. To reinforce information given, I would give the patient an information booklet (Haemophilia Society)) to read at home, and recommend that they discuss with wife or partner. By the end of 1995 I had had this conversation with many patients, so it was well-rehearsed.

- I would normally have this conversation in private with the patient, respecting their right to confidentiality, but recommending that the patient consider who they would wish to share the information with and discuss with (for example, spouse or partner) and offer an early appointment including them for further discussion. If Mr GRO-B s wife did attend our discussion, I would usually record this in the case records, and in my letter to the general practitioner – but these do not mention that Mrs GRO-B was present, so I am unsure whether she recalls that the conversation was not "long" because she was present, or whether this was what was reported to her by Mr GRO-B

- Whether or not Mrs GRO-B was present at my discussion with Mr GRO-B I do appreciate that there is a literature on recollections of doctor-patient discussions, for which there are often different accounts from doctors, patients, and others present at the discussion.

8. At paragraph 14 of her statement, Mrs GRO-B states that it was recorded that her two daughters were present at the consultation when Mr GRO-B s infection was discussed. In addition, Mrs GRO-B also states that their daughters were then subsequently tested for Hepatitis C. Mrs GRO-B claims that this was not true. Mrs GRO-B states that she and Mr GRO-B told their daughters themselves and their family GP had completed the testing. For information, see the letter at exhibit WITN2288006.

   - The case records confirm that in my letter to Mr GRO-B s general practitioner of 7 December 1995 (WITN2288006) I record that *"His two daughters* GRO-B *aged 13 and* GRO-B *aged 9 attended with him and we took blood to check their* ***Factor VIII***

levels." (Not Hepatitis C tests). As previously noted in Dr Hung's letter of 27 November 1995 (WITN2288003), his daughters were obligate carriers of Haemophilia A, and it was routine practice to recommend Factor VIII assays, as a percentage of carriers have low Factor VIII levels and hence an increased risk of bleeding after injury, surgery or childbirth; and thus consideration of Factor VIII treatment to prevent or manage this. The results of their Factor VIII levels were given to Mr GRO-B s general practitioner In Dr Kirke's letter of 14 February 1996 (WITN3496007).

- I am very happy to accept Mrs GRO-B s statement that "*Our own GP took their blood for tests for hepatitis C which were negative*", and this is also noted in Dr Morris's letter to Mr GRO-B s general practitioner of 1 December 1996. Our Centre policy was to offer hepatitis C testing of spouses and children **either** at the Haemophilia Clinic, or by their own general practitioner, and the choice was for them to make.

9. Comment of Inquiry Chair.

I have read the letter from Dr Annielle Hung, Haematology Registrar, to Mr GRO-B s general practitioner on 27 November 1995 (WITN2288003), to report the review at the Haemophilia Centre Review Clinic on 7 November 1995, and the results of blood tests performed at that visit. The Inquiry Chair highlighted this sentence from this report on Mr (not Ms) GRO-B: *"As suspected, Hepatitis C screen was positive with Hepatitis C virus antigen positive by PCR."*

I have also read my letter to Mr GRO-B s general practitioner on 7 December (WITN2288006), to discuss these findings with Mr GRO-B I cannot see any statement that "because he was a haemophiliac he almost inevitably would have had hepatitis."

Our Centre staff at this time were indeed aware that many haemophilia patients treated with clotting factor concentrates before 1987 would have been exposed to the hepatitis C virus, as detected by a positive HCV antibody test. While some of these patients had cleared the infection (as detected by a negative polymerase chain reaction (PCR) for HIV RNA); most did not (as detected by a positive PCR test for HCV RNA). This evidence was summarised in Guidelines on the Diagnosis and Management of Chronic Liver Disease in Haemophilia, published by the UKHCDO Working Party on Chronic Liver Disease in Haemophilia in December 1994 (WITN3496011); and later updated in Guidelines on the diagnosis, management and prevention of hepatitis in haemophilia by the Working Party in 2001 (Haemophilia 2001; 7: 339-345 (WITN3496012) These guidelines recommended that all patients treated with clotting factor concentrates

should be tested with both assays.

In accordance with this guidance, routine testing of all such patients for hepatitis C was added to routine testing for other hepatitis viruses (hepatitis B, hepatitis A) at their routine clinic reviews.

In my opinion it is incorrect for the Inquiry Chair to infer that *"they did nothing about it except at the request of the individual who might be suffering".*

As noted above, the Haemophilia Centre sent Mr GRO-B numerous appointments for routine reviews from 1987, and letters from Centre Doctors noting that he had not attended and encouraging him to attend.

I also note that when Mr GRO-B finally attended for Clinic Review on 7 November 1996, both his address and his general practitioner had changed from his only previous attendance at the Haemophilia Centre - for treatment - on 14 September 1988 (WITN2288003; WITN2288005). I cannot find in the case records any prior notification of these changes from Mr GRO-B or his general practitioner. I therefore think it possible that lack of such notification may have been that his appointments had not been forwarded by recipients to his new address or new general practitioner.

As I have stated above, I should comment that non-attendance at review clinics was very common among other patients with mild severity haemophilia, perhaps understandably in view of infrequent bleeding or need for surgery, compared to patients with severe or moderately severe haemophilia. I note that this non-attendance persisted across the UK until 2001, when the updated UKHCDO Guidelines stated (p 339): "Although most patients will have been tested already, the working party recommends so far as possible tracing and testing every individual who has received clotting factor concentrate, especially those treated prior to 1987. Patients with von Willebrand's disease, mild haemophilia and haemophilia carriers are likely to constitute the main group of untested patients.

Our Centre followed normal UKHCDO procedures in regularly sending Mr GRO-B appointments for routine reviews, and reminder letters after repeated non-attendance. From

October 1991, if Mr GRO-B had attended for review at the Centre, he would have been informed of the risk of HCV infection, and HCV testing recommended to him.

When Mr GRO-B did attend for review ion 7 November 1995, the recently published (December 1994) first UKHCDO Guidelines on Management of HCV infection were followed, including full discussion (supplemented by provision of the Haemophilia Society Hepatitis booklet for patient and family information); full investigation; arranging of further discussions on diagnosis, prognosis, investigations and treatments; and referral to hepatologist, Dr John Morris, who was establishing a joint Haemophilia/Hepatitis C clinic at Glasgow Royal Infirmary, and who prescribed antiviral treatment with Interferon from February 1997.

Section 3: Other Issues

Statement of Truth

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

Signed GRO-C

Dated 28 January 2020

Table of exhibits:

Date	Notes/ Description	Exhibit number
	Letter from Professor Lowe to Mr GRO-B dated 25th January 1988	WITN3496002
	Letter from Professor Lowe to Mr GRO-B dated 13th October 1989	WITN3496003
	Letter from Mr Walker to Mr GRO-B dated 11th October 1991	WITN3496004
	Letter from Mr Murray dated 5th October 1988	WITN3496005
	Note from 19th December 1995 advising Mr GRO-B did not	WITN3496006

	attend his appointment	
	Letter from Dr Kirke to GP dated 14th February 1996	WITN3496007
	Letter from Dr Morris to Mr GRO-B dated 22nd August 1996	WITN3496008
	Letter from Dr Morris to GP dated 1st December 1996	WITN3496009
	Letter from Dr Morris & Sister M Neilson to GP dated 21st February 1997	WITN3496010
	Guidelines on the diagnosis and management of Chronic Liver Disease in Haemophilia - 1995	WITN3496011
	Guidelines on the diagnosis, management and prevention of hepatitis in haemophilia - 2001	WITN3496012
	WITN2288002 – Exhibit from Ms GRO-B s evidence – Letter from Professor Lowe dated 25th May 1987	WITN2288002
	WITN2288003 – Exhibit from Ms GRO-B s evidence – Letter from Annielle Hung to Dr GRO-B dated 27th November 1995	WITN2288003
	WITN2288005 - Exhibit from Ms GRO-B s evidence – Letter from Ishbel McDougall to Ms GRO-B	WITN2288005
	WITN2288006 - Exhibit from Ms GRO-B s evidence – Letter from Professor Lowe to GP dated 7th December 1995	WITN2288006