Infected Blood Inquiry

Professor
Brian Edwards
6:10:20

A Haemophiliac Specialist

The next witness, Dr Mark Winter, is another specialist in Haemophilia and HIV. He takes the Inquiry through his clinical experience at Guy's and Kent and explains that early treatments for haemophilia such as cryoprecipitates [a frozen blood product made from plasma] were not very good and the introduction of concentrates like Factor 8 in the 1970's heralded a "golden interval " for haemophilia patients.

However, evidence of an unknown virus called "Non-A non-B "did slowly emerge. Clinicians knew little about it, but it did not appear to do much harm compared to the benefits patients gained.

It had been known for some years that hepatitis B was a constant risk for haemophiliacs. This all changed in 1978/9 when a group of clinicians in Sheffield showed significant liver damage in haemophilia patients who had been given factor 8.

This study "blew out of the water" the theory that any damage was only minor. Testing via liver biopsy was dangerous for patients with haemophilia.

When presented with evidence that researchers had identified a "non A non B" virus earlier in the 1970's he responded that haemophilia doctors did not dismiss this emerging evidence but there might have been an unwillingness to think that Factor 8 could be a problem because this new treatment had brought such spectacular benefits to patients who were so enthusiastic about its results.

People were reluctant to admit, without substantial evidence, that it presented serious problems. This sounded like an honest appreciation of the clinical world in the 1970's.

Should the patient be told of all risks? That was a philosophical question, Dr Winter responded, but in principal patients should have been told about the risks of chronic liver disease partly as a lever to persuade them to moderate their drinking.

Papers based on studies involving chimpanzees would not be related to patients as results from this source had been shown to be unreliable.

I am reminded here of the leaflet patients get, but few read, with their medicines listing dozens of potential risks.

They are produced primarily so that companies and their lawyers can rest easier having listed all the risks.

Patients need to trust their doctors to tell them what it is important for them to know. Patients do not want all the details only those they can understand. What doctors should do is respond honestly to patient questions. Later in his evidence Dr. Winter explained that when he was in training many consultants, with a diagnosis that would lead to an early death ,consulted family members first and asked what they wanted the patient to be told.

This is indeed difficult territory which the Inquiry may have to confront.

Dr Winter said that he would select Factor 8 from Elstree when a choice was available.

When it was not he had to select which patients would be treated with the factor 8 from America.

10% of patients with haemophilia had an inhibitor; an antibody that recognised Factor 8 and destroyed it.

There was little clinical difference between the products that came from overseas as far as he could tell. The choice was UK supply from donors, a commercial product manufactured predominantly in the US, from a large pool of paid donors or an old unsophisticated treatment cryoprecipitate.

After a break, the questions to Dr Winter focussed on his expertise in treating patients with HIV.

From 1982/3 it was becoming clear that HIV was a transmittable disorder and could be transmitted by blood and blood products. He was then presented with a recording of a television programme from 1988 in which showed him as a young doctor, explaining the emerging evidence of transmission via blood.

Alarm bells were ringing loudly in the clinical community but not it appeared in the Department of Health who did not appear to have any plans to accelerate the move to UK self-sufficiency.

He was not impressed and in some case frustrated by the DHHS doctors who routinely attended their meetings.

His patients were told about the comparative risks and urged to only use factor 8 at home when they felt they had to.

The Haemophilia Society was also telling its members about the risks at this time. Whether the scale of the risk was fully communicated will be judged later.

He judged Prof Bloom's advice to the Haemophilia Society in May 1983 that there was no evidence that HIV could be transmitted by blood, to be plain wrong.

Although treatment via cryoprecipitate was cumbersome to use in a home setting [it required a deep freeze] it did carry a lower risk of transmission as the donor pool was much smaller.

Dr. Winter did not think it was ever a viable option to switch all patients back to cryoprecipitates.

Ms Richards indicates that later witnesses may disagree. Once HIV transmission was proven the treatment options for doctors changed.

It was suspending treatment, which was unthinkable for haemophiliacs, continue with UK supplies when available or switch to a heat-treated product which had been shown to be safer.

He chose the latter despite the extra cost [50% higher]. In later evidence he explained that whilst the heat treatment did iradicate the HIV virus it was less successful with hepatitis C. [A heat-treated Factor 8 that did iradicate both HIV and hepatis C would emerge in the 1980's}.

At this point the Blood Products Laboratory could only dry heat 30% of its products so was in short supply and commercial heated products, including those from the US, continued in use.

Winter explained that Dr Bloom thought he and one or two of his colleagues was 'mad to make the switch to heated commercial products'.

The product from the UK would not, Bloom claimed, have the HIV virus. This represented a major difference of opinion between haemophiliac physicians.

We then come to what may turn out to be an important exchange.

Did every haemophilia doctor follow the advice of the Haemophiliac Centre directors?

Was their advice advisory or mandatory?

It was advice, explained Dr Winter. At that time doctors valued and protected their clinical freedom.

The advice would have been respected but individual doctors and patients could divert from it if they judged that to be appropriate.

Would it have been different if the advice had come from the CMO asked Ms Richards.

There was no powerful central advice said Dr Winter and that was a problem, particularly when HIV broke.

A test for HIV became available to Haemophilia Centres late in 1984.

Dr Winter called all his patients into hospital for blood tests and explained why.

Some other centres sent stored blood for testing without the knowledge of their patients. The results were unexpected and startling.

Many haemophiliac patients had HIV. He told all his patients personally and had to advise them about sexual transmission and need to use condoms.

Later he arranged for partners to be offered tests. However, other centres sent their patients a letter or told them in corridors or in groups.

Many patients were badly let down by their Centres who showed a lack of humanity, he said.

There were, at that time, mixed views in the clinical community as to whether children should be told the results of their test.

Dr Winter decided that it was right that they should be told, and so difficult family consultations took place.

At this point Dr Winter shows real emotion.

It was a very difficult time. It also becomes clear that on a number of occasions haemophiliac patients admitted to other hospitals with bleeding after accidents and surgery were given unheated commercial Factor 8 and suffered the consequences.

His centre should have been consulted but were not.

There were strong disagreements among physicians as to whether written consent should be obtained from patients before treatment was initiated or changed.

We will no doubt return to this issue.

Towards the end of this section of evidence Dr Winter ventured that if the David Owen initiative had been pursued more vigorously the outcome for English patients might have been hugely different.

A challenge for the Department of Health to address in due course, as is the criticism that they should have played a more decisive role in shaping the response to the growing crisis. The CMO for most of this period was Henry Yellowlees.

This was evidence from a credible clinician who explained clearly and honestly the dilemmas he faced as it became clear that the wonder treatment that had transformed his patients' lives became discredited.

Evidence from other clinicians is to follow in the coming weeks but Dr Winter has provided a very powerful foundation.