

# Patients' fury over blood test 'betrayal'

Doctors at NHS hospital carry out 'mad cow' analysis without permission

by Ned Temko

DOCTORS WERE accused of gross betrayal last night after haemophilic patients discovered that their blood samples were being tested for the human form of 'mad cow' disease without their knowledge.

They compared the move by one of Britain's leading NHS hospitals to the

Alder Hey organ scandal, when samples were taken from the bodies of dead children without their parents' permission.

The secret blood testing for new variant CJD was discovered in the minutes of a meeting of America's Food and Drug Administration, which was attended last year by a leading member of Britain's National Institute for Biological Standards Control.

The minutes revealed that the British

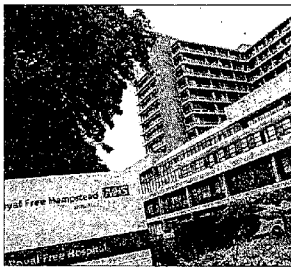
scientist told the FDA that haemophilic blood samples taken from the Royal Free Hospital in London would be 'provided for variant CJD analysis'. He described the samples as 'a bit of serendipity' that could provide 'icing on the cake' for testing the development of an effective blood test for the disease.

Last night testing was criticised by Professor Christine Lee, until recently the head of the Royal Free's haemophilia

unit, who said that passing on blood samples without patients' knowledge or consent raised serious ethical issues – particularly in the wake of controversies like the Alder Hey organ scandal.

'You can't go around just grabbing stored samples,' she said. Acknowledging that she had used samples for hepatitis and HIV infection research 'at an earlier time' in her two decades at the hospital, she said that attitudes had changed. 'You

Samples of blood were taken from the Royal Free Hospital.



can't go ahead and test people without their knowledge. It's just not on.'

She said she had been shocked when she had learnt of the disclosure of the blood testing plan and had strongly urged both the institute and her successor at the Royal Free, Professor Edward Tuddenham, to drop the idea.

But when contacted yesterday Tuddenham said: 'Yes, we are in the process of transferring them [the blood samples] to the CJD surveillance group at the National Institute for Biological Standards Control. We still have them in the freezers here.' He said the samples had been taken during testing for hepatitis C and HIV, but that those analyses were finished and the samples 'were just going to be incinerated otherwise'.

'I got in touch because it occurred to me that the CJD people might be interested, and they were indeed extremely interested. So I was pleased to find a useful research end for the samples.'

But patients are demanding that the blood testing be halted until they have been consulted. 'I'm sickened by this,' said GRO-A 138, a longtime haemophilic patient at the Royal Free. GRO-A, who contracted HIV from US-sourced blood but was not informed until the hospital had tested him for the virus without his knowledge, said: 'They're doing the same to us as they did 20 years ago.'

He said that, if asked, he might agree to have his blood samples used to speed the development of a test for vCJD. But to do so without telling him was 'simply wrong,' he said. 'We live in a world where we are supposed to have rights, but I feel I'm being treated like a laboratory rat.'

Though the Royal Free knows the identity of the sample donors, the plan is to 'anonymise' them for the purpose of the variant CJD research.

But Lee warned her successor that even that approach was fraught with enormous 'patient counselling issues'. She said that, if indications of vCJD were found in any of the samples, the question would arise of whether and how to inform the individual of the possible health risks to himself or others. She said the hospital's plan 'has to come above the parapet. The patients have got to know about it – and give explicit permission'.

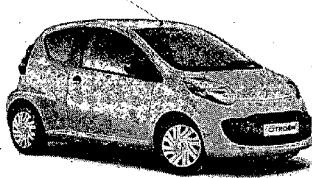
So far 160 people in Britain have contracted variant CJD, including four transfusion patients who have either begun showing signs of the disease or were found to have symptoms following a post mortem. So far, no haemophilic has developed the disease, but concern has centred on the fact that two dozen batches of blood used for transfusion have included samples given by people who went on to contract the disease.



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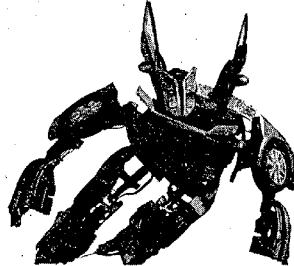


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### NEWS IN BRIEF

#### Woman found by M27

The body of a young woman was found yesterday on the side of the M27 near Southampton. Police said the woman, believed to be in her early twenties, was white, had red hair and was wearing jogging bottoms and a hooded fleece. Police are appealing for any motorists who were travelling between junctions two and three of the M27 in the early hours of the morning to contact them.

#### 16-year-old takes solo flight

A schoolboy too young to drive has taken his first solo flight. James Hepnar, 16, from Stone Cross near Eastbourne, East Sussex, took to the skies in a Piper Warrior from Shoreham airport.

#### Poet dies, aged 69

The author John Moriarty has died, aged 69, it was announced yesterday. The poet had been battling cancer. His last work, *Serious Sounds*, about growing up in Kerry, was published earlier this year.

#### Road driver shot with air gun

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