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Statement No: WITN2368019

Exhibits: WITN2368020-WITN2368051

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INFECTED BLOOD INQUIRY

EXHIBIT WITN2368043

Haemophilia Wales

From: "Haydn Lewis" <haydn.lewis@GRO-C>
To: <today@bbc.co.uk>
Cc: "Haemophilia Wales" <info@haemophiliawales.org>
Sent: 03 February 2004 10:42
Subject: House of Lords 5/2/04

Today Programme, Editor/Radio 4

Date 2/2/04

Ref: Government ex-gratia recompense/hepatitis c

(Exclusion of widows) on "compassionate grounds"?

Dear John Humphrys

Today on radio 4, Woman's Hour, broadcast an interview with Melanie Johnson MP, (public health). Concerning a matter of which, I have been personally involved in for the past 20 years.

I refer to the death on average of one person with haemophilia every week since 1983.

By the content of her comments it was so obvious that the minister had little, or no understanding about the history of this issue (political or medical), I found some of her comments, patronizing and insulting to the intelligence of the widow and the CEO of The Haemophilia Society (Karin Pappenheim). It is quite obvious that she is reading from the same brief as her predecessor Hazel Blair MP who I responded to concerning this matter over six months ago, (still no reply) a copy of the letter below.

This is another example of why a full public inquiry into this matter is needed, as it demonstrates how little the current government know about the true history of what has been described many times as "the worst treatment disaster in the history of the NHS" (this may be so), but the true tragedy is the faults lay at the door of number 10 and the DOH, not the NHS. So why any of this payment scheme, should be funded out of the budget of the NHS and not Gordon Brown's war chest remains a mystery.

To further highlight government ignorance, a written statement released on Hansards by the noble Lord Warner headed "Hep c Compensation scheme" typing error, or are the house of lords confused, as the use of the word compensation implies fault, government and the media must refrain from using this word as it gives the general public the impression that this matter has been sorted legally. On Thursday this week Lord Morris will try to get some sanity from his fellow Lords and government, about the exclusion of widows who's partners died before the 29th Aug 03.

Having read the financial package details and spoken to many haemophiliacs since last Friday, We hope that all those entitled will reject the offer from John Reid MP as wholly inadequate. As a community we should not be accepting any offer that rejects widows.

It is very important that there is open discussion/public inquiry on this matter as I am aware of current safety violations, which could lead to further contamination and in particular possible exposure to vCJD via U.S. plasma products.

These products are not just imported for haemophiliacs, but for the general public who may need plasma and plasma products in hospital.

This demonstrates that little has changed with regard to safety in the international plasma industry.

03/02/2004

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WITN2368043_0002

H.W.Lewis

GRO-C

Cardiff

GRO-C

F.A.O, Sunday Times letters editor.

Date 2/10/01

Re; Sunday Times Article 30/9/01(Jonathan Leake Science Editor)

Subject;

Patients were exposed to CJD

The article was very informative as to the risks to the public and how many people had received transfusions with blood, by donors who have since died from CJD.

The National CJD Surveillance Unit has so far traced 22 patient but they have not been informed, under guidelines set by the Department of Health, this is under review at the moment. The article states that Alan Milburn the health secretary is thought to be deeply concerned about the impact on people of being told that they have been exposed to a disease for which there is no conclusive test or cure. The ministry for health may be able to stop them donating blood or organs to the rest of the general public, but this will not stop the risk of this disease being spread to their family and close friends, who may at this very moment could still nursing the patients back to health after their operation during which they needed to receive blood.

I think Alan Milburn should refer to his own words and put them into practise immediately. (Quote)

The long-term Medical Alliance in London on 29/1/01, "...The culture of the health service has to change. The days of cover-ups have got to end. Where the system fails the lessons need to be learned. The days have gone when the NHS could act as a secret society. It cannot operate behind closed-doors; it cannot keep patients in the dark. It has to take patients into its confidence; it has to communicate the risks of treatments. It has to explore options for the patient, if things go wrong it needs to explain why. It needs to be quicker at saying sorry".

As to the impact on people being told, would it not be a good idea if Alan Milburn met with people who have already been informed due to the fact that they still need to receive blood products, which may have been exposed to CJD. A good example would be any person over the age of 16 (sixteen) with Haemophilia who by the fact of their postcode, are still not receiving the safest treatment available on the NHS.

Due to fate I seem to fall into the above category and have also been informed in January 2001 that in 1996, I received blood products, which had been exposed to CJD. I personally know 3 (three) other people who are in the same predicament, all Would be willing to share their views with the health minister to help him cope with his dilemma until a test becomes available, hopefully in the next 12 to 18 months.

Yours sincerely

H.W.Lewis

Dear Editor

Ref; Echo Wednesday 10th Sept 03 article page 10
"Memorial to Victims of Mix-Up"

I found the heading insensitive and offensive. I felt a deep sorrow for the 800 plus widows and partners who have lost their loved ones over the past 17 years. The plight of individuals and their families, who have suffered extremes of hardship and ill health as a result of their infection, has been well documented yet remains largely unknown among the general public.

It is a poignant reminder that one Haemophiliac has died every week on average since 1985.

The infection of 1200 Haemophiliac's with HIV has been described many times in the House of Lords "as the biggest tragedy ever in the history of the NHS"

To use the phrase "Mix-Up" I find insulting as it implies that the death of an infected Haemophiliac is some kind of unavoidable incident. The real tragedy is that it qualifies as a scandal of serious consequence which could have been avoided.

I am most grateful to the editor for writing the article, which highlights the issues around this tragedy. While I believe it is irresponsible for the media to use such an inappropriate phrase without knowing the history behind this matter.

Hopefully by spring next year, when the memorial will be officially opened, a Full Public Inquiry will reveal which phrase will be appropriate as to why this tragedy occurred.

Yours sincerely

Haydn Lewis
(Secretary Haemophilia Wales)

[Private do not share]

From: "Susan Watts" <susan.watts@GRO-C >
Subject: Final copy of letter sent to Dr Hewlett (has been run past Roger)...s
Date: 23 March 2007 17:48:21 GMT
To: "mags gavan" <magsgavan@GRO-C >, "Mary Wilkinson" <mary.wilkinson@GRO-C >, "Haydn Lewis" <Haydn.lewis@GRO-C >

From: Susan Watts
Sent: 23 March 2007 17:45
To: 'colin.hewlett@GRO-C'
Subject: BBC Newsnight programme

Dear Dr Hewlett

You recently declined our offer of an interview with BBC Newsnight, so I am setting out below the issues and questions raised with us in reference to the treatment of GRO-A. Some of these will be explored during the course of our programme on the past treatment of haemophiliacs in the UK, which we now expect to broadcast in April.

As you probably recall, GRO-A was treated at both the Heath hospital in Cardiff and the Royal Gwent hospital in Newport, for severe haemophilia.

Recently his mother asked for his medical records, and their contents raise many questions in her mind about her son's treatment – specifically about her son's HIV and Hepatitis C infections.

1. On 22-08-1983 and 19-09-1983, GRO-A was given the commercial product Kryobulin. Can you tell us whether the commercial product Kryobulin was from the USA or Germany? The relevant batch numbers appear to be 09MD 1882 and 09MD 5682.
2. Can you tell us if this commercial product was heat-treated or not?
3. At that time, commercial blood products – especially sourced in America – were known by experts in your field to be far less safe than alternatives. Why did you choose the Kryobulin treatment option?
4. Furthermore, why did you choose a commercial product for GRO-A when it had been recommended at a European level that children under the age of 4 should be given safer products?
5. In 1984, you treated GRO-A for minor surgery on his ear. In view of the information known at that time about the risk of using commercial factor 8, with regard to both Hep C and HIV, why did you go ahead with surgery that could have been delayed until products became safer, as indeed was current best practice?
6. Why did you decide – according to GRO-A parents, only at the very last minute - to take out GRO-A adenoids when this would make the use of even more factor 8 likely? It is hard to see how this could be described as urgent surgery, or necessary to ameliorate a life-threatening situation in any way, making this course of action all the more difficult to understand, given the known dangers of using factor 8 at that time.
7. We have had sight of documents that set out the need for "PUPs" - previously untreated patients – from within the haemophilia community at that time. Such PUPs were needed for research into the comparative performance of various heat-treated factor 8 products. Our information suggests that GRO-A met these criteria. Did this form any part of your reasoning behind your decision to give GRO-A the commercial product?
8. In GRO-A treatment notes during 1984, you state, in a letter to professor Arthur Bloom at Cardiff's Heath