

# Disquiet grows over hepatitis risk to haemophiliacs

People who use clotting agent Factor VIII sense a repeat of the HIV furore. Celia Hall reports

For the past three years, disquiet has been growing in haemophilic circles. Specialists began to notice an increase in the number of cases of serious liver disease in some of their patients and a link was made with the viral infection, hepatitis C, itself only identified in 1989.

The picture was obscured by the fact that haemophiliacs, who need regular supplies of the blood clotting agent Factor VIII, have always been prone to liver complications.

But blood and liver function tests revealed a darker story. The Haemophilia Society says 90 to

95 per cent of patients who received Factor VIII before 1985 now have hepatitis C (HCV). Data still being collected shows that 12 died last year, a rate of one a month. This is the same number of haemophiliacs who died from brain haemorrhages, an established risk in older haemophilic men.

During the year, six regional meetings have quietly been held to answer haemophiliacs' questions and more are planned for next year.

This is the second blow to the haemophilic community. In the mid-1980s at the height of the Aids hysteria, it emerged that contaminated Factor VIII had infected haemophiliacs with HIV.

Haemophiliacs were stigmatised and, most cruelly, schoolchildren were ostracised. Parents who knew there was a haemophilic child in a class withdrew their own children and demanded that the haemophilic be removed.

Then began a legal battle with the Department of Health for compensation. In 1991, the department agreed to pay a total of £42m to 1,200 haemophiliacs with HIV. It was — and is — careful to deny that this is compensation. The department admitted to no fault. The money was to help families with extra expenses incurred by illness.

Understandably the haemophilic community — there are about 10,000 men and boys with

haemophilia in the UK — is sensitive about this latest burden. The question of "compensation" for infection with hepatitis C is not clear. Simon Taylor, vice-chairman of the Haemophilia Society and a haemophilic with HCV, says the problem is that people have the disease for a long time but remain well.

"It is all very new. We have so little information. We are still working hard to collect it. If we go to the Government at this stage, they will

say that most of us are fine. But we are talking to the department."

Haemophilia specialists are also working hard to collect information. Since the virus — formerly known as non-A non-B hepatitis — was identified only five years ago, and since symptoms of liver disease can take up to 30 years to appear, a reliable epidemiology of the disease is not yet established.

Hepatitis C in a non-haemophilic can take 20, 30 or even 40 years to produce symptoms. About half will develop liver disease. In haemophiliacs that may rise to

70 per cent and doctors at the hepatitis clinic at King's College hospital, London, are seeing symptoms developing in some haemophilic patients after about 10 years.

Treatment for hepatitis centres on the drug interferon, which counters the virus and boosts the immune system. It is successful in 20 to 25 per cent of cases.

Dr Christopher Tibbs of the King's Liver Unit said: "It is a very slow disease and there is a great deal of research going on. By the time symptoms develop we hope we will be better at treating it."