

Witness Name: Gaynor Lewis

Statement No: WITN2368019

Exhibits: WITN2368020-WITN2368051

Dated: 4 December 2020

INFECTED BLOOD INQUIRY

EXHIBIT WITN2368026



South Wales Haemophilia Group
1st Floor
110 Caerphilly Road
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Cardiff
CF4 3QG

5th January 2000

Dear Jonathon,

On behalf of the South Wales Haemophilia Group, I would like to thank you for meeting with us to discuss the relocation of the Haemophilia Centre. After receiving the notes from the meeting, the members of the Group discussed them in detail and the following points were raised:

1. We have considered your proposal, and although another entrance would greatly assist Haemophiliacs, we have decided that an entrance via Trauma for additional access would not be practical. As a responsible patient group we accept the access as shown in the Estate's plan. When the Unit is operative, we are prepared to monitor the situation.
2. The Group feels let down by your decision not to brick up the doors to both treatment rooms.
 - ❖ The entire reason for our request is based on the need to feel safe, patient privacy and confidentiality that has been discussed and stated in numerous letters. You have reasoned that it would be convenient not to brick up the entrance at present because in the future (up to 10 years), there will be a requirement for the Haematology Day Unit to use the treatment room. This is meaningless to many of our members (young men) who will be dead by then from Aids/Hepatitis C. We ask you to give them their dignity before their time runs out.
 - ❖ You have already stated that the Haematology Unit will be having additional facilities including a treatment room of their own. I would not wish to suggest that their case is less deserving, but they only have one doctor (at any one time), hence the reason for a further treatment room is puzzling. The Day Unit will gain an

additional treatment room once we vacate the office now being used as a nurse's office. They will also have sole use of the counselling room which is now shared.

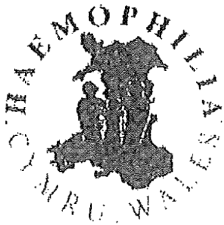
- ❖ Our whole objective is compromised by this one decision, and there are many examples of the problems this has already caused. People do not feel it is the self contained Unit that we expected and that we have lost as a result of the original move.
3. I am concerned that in the notes, it states that car parking spaces should be available as opposed to will be available. Can you please confirm how many dedicated car parking spaces will be made available and on which date.
 4. On the 12th October 1999, you received complaint forms from patients and families. I would grateful if you could now return these forms to me as they were received in strict confidence in accordance with our procedures.

I would be grateful for your prompt consideration of these matters and look forward to your reply before our next committee meeting on 1st February.

Regards,

Jan Wallace
Secretary
South Wales Haemophilia Group

Copies: Heather Cottrell
Peter Collins



Haemophilia Wales
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Tel: 029 2037 2719

Thursday, 29 November 2001

Dear Jane,

The Irish Haemophilia Society (IHS) and the Irish Minister for Health have agreed on a further compensation package for people with haemophilia who were infected with HIV as a result of receiving contaminated blood products. Under the agreement, which amends the Hepatitis C Compensation Tribunal Act, those infected will be assessed individually for compensation.

It will allow family members of the 64 people who died as a result of HIV infection to claim damages for pain and suffering of the deceased. The next of kin can claim for post-traumatic stress disorder, loss of friendship and support, and loss of intimate relationships. This HIV compensation legislation overturns 150 years of legal precedent in Ireland.

This compensation also reflects that the government agrees that people with haemophilia who were infected with HIV did not receive adequate compensation in 1991, and has the effect of overturning that full and final settlement.

In May, I was very fortunate to attend the World Federation of Haemophilia Congress in Seville. I learnt that, not only had many countries compensated their haemophiliacs who were infected with Hepatitis C as a result of receiving contaminated blood products, but that many other countries have been fairer than Wales and more generous in their compensation packages awarded to haemophiliacs who were infected with HIV as a result of receiving contaminated blood products.

I am writing to ask you to commit to reviewing the current settlement, and in particular, to look again at the compensation package awarded to haemophiliacs infected with HIV in Wales, with a view to overturning it and agreeing on an improved compensation package. Haemophilia Wales believes that the settlement was unfair and inadequate. We believe that consideration should be given to the families of the haemophiliacs who have already died (and will die) from HIV and that they should be able to claim damages for the pain and suffering to which the deceased would be entitled were he in a position to make his own claim.

We believe that new legislation would go a long way to alleviating the pain and suffering of our members. I look forward to your reply.

Yours faithfully,