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Witness No: WITN2438001

Exhibits: WITN2438002-WITN2438017

Dated: 23 September 2020

INFECTED BLOOD INQUIRY

EXHIBIT WITN2438014

INFECTED BLOOD INQUIRY

CONSULTATION ON TERMS OF REFERENCE

Response by (1) Haemophilia Wales and (2) the Cross-Party Group in the Welsh Assembly on Haemophilia and Contaminated Blood

1. Haemophilia Wales was established as an independent charity in 2003 and provides information, support and advocacy to over 300 members in Wales

2. The Cross Party Group on Haemophilia and Contaminated Blood at the Welsh Assembly was formed to raise awareness of the issues affecting the community of infected patients and to improve provision of treatment and support across Wales.

3. The Inquiry is referred to the joint position paper for further information about both groups, who act in unison.

Timeline

4. It is our view that the Inquiry should take a timeline of 1970 to the present day for a number of reasons:
    a. By 1975 the Government's stated aim was to achieve self-sufficiency in respect of blood and blood products and a budget was set-aside for achieving that aim;
    b. In 1975 Stanford University wrote to the Government warning of the risks associated with American blood products;
    c. Documents dating back to 1970 relating to infected blood have been published on the Department of Health website;
    d. The Penrose Inquiry recommended that everyone who received blood before September 1991 should be tested;

e. The settlement of the personal injury claims (as to which see below) took place in 1991;

f. Andy Burnham, then a Member of Parliament, said in his valedictory speech in Parliament on the 24th of April 2017 that he had evidence of blood testing being carried out without patients' consent in 2013. This touches upon both the issue of concealment and the issue of care after infection;

g. He also said that he had evidence of recent false diagnoses of symptomatology to conceal the earlier provision of infected blood or blood products – a matter which the Inquiry provisionally intends to deal with. This is an ongoing issue. We too have members who have evidence to give of recent false diagnoses;

h. As set out below, the issue of testing and missed opportunities for treatment is an ongoing issue.

Blood and blood products

5. We agree with the terms of reference provisionally drafted in the consultation document under the heading "blood and blood products". Most of the terms of reference previously submitted on our behalf are covered by the same.

6. In so far as there are separate considerations in Wales that relate to those general terms, they are:

   a. Is there documentation available in the Welsh Office archives that would assist in filling the hole created by the destruction of documentation by the Government;

   b. Did the Secretary of State for Wales and/or the NHS effectively supervise the National Blood Authority in Wales;

c. Why is there a higher rate of infection of haemophiliacs in Wales than in England;
d. Why is there a higher death rate from Hepatitis C (stages 1 and 2) in Wales than in England;
e. What did the Haemophilia Society know about the risks and tests when it lobbied Government to continue to allow the import of products from the USA during the 1980s (see the Trustees' public statement of the 27th of March 2017).

7. It is vitally important that where patients wish for their medical records to be inspected, this is done. Many patients or their families feel that; (i) the supply of blood or blood products to them was not recorded in their medical records; or (ii) their medical records have been altered; or (iii) their medical records have gone missing. We have one particularly strong example where the fact of supply was not recorded in the patient's medical records in the UK, but the patient is able to prove by correspondence between a UK medical practitioner and an Australian medical practitioner that they were in fact supplied with blood or blood products and that there was an attempt to conceal this fact from the patient.

8. We as an organisation are currently assisting our members to obtain their medical records and will be able to assist the Inquiry in this regard in due course.

9. Plainly, documentation should be sought from the Department of Health, the National Archives, the Welsh Government (who have access to the Welsh Office archives), the NHS, the National Blood Authority, the health authorities, the Welsh Blood Service, the United Kingdom Haemophilia Centre Doctors' Organisation (national database) and the suppliers (including financial information which

may need to be inspected by a forensic accountant). In Wales, the Haemophilia Centre may hold relevant documentation. The Welsh Assembly may also hold relevant documentation as they set up the "2010 Blood Borne viral action plan" which led to the production of a research document regarding those suffering with Hepatitis C.

The care and support provided after infection

10. It is our strong view that the Inquiry should consider the care provided after the supply of infected blood. In particular, it is our view that the Inquiry should ask:

    a. Why the UK Government, the Welsh Government or the NHS failed to inform patients who were supplied with blood or blood products that they were at risk and offer blood testing;
    b. Were patients deprived of the opportunity of successful treatment;
    c. Were patients deprived of liver transplants because of their Hepatitis C infection and/or were they routinely provided with transplants from other infected patients;
    d. Has the NHS carried out testing of patients' blood without consent;
    e. Has the NHS provided patients with false diagnoses, rather than treat Hepatitis C, in order to conceal the earlier provision of infected blood or blood products;
    f. Has the selection of treatment for Hepatitis C prolonged and/or exacerbated the suffering of infected patients;
    g. Why were the families of infected patients who died in Wales denied post-mortems.

11. The inevitable consequence of the above is that the period of time of the Inquiry's focus will be extended, but that it should not have a

disproportionate effect on the length of the inquiry, given the discrete nature of the issues and their importance.

12. In terms of response other than care, it is our view that the Inquiry should investigate;

    a. whether the Government settled patients' claims for personal injury damages during the 1990s without disclosing the risk of Hepatitis C infection;

    b. whether the Government knowingly continued to present misleading and inaccurate information in reports, briefing papers and correspondence regarding blood policy until 2017.

13. Further, it is our view that the Inquiry should make recommendations regarding the scheme of payments to patients and their families. If the Inquiry makes findings of fault, the payments should be compensatory and paid timely to those who will be eligible. Furthermore, there would be no rational reason for a difference in the schemes across the UK. The recommendation of such a scheme would be preferable to a situation where patients and their families are left to bring claims for personal injury damages, notwithstanding any findings of fault by the Inquiry.

Identifying responsibility and making recommendations

14. We agree with the proposal in the consultation. Even today patients have not been informed that they are at risk. They are discovering that they are infected with Hepatitis C long after the event and have missed out on effective treatment. The Inquiry must make recommendations to correct the position.

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On behalf of

Haemophilia Wales and the Cross Party Group on Haemophilia and Contaminated Blood at the Welsh Assembly