

# ANONYMOUS

Witness Name:

GRO-B

Statement No: WITN1234005

Exhibits: WITN1234006-11

Dated: May 2019

## INFECTED BLOOD INQUIRY

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EXHIBIT WITN1234011

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ANONYMOUS

# Central Manchester and Manchester Children's University Hospitals



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19<sup>th</sup> December 2003

Mrs GRO-B

GRO-B

Cheshire

GRO-B

Dear Mrs GRO-B

GRO-D Modern Matron, has passed on to me a number of questions and concerns that you raised with her in relation to care of your late husband. As you know, I only met you and your husband perhaps on one or possibly two occasions and was not significantly involved in his management. Nevertheless, I have access to his notes and will do my best to address those issued that you have raised. These have been summarised for me by GRO-D and in one or two cases may have lost something in the translation. If, therefore, you find that I have not properly addressed one or more of your concerns, do not hesitate to get back to either myself or Modern Matron GRO-D for further clarification. I hope I am able to clarify matters for you.

1. Mr GRO-B had two sets of hospital notes, 1 set which remained in the Haematology Department and 1 set in the main MRI record room. Did this not pose a risk in terms of patient management?

It has been for many years, and remains the practice, to keep a set of records within the Haemophilia Centre in case the patient is admitted as an emergency so that the haematology set of notes may be readily available in case the patient presents with a bleed. This strategy is aimed at reducing risk rather than to increase it. When a second set of notes is discovered we usually aim to amalgamate the two. When the patient seen another physician or surgeon within the hospital the notes may disappear from the haematology department for days or even weeks, however, and the practice of keeping a separate set within the department is aimed to make sure that there is always a core haematology set of notes available.

2. Mr GRO-B's notes had his HIV status documented on the front clearly in view of any other individual.

This information is not written on any of the surviving front covers of the two sets of notes available. I would like to assure you that there is no evidence on either the front cover or the case-sheet of the patient's HIV status. I cannot exclude the possibility that this may have been written on an earlier case-sheet or binding. Policy on what should and should not be written on front covers has evolved gradually over the years because of the issue of confidentiality. There is a conflict here in that certain pieces of information are best placed in a prominent place for the patient's safety, such as drug allergies. I think it is extremely questionable however whether such sensitive information as the patient's HIV status should ever have appeared on the front of the notes even in the early 1980s. It was certainly my policy as Director of another

convenient, his notes have been rebound since his death or instead ordered.



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haemophilia centre that this should not be done because of the risk it poses to the patient's confidentiality. These days the policy is very clear and this information would not appear on the front cover.

3. After Mr GRO-B squint surgery he received a 3-week course of treatment. Was this appropriate as previously when he had a tooth extraction he only received 1 dose?

I will take this along with:-

4. Why was Mr GRO-B not given DDAVP after his squint operation?

Dental extractions are usually managed with a single dose of treatment and Tranexamic acid for about 5-days. Mr GRO-B's response to DDAVP was adequate for dental extraction, requiring only a 50% factor VIII level. More critical surgery, such as a squint operation, where a local bleed can jeopardise the outcome of the surgery, is generally managed by keeping the factor VIII level in the normal range until wound healing has taken place. This is usually taken as a week to 10-days post operatively. One of the problems with DDAVP is tachyphylaxis, which is to say that the effect is reduced by 30-40% with each subsequent dose. It is likely, therefore, that DDAVP would not have been adequate to maintain the factor VIII level within the normal range for the prescribed period. Therefore, factor VIII concentrate was used.

5. When Mr GRO-B presented with symptoms of diabetes and a blood glucose of 15.8 why was he not recalled and treated. His diabetes treatment was instigated by the GP.

Unfortunately, I cannot find reference to this in Mr GRO-B's hospital notes. The normal approach to finding a high blood sugar would be to refer the patient on either through the GP or directly to a diabetic physician. Mild diabetes is often managed principally by the GP. It is not generally managed by haematologists. I am sorry I cannot clarify this any further for you.

6. The family GP was given the wrong information on several occasions. The body of one letter was wrong. Mrs GRO-B has always had a concern that her late husband's information was mixed-up with another patient, Mr GRO-B

I have been unable to find any letters relating to any other patient other than Mr David GRO-B in the patient's notes. I do not know what wrong information may have been given to the GP and am unable to comment on this directly without more specific details.

7. Notification of the need to investigate HIV testing came to Mr GRO-B in a letter, which stated that he might have been given contaminated blood products and required HIV testing.

Several centres originally contacted their patients by telephone. This would, hopefully, not happen now and was arguably poor practice then. Certainly in the centre that I worked in these questions were always raised face to face so that the patient had the opportunity there and then to have the risks put in to context and to have their questions answered as far as it was possible to do so. In those centres where the mail was used, patients felt, quite rightly, that the matter was dealt with insensitively and this led to long standing bitterness amongst this group of patients contacted in this thoughtless manner. The other reason for not using the mail is that letters can go astray and there is a risk to patient confidentiality. Policies gradually changed so that it is quite clear that this would no longer be acceptable.

8. Family members were also tested and Mrs GRO-B's results were filed in her husband's case notes.

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It was common practice when doing family studies, at that time, for the results to be filed in the same case-sheet for ease of reference and that the family members would only get their own case-sheet if their test was positive and they required long term follow-up. This has, for a number of years, not been considered acceptable and when anyone is tested these days they are issued with their own case-sheet. For a number of years procedures have also been in place to permit anonymous coded testing.

*9. Mrs GRO-B was informed of Mrs GRO-B's HIV result during a telephone conversation.*

I have no confirmed record of this, but it would certainly be unacceptable. When patients are tested arrangements are made for them to come and receive the result face to face. Requests for results, which we frequently receive by telephone, are always refused. When someone phones and claims to be a certain person you can never be certain that they are who they say they are and so there is a risk to confidentiality. Furthermore, 'bad news' is best dealt with face to face and not over the telephone. Again I am sorry this is what you experienced.

*10. Why was Mr GRO-B's HIV not treated by the Haemophilia Centre?*

I know it was my predecessors' policy, initially, not to manage HIV, which he felt fell outside his area of expertise. Subsequently patients have been managed within the haemophilia centre and clinics were set up in which patients were seen jointly with an HIV physician. By the time I took over it appeared to me that Mr GRO-B felt extremely bitter towards the department and did not wish to be managed by the unit. This may have played a part in his referral to an HIV specialist.

*11. Why was Mr GRO-B not referred to an HIV Liver Specialist?*

As far as I can see Mr GRO-B was referred to Dr Warnes, Consultant Gastroenterologist, in 1990 and followed-up by a hepatologist from that time until the time of his death. This seems appropriate and I note that the referral anti-dates by more than 5-years' licensing of Interferon therapy of hepatitis. Earlier referral would, therefore, not have made any difference to the outcome in this case. The sub-specialty of an HIV liver specialist did not and does not exist.

*12. Mrs GRO-B's brought up issues about how consent was sought for the AZT trial.*

Sadly, I am not in a position to comment on this and cannot clarify this point for Mrs GRO-B.

*13. Why was Mr GRO-B's liver biopsy cancelled?*

After review, I am not sure why the liver biopsy was cancelled, but I would say that it is no longer normal practice to do liver biopsies in patients with haemophilia and hepatitis C, unless there is some diagnostic dilemma and increasingly it is the trend not to do liver biopsies in non-haemophiliacs with hepatitis C even though a liver biopsy will give a clearer picture than any other investigation of the actual state of the liver at that particular time. The result does not in fact influence the patient's management.

*14. At one point Mr GRO-B was under the care of 3 different consultants in the Trust and at each clinic appointment they all take blood samples, there did not seem to be any sharing of blood results etc.*

Unfortunately, there is this risk when attending more than one consultant. Although examining the patient's notes, it would appear most, if not all of the results, have found their way back in to the one case-sheet. Increasingly in recent years we have made positive efforts to try and make patients' visits to coincide so that

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they see more than one physician on one day and all the blood samples are taken after the last consultation of the day to minimise this problem. The results will find their way into the same set of notes so results are shared and can now be shared electronically if ordered via the ward order communication system.

*15. "Possible confusion with regards to counsellors' role as they also perform nursing tasks i.e. take blood samples"*

HIV Nurse Counsellors are also practicing nurses and it is part of their job to counsel patients about blood samples and also to take the sample, thus minimising the circle of confidentiality. This seems appropriate.

I hope that this is helpful.

With best wishes.

Yours sincerely

GRO-C

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Honorary Senior Lecturer in Medicine

Modern Matron

GRO-D

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