Witness Name: Romaine Maharaj

Statement No.: WITN6968001

Exhibits: WITN6968002 - WITN6968004

Dated: March 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ROMAINE MAHARAJ

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 31 January 2022.

I, Romaine Maharaj, will say as follows: -

Section 1: Organisational history & structure

1. Please set out your full name and address.

1.1. My name is Romaine Maharaj and my address is GRO-C GRO-C

2. Please set out your date of birth.

2.1. My date of birth is GRO-C 1965.

3. Please set out your current role with the UK Thalassaemia Society.

3.1. My current role with the UK Thalassaemia Society is as Executive Director.

4. Please describe The purpose, functions and responsibilities of the society, both currently and historically:

4.1. The United Kingdom Thalassaemia Society is a non-profit, non-governmental organization which acquired official charity status on 1st March 1978.

4.2. At the beginning the prognosis for children diagnosed with thalassaemia major was very bleak and most of the families were warned that there was little known information and treatment of the condition. Consequently, at that time families were encouraged to form a group to support each other.

4.3. However, over the past forty-three years, the UK Thalassaemia Society have been providing support, counselling and information to all those living with and affected by thalassaemia. The volunteers also coordinated and promoted research and helped to educate patients and healthcare professionals on the latest and most successful treatments. They also provided and produced resources which were used to educate the wider population about thalassaemia and encouraged as many people as possible to undergo thalassaemia screening so that carriers can be identified and can receive appropriate counselling.

4.4. Further, they were able to establish links between patients and families and encouraged positive outlooks and inspiration to individuals living with thalassaemia in order to help them cope with the challenges related to the condition.

4.5. The Society has been run by a management committee of trustees and volunteers, GRO-A

GRO-A

5. Please describe the society's lobbying activities prior to receiving charitable status.

5.1. The exact date in which families (parents and patients) were first encouraged to form a support group was not recorded.

5.2. The only information which is available from that period suggests that the group was formed in the late 1960s by a few parents. Although there are no documents which state who the members were, what their goals or terms of reference were, stories inherited over the decades suggested the group's main purpose during the early period was to bring families affected by thalassaemia together and provide much-needed peer support.

5.3. As very little was known about thalassaemia, many parents were faced with their ultimate nightmare when their infants and young children died prematurely from a condition they did not know how to treat.

5.4. At the time, very little was known about thalassaemia and due to the stigmas associated with the condition, most families struggled to disclose their child's condition even to their own family members in fear of judgement and victimization.

5.5. Some of the families affected by thalassaemia realized that the only people who truly understood the nightmare they were living through were other families facing the same fate. Thus, the support group provided a safe haven for parents where they could voice their worries and concerns and learn from each other's experience.

5.6. As time went on and the group's membership expanded, the inheritance pattern of the condition and communities affected were discovered. Consequently, the group's aims expanded to include awareness and raising funds for education, research and treatment.

6. Please provide a list of individuals who held decision-making roles from 1970 to date.

6.1. Please refer to attachment 1 [WITN6968002] which includes all the information we have on file.

Section 2: Questions following a review of digital copies of 'News Review' on the Society's website

7. Please describe the Society's involvement in any other inquiries, investigations or criminal/civil litigation in relation to the 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.

7.1. To the best of our knowledge, we have not been involved in any other investigation or criminal/civil litigation in relation to the 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.

8. The Society website provides digital copies of a quarterly newsletter, entitled 'News Review' and later 'Thalassaemia Matters', from March 1980. Were any regular publications provided by the Society prior to March 1980? Were any other regular publications provided by the Society in the 1970s, 1980s and/or 1990s?

8.1. The first newsletter was published in March 1980. We have not found any evidence of any other publications prior to this date.

8.2. All the materials published to date, which are available, have been uploaded to our archive library on our website.

9. Issues 41 to 49 of the newsletter, covering the years 1990 and 1991, are not available on the Society's website. Does the Society have any copies, including digital copies, of these issues of 'News Review'? If so, please provide them. If not, please explain why.

9.1. Before the UKTS' building was refurbished in October 2018, most of the Society's documents, resources and publications were housed in the garage of our present location due to the lack of available storage within the office. During a consultation by the building contractors pre: refurbishment, it was discovered that the building and the garage were not properly insulated and following issues with a leaking and rotting roof and walls which were not properly insulated and were prone to flooding whenever it rained over the years, many of the items stored in cardboard boxes and other perishable/ unpreserved containers such as documents, books, clothes and furniture etc were badly damaged and unrecognizable. As a result, they had to be destroyed. The documents uploaded to our website were based on the publications we had access to at the time.

9.2. However, following this, we contacted our membership to enquire about editions that we were missing and can confirm that all missing editions have since been uploaded.

10. Please outline who the Society believes reads its newsletters and other publications and whether this includes doctors, nurses, hospitals and patients/family members.

10.1. The newsletters and publications are shared and made available to all of the society's members which includes but is not limited to patients, family members, doctors, nurses, and anyone with an interest in thalassaemia. In the last 3 years, the magazines have also been sent to all the units treating individuals living with thalassaemia.

11. Issue 01, dated March 1980, mentions a Society general meeting having taken place on 25th November 1979 at which a new committee was elected

[RLIT0000778]. Does the Society have any copies, including digital, of meeting minutes or other relevant materials related to the Society's general meetings and/or committee meetings?

a. If so, please provide copies.

b. If the Society does not hold copies, please explain why.

11.1. All the minutes held by the charity have now been shared with the infected blood inquiry team who visited our office on 27/01/2022.

12. Please give details of committees set up by the Society and explain their purpose and remit.

12.1. Numerous committees were formed for projects undertaken by the charity over the last 43 years. We are unable to provide a total list of all committees formed as this information is not available to us. However, to our knowledge some of the committees included:

- Fund-raising
- Development of educational resources (resources available on our website)
- Patient and Medical Conferences/Meetings
- Research projects
- Awareness Campaign committee
- Asian Awareness Campaign Committee
- Patient and parent support committees
- Media relations committee

13. Each issue of 'News Review' contains a section entitled 'Scientific Advisor's Report'.

a. Please provide a list of the Scientific Advisors to the Society and the dates which they held the role.

b. Please give an overview of the duties and responsibilities of the Scientific Advisor to the Society.

13.1. A total list of scientific advisors for the society was never maintained, however we have since searched our archive and found the relevant documents, which are included in appendix 2. [WITN6968003]

13.2. The society, at present, does not have the capacity to look through all our previous newsletters and magazines to complete the list.

13.3. Please note, there are no guidelines available to us which can be shared with regards to the duties and responsibilities of a Scientific Advisor.

13.4. Scientific Advisors were chosen on a voluntary basis based on their availability, specialty and experience related to thalassaemia- specific issues.

14. The Scientific Advisors Report in Issue 02, dated June 1980, describes a method of transfusion using young red blood cells [RLIT0000779]. Issue 05, dated March 1981, mentions the Society providing funds in the region of £6,000 for the operation of a cell separator at University College Hospital and that members would be informed as soon as the Society had any concrete results [RLIT0000780].

The advantages of using young red cells that are mentioned in both Issues are that it should reduce the frequency of transfusions and possibly of iron accumulation.

a. Please explain what is meant by "young red blood cells".

b. Please outline, if any, the benefits and/or risks associated with young red blood cells.

c. Did the Society ever advise that treatment with young red blood cells was preferable to treatment with whole blood? If so, please outline the advice provided and set out where this information was sourced from.

14.1. The scientific advisor listed for the period was Mary Mouzouras, however, the article did not include details of the author or her credentials. We are unaware of who this person is so we are unable to interpret or comment on what this author meant in her article.

14.2. However, our interpretation in 2022 of young red blood cells is as follows. Red blood cells typically have a lifespan of up to 120 days. To our knowledge, haemoglobinopathy units try to ensure people with transfusion- dependent thalassaemia receive red blood cells within 14 days of donation. This is to ensure patients receive the "youngest red cells" possible to reduce the frequency of transfusions.

14.3. We cannot comment on what was previously advised or mentioned by the society over the years because none of the current trustees or employees were involved with the UKTS at that time. However, the society's ethos has been based on medical advice only being given by practicing health care professionals involved in patient care and not by patients, parents and employees.

14.4. The society has published 3 editions of "Standards for the clinical care of children and adults with thalassaemia in the UK- in 2005, 2008 and 2016. These medical publications were written by clinicians and did include a chapter on blood transfusion which covers their advice in more detail. The standards include a list of references which clinicians used to cite their advice. A copy of the latest edition is available on our website and is attached as part of the evidence pack here [RLIT0001065].

15. Was the use of red blood cell concentrates ("RCCs") ever recommended by the Society instead of whole blood transfusions? If so, please explain:

a. The circumstances in which RCCs were recommended.

b. The perceived benefits and/or risks associated with RCCs and specifically, those benefits and/or risks in comparison to those perceived of whole blood transfusions.

c. If the above is applicable, where was this information sourced from?

15.1. As stated in the previous answer, we are unable to comment on this as there is no information available aside from the articles published and what is mentioned above. The society has published 3 editions of "Standards for the clinical care of children and adults with thalassaemia in the UK- in 2005, 2008 and 2016. These medical publications were written by clinicians and did include a chapter on blood transfusion which covers their advice in more detail. The clinical standards include a list of references in which clinicians used to source their advice. A copy of the latest edition is available on our website and is attached as part of the evidence pack.

16. What treatment did the Society recommend for patients with Thalassaemia? Did this change over time? If so, please detail why and how any changes occurred and how these were communicated.

16.1. The society has never been one to recommend or prescribe any treatment to patients, the objective was simply to share the information and research on the various treatments and updates so that families could discuss this with their treating doctors.

16.2. Based on the guidelines outlined by health care professionals, the society has educated families on the need for blood transfusions (if transfusion- dependent), iron chelating agents and curative options if available. This advice has been based on guidelines published by the thalassaemia international federation (TIF) and clinicians in the field.

17. Issue 32, dated December 1987, mentions the Society's protocol describing the recommended treatment for Thalassaemia major and describes it as useful for doctors and nurses. Readers are invited to contact the Society for a copy [RLIT0000784]. Please explain:

a. The recommended treatment that is detailed in the protocol at this time. If

possible, please provide a copy of this document.

b. Why was the protocol described as useful for doctors and nurses?

17.1. We do not appear to have a copy of this document on file, nor do we have any information stored which would indicate where it originated or who the author/ authors were.

17.2. The current team at UKTS cannot comment or provide any information on what was previously said and published because we were not involved with the society at the time.

17.3. However, we have found a publication in 1987 titled "A short guide to the management of thalassaemia" by A Cao, V. Gabutti, G. Masera, B. Modell, G. Sirchia and C. Vullo reprinted from "Thalassaemia Today- The Mediterranean experience" by G. Sirchia and A. Zanella Eds [UKTS0000001].

17.4. A copy of this was provided to the visiting team on the 27/01/2022.

18. Please outline the ways in which the Society has sought to keep itself updated with the latest scientific studies into treatment and any risks associated with treatment.

18.1. The society is aligned with most of the other groups and societies globally and is kept abreast of developments from conferences, medical updates and members.

18.2. The society keeps abreast of all latest treatments, news and risks from clinicians, the international thalassaemia federation (TIF) and through our own research from peer reviewed journal articles in thalassaemia and related conditions.

19. Please outline the ways in which the Society has sought to keep patients with Thalassaemia updated with the latest scientific studies into treatment and any risks associated with treatment.

19.1. In the past, the society has provided subsidized financial support to help patients and family members attend international (TIF) and national patient conferences. Topics chosen by the various organizations have included an update on latest scientific studies, however, they were only ever presented by doctors in the field.

19.2. Reports are also included in the newsletters and magazines in order to ensure that the others not able to attend are also made aware of any developments.

20. To the best of your knowledge, did the Society publish any materials for their members during the 1970s - 1990s about the risks of Hepatitis or other infections

to people receiving blood transfusions? If so, please provide details and copies if possible.

20.1. The only information that the current team at the UKTS is aware of is what is available on our website.

21. To the best of your knowledge, did the Society publish any materials for its members about HBV and HCV at any time? If so, please provide copies where possible and explain where the Society got the information provided in the materials.

21.1. The only information that the current team at the UKTS is aware of is what is available on our website.

22. Issue 30 dated June 1987 notes a discussion on the subject of AIDS with Dr Wonke, Professor Francum, patients, parents and members taking place at the Society on 23 March 1987 [RLIT0000782].

a. Please explain the relationship between the Society and Dr Wonke at the time of this discussion.

b. Please explain the relationship between the Society and Professor Francum at the time of this discussion.

c. Does the Society have copies, including any digital copies, of the minutes or other relevant materials from, or related to, this discussion?

If not, please outline what the discussion entailed.

d. Dr Wonke is reported as saying that thalassaemic patients were at low risk of HIV infection from blood transfusions. Was the Society ever concerned that thalassaemic patients could be at risk of contracting HIV from blood transfusions? If so, how was this concern communicated to members?

e. Page 13 of Issue 30 states that the Society knew of no thalassaemic patients with AIDS to date. Has the Society become aware of anyone with Thalassaemia who may have contracted HIV as a result of blood transfusion?

22.1. Dr Wonke was one of the main doctors treating patients at the Whittington Hospital. As part of the society's work, from time to time, doctors were invited to speak to the group in order to provide updates on treatment and to address any concerns or questions raised during the meetings themselves.

22.2. There are no minutes available for this meeting and as such we are unable to comment further on this.

22.3. We do not have any information presently on the possibility of any patient contracting HIV as a result of a blood transfusion.

23. To the best of your knowledge, did the Society publish any materials about HIV at any time? If so, please provide details and explain where the Society got the information that was provided in these materials. If possible, please also provide copies.

23.1. We do not have any information on this. The only information that the current team at the UKTS is aware of is what is available on our website.

24. In Issue 30, dated June 1987, the risk of contracting HIV is described as lower for thalassaemia patients because blood was filtered [RLIT0000782]. Issue 31, dated September 1987, contains a plea to thalassaemia patients to ensure the blood they received was filtered as it had come to the attention of the Society that some hospitals were not giving filtered blood because it was too expensive [RLIT0000783].

a. Please explain what is meant by "filtered blood".
b. Please explain what the Society understood regarding the benefits and/or risks associated with "filtered blood" and specifically, those benefits and/or risks in comparison with "unfiltered blood"
c. Where was this information sourced from?

24.1. Aside from the article itself we do not have any additional information on the source and references were.

24.2. Our interpretation or understanding of what "filtered blood" is in 2022 is blood that has been filtered based on the removal of leucocytes. However, we cannot comment on what was said in 1987 as the current team at UKTS was not involved at the time.

24.3. Previous advice on these topics has been based on guidelines published by the thalassaemia international federation (TIF) and clinicians in the field.

25. Issue 97, dated April 2004, has an article entitled 'New blood safety measures disqualify 52,000 donors' on the announcement to prevent anyone who had received a blood transfusion in the UK since January 1980 from donating blood due to the risk of transmission of variant vCJD [RLIT0000786]. How did the Society become aware of the risks of transmission of vCJD associated with the use of blood transfusions?

25.1. We are unable to comment on what was published in 2004 as the current team at UKTS was not involved at the time.

25.2. Our current research however, revealed that the information published was based on statements made by the Health Secretary John Reid on Tuesday, 16 March 2004 and included in articles by several media companies. Attached are articles from BBC and The Independent. (see appendix 3) [WITN6968004]

26. Issue 97, dated April 2004, has an article entitled 'New blood safety measures disqualify 52,000 donors' on the announcement to prevent anyone who had received a blood transfusion in the UK since January 1980 from donating blood due to the risk of transmission of variant vCJD [RLIT0000786]. How did the Society become aware of the risks of transmission of vCJD associated with the use of blood transfusions?

26.1. As per response for number 25.

27. The article notes the Society would be interested to hear if any readers subsequently experienced any difficulties. To the best of your knowledge, did the Society hear from any readers of any difficulties related to vCJD?

27.1. We do not have any additional information regarding this on file.

28. To the best of your knowledge, has the Society published any materials about vCJD at any time? If so, please provide details and explain where the Society got the information that was provided in these materials. If possible, please also provide copies.

28.1. All the information published is available on our website. We are also unable to provide any additional information on this.

29. Issue number 95 of 'Thalassaemia Matters' contains the article 'Government Pledges Payouts For Victims Of Hepatitis C Blood Contamination' welcoming the decision to provide financial assistance to Hepatitis C sufferers and informing readers that they will be kept up- to- date [RLIT0000785]. An article in Issue number 97, dated April 2004, provided more information about the ex-gratia scheme, including what to do if readers thought they might be eligible [RLIT0000786]. Were any other publications provided by the Society on accessing financial or other assistance in relation to infection via contaminated blood? Please detail any support, financial or otherwise, provided by the Society to those who may have been affected by contaminated blood.

29.1. All the information published is available on our website. We are also unable to provide any additional information on this.

Section 3: Stigma

30. Please explain, to the best of your ability, any stigma associated with Thalassaemia both in wider society and within certain communities.

30.1. Thalassaemia major is an inherited severe blood disorder and we have been told that in most communities, the diagnosis of the condition was hidden from relatives, friends and the wider community.

30.2. This was mainly because of the stigma attached to the people affected initially, causing family members and relatives to be excluded as potential marriage partners and friends.

30.3. This was amplified during the panic which came about during the HIV and Hep C era as families with patients who were transfusion- dependent were shunned and treated differently.

30.4. Although there have been a lot of changes and treatments available since then, there are still a lot of families and patients who are unwilling to even disclose that they are affected by thalassaemia.

31. Please explain, to the best of your ability, the Society's understanding of any stigma connected to being infected or affected by contaminated blood within those communities most affected by Thalassaemia.

31.1. Despite the strides made in this area, most families are still worried that they would not be accepted by society once information relating to infected blood is shared publicly.

31.2. Additionally most of the persons affected were subjected to several trials and treatments which impacted their lives significantly and although some have managed to be "cured" they still depend on regular blood transfusions and have not been properly supported to deal with the anxiety and negative emotions which would have resulted from the experience itself.

32. Please detail whether the Society is aware of the stigma associated with infection from contaminated blood affecting the treatment received by people with Thalassaemia.

32.1. The society is aware of the stigma associated with infection from contaminated blood affecting the treatment of people living with thalassaemia.

32.2. Several attempts have been made to get the people infected or affected with infected blood to come forward and provide evidence to the inquiry team.

32.3. We have not had positive responses from most of the members.

Section 4: Relationships

33. An invitation to accept appointment to the National Blood Service User Group ("NBSUG") for two years was sent to Mr K Charalampous c/o the Society in July 1996 [DHSC0020763_002]. Please give details on the Society's involvement with the NBSUG. Please include the dates the Society was involved.

33.1. We do not have any additional information on this.

34. A press notice on lifting the lifetime ban on blood donation by men who have had sex with men notes that representatives from the Society participated in the review by the Advisory Committee on the Safety of Blood, Tissues and Organs ("SaBTO") [DHSC0004233_061]. Please outline, to the best of your ability, the Society's involvement with SaBTO both currently and historically.

34.1. Over the years the society has been invited by NHSBT to provide patient and representatives to join the various advisory committees and stakeholders' groups set up for discussions/ reviews. Unfortunately, I am unaware of whether UKTS had previous interaction with SaBTO before my time.

34.2. With regards the FAIR 1 Committee (lifting the lifetime ban on blood donation by men who have had sex with men) GRO-A (patient representative and now trustee) was invited to join the steering group based on being a recipient of a blood product. During the meetings, GRO-A was invited to share her thoughts and concerns with regards to the discussion at hand.

34.3. As far as we are aware, recommendations from this committee were then presented by the chair of the FAIR steering committee and other scientists in the group to SaBTO. UKTS or trustees had no direct involvement or interaction with SaBTO for this.

34.4. Unfortunately, I am unaware of whether UKTS had previous interaction with SaBTO before my time.

34.5. UKTS was then approached by a research team at Nottingham university to help recruit patients to take part in their one- to- one interviews and later online questionnaire with regards to lifting the lifetime ban on blood donation by men who have had sex with men.

34.6. On both occasions UKTS sent an email out to the membership to advertise the study to which interested parties were forwarded the details of the research teams to get in touch. Details for the online survey were also shared on UKTS social media accounts.

35. Please outline the Society's involvement in other reviews of blood safety, both currently and historically.

35.1. We do not have information on this, aside from what was included in the minutes of the previous meetings. This information was already perused by members of the Infected Blood Inquiry team.

36. An internal memo from the Department of Health in 1990 [DHSC0002456_083] refers to the provision of £15,000 annually to the Society for "counselling and associated services". The document also refers to funding videos on Thalassaemia through the Society. Please give details of any funding received from the Department and how it was used.

36.1. In 2010 three videos were produced by the society:

There are 3 new videos, Thalassaemia – your life, your choice, your test (screening), [UKTS, "Thalassaemia – your life, your choice, your test (screening)", YouTube, uploaded by UKTS, 7June 2019], My Thal (living and coping with thalassaemia) [UKTS, "My Thal (living and coping with thalassaemia)",YouTube, uploaded by UKTS, 7 October 2020] and UKTS – making a difference (the work of the Society). [UKTS, "UKTS – making a difference (the work of the Society)", YouTube, uploaded by UKTS, 13 August 2018]. These can be viewed via our YouTube channel.

36.2. UKTS has always worked alongside the NHS Screening to support counselling and awareness activities. The videos produced in 2010 were an example of work done.

37. Please describe the relationship between the Society and the Department of Health.

37.1. As mentioned above, the United Kingdom Thalassaemia Society and the Sickle Cell Society have been supporting the projects undertaken over the years by the NHS Screening Programme and have been involved in all activities relating to screening and genetic counselling.

37.2. In 2015/2016 both societies joined forces and applied/ won a tender for a contract which is also now focused on newborn screening and other awareness activities.

38. Please give details of any relationships between the Society and NHS hospitals. Please comment specifically on the relationship between the Society and The Whittington Hospital.

38.1. The society has been liaising with the various teams from the units treating thalassaemia major patients scattered throughout the United Kingdom. This has allowed us to share information directly to the units, members and patients being treated in each unit.

38.2. Since 2019, instead of sending the magazines out to each individual member, the shipments were directed to the units to ensure that the non-members also benefitted from the information contained.

38.3. We have also been fundraising to purchase vein finders for each unit.

38.4. The Whittington hospital unit is the largest unit treating some of the oldest patients globally. Based on this, the specialists at that hospital are the most experienced and are normally relied on for referral of cases from the smaller units.

38.5. The team at the Whittington have always been supportive in assisting with our updates and assistance, when possible.

39. Issue 98 dated July 2004, of Thalassaemia Matters' contains an article on the retirement of Dr Wonke (RLIT0000787). Please outline the following:

a. The relationship between the Society and Dr Wonke prior to her retirement.
b. The relationship between the Society and Dr Wonke since her retirement.

39.1. Dr Wonke has been acknowledged as one of the top consultants for thalassaemia in the UK as she looked after most of the oldest patients and one of the largest centres treating patients.

39.2. She was also recognized and praised for her dedication and experience by the International Thalassaemia Federation (TIF) and other global specialists in the field.

39.3. During her years as a consultant, she was always willing to support patients and families and was able to change the prognosis given to most of the families which did create a very positive atmosphere for most, despite the severity of the condition.

39.4. The society and families were grateful to her for her service and dedication and were involved in a farewell function to thank her for her service.

39.5. For our 40th anniversary celebration, the society took the decision to honour those persons who made a difference in the lives of the families and Dr Wonke was chosen to be one of the recipients.

39.6. Aside from this, after retirement she has not been an active part of the thalassaemia community.

40. Please outline the relationship between the Society and Professor Dusheiko during the 1970s, 1980s, and 1990s.

40.1. We are unable to comment on the relationship between the society and Professor Dusheiko during the 1970s, 1980s, and 1990s as the current team at UKTS was not involved at the time.

41. Please outline the current relationship between the Society and Professor Dusheiko.

41.1. We are aware that Professor Dusheiko had meetings and gave advice to some board members of the society during 2010 to 2018, but we were not all privy to the information or discussions. These board members are no longer a part of the society.

41.2. In particular, the main board members who were involved in these discussions were Mr GRO-D and Dr GRO-D

42. Professor Dusheiko has told the Inquiry that he provided advice and acted as Medical Advisor to the Society (WITN3754048 at 2.37, 3.1 and 48.8). Please provide details on the following:

a. The role of Medical Advisor to the Society;

b. The dates Professor Dusheiko held the role:

c. The process by which advice was sought and obtained from Professor Dusheiko; and

d. The Nature and contents of advice given by Professor Dusheiko to the Society.

42.1 We are aware that Professor Dusheiko had meetings and gave advice to some board members of the society during 2010 to 2018, but we were not all privy to the information or discussions. These board members are no longer a part of the society.

42.2. In particular, the main board members who were involved in these discussions were Mr GRO-D and Dr GRO-D.

43. In 1990 Professor Dusheiko wrote that the existence of non-A, non-B Hepatitis ("NANB2), now known to be HCV, had long been recognized and most clearly seen after blood transfusions. He listed thalassaemics among those at increased risk of post-transfusion hepatitis (DHSC0002541_068). Please comment on the following:

a. Whether this was communicated to the Society by Professor Duesheiko and if so, when.

b. Whether the Society was aware of an increased risk of post-transfusion NANB Hepatitis and whether this was communicated to people with Thalassaemia by the Society. If so, how was it communicated?

43.1. We are unable to comment on the relationship between the society and Professor Dusheiko during the 1970s, 1980s, and 1990s as the current team at UKTS was not involved at the time.

44. The Society's newsletter 'Thalassaemia Matters' carried information regarding the set up of Skipton in October 2003 (Issue 95) (RLIT0000785) and April 2004 (Issue 97) (RLIT0000786) and the increase in money being made available by Skipton in March 2011 (Issue 118) (RLIT0000788). Please outline any relationship that exists between the Society and Skipton.

44.1. We are unable to comment on a relationship between the society and Skipton as there is no information available.

44.2. We are aware however, that similar to our present day operation, we strive to ensure that all pertinent and printed information is circulated to all members.

45. The Haemophilia Society meeting minutes from Sept 1995 (HSOC0023337) mention contacting the Society over members also having contracted HCV. Please explain the relationship between the Society and the Haemophilia Society in relation to members having contracted HCV.

45.1. We have not been able to locate any information relating to this meeting and are unable to comment on the relationship between both societies in 1995.

46. Please outline whether there was a relationship with the Haemophilia Society during the 1970s, 1980s, and 1990s and what this involved.

46.1. We are unable to comment on this as we do not have any information at hand.

47. Please provide details of any other current or previous relationships the

Society has that you believe may be of relevance to the Infected Blood Inquiry, having regard to its Terms of Reference and to the current List of Issues.

47.1. The society has been involved in patient and family support during its existence. Our thrust has been to educate and update everyone with any new advances or pertinent information.

47.2. Aside from this, we have been involved in any research which could improve patient lives and extend the grim prognosis which was given in the beginning.

47.3. Any relationship forged, therefore, would have been done on this basis.

Section 5: Other Issues

48. Please explain, in as much detail as you are able to, any other matters that you believe may be of relevance to the Infected Blood Inquiry, having regard to its Terms of Reference and to the current List of Issues.

48.1. We do not have any further information or details which could assist.

Statement of Truth

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

Signed GRO-C

Dated 08/04/2022

Table of exhibits:

Date	Description	Exhibit Number
2021	Appendix 1: List of individuals who held decision-making roles from 1970 to date	WITN6968002

	Appendix 2: Scientific advisors to the society (incomplete)	WITN6968003
2016	UK Thalassaemia Society *Standards for the clinical care of children and adults with thalassaemia in the UK* (3rd ed. 2016)	RLIT0001065
1987	A Cao, V. Gabutti, G. Masera, B. Modell, G. Sirchia *A short guide to the management of thalassaemia*, reprinted from C. Vullo *Thalassaemia Today- The Mediterranean experience* by G. Sirchia and A. Zanella Eds	UKTS0000001
2004	Articles from the BBC and The Independent	WITN6968004