



## **Treatment Safety and the Inquiry**

**Important - it's recommended that everyone with a bleeding disorder gets vaccinated against hepatitis A and B, in case they ever need treatment with bloods products.**

### **What's all this about blood products making people sick?**

You might have heard on the news or Haemophilia Society website that there is an inquiry going on into infected blood products. Because Governments have refused to hold a Public Inquiry into how this happened, an Independent Non-Governmental Inquiry is now looking into the issue.

The new Government in Scotland has also said that it will hold its own Inquiry into this issue.

### **What did happen?**

In the late 70s and early 80s, people with haemophilia were still being treated with plasma from human blood. Sadly a lot of this blood was infected with viruses like HIV and hepatitis C which then got into the blood products people with haemophilia were using.

Lots of people with bleeding disorders caught HIV and hepatitis C from the plasma, and many are now sick. Tragically some have died from their illnesses.

### **What's hepatitis?**

It means literally swelling of the liver. There are three main types of hepatitis - A, B, and C. Some people with haemophilia got all of them, but hepatitis C was the most serious for their health. In fact some people have died after becoming sick with liver disease. It's sometimes written as 'HCV' - Hepatitis C Virus.

### **What is HIV?**

Human Immunodeficiency Virus (HIV) slowly destroys the immune system of people who are infected with it. This makes it more likely that they will get infections or cancers. There are anti-HIV drugs that people can take to keep the HIV infection under control. If a person's immune system gets so badly damaged by HIV that it can't cope anymore it's known as Acquired Immune Deficiency Syndrome (AIDS) - these days people tend to call this advanced HIV infection.

Many people manage to stay well with HIV these days, as there is good medication.

### **What does it mean for me?**

Most young people are now being treated with 'recombinant' or artificial products. No-one has been infected with HIV or Hepatitis C as a result of taking recombinant.

You might be using plasma, particularly for von Willebrand's. Since the mid-80s the plasma has been treated with heat to kill the viruses. It's much safer now. If you're worried about taking it, do talk to your haemophilia centre or get in touch with us here. We can explain how it works. Remember the plasma will help you with bleeds.

### **I'm upset about the Inquiry**

You might be upset because it affected your family, or maybe you can't get anyone to talk to you about it. Maybe you're just worried - it's ok to feel concerned about any medicine you might be taking. Either way, we're happy to talk to you about how you feel. You can email or call our helpline on 0800 018 6068 (free from landlines).

You might find some people bullying you because they've heard haemophilia is linked to HIV. This was a long time in the past and anyone who bullies you is probably afraid themselves, and just doesn't understand about HIV or bleeding disorders. It's not acceptable for anyone to bully you, about anything.

## **What about vCJD?**

If you got treated with plasma or plasma products in the 80s or 90s, you may have been told you are 'at risk' of developing CJD (sometimes called 'mad cow disease' when it happens in cows). We know this must sound really scary but if you find out the facts it will help.

Everyone in Britain who ate beef during this time is also in theory 'at risk' of CJD. However, the risk seems to be tiny and there have been very few cases of people who actually developed it. People who got given blood products were told they are in theory a bit more 'at risk' because of the possibility that it can be passed on in blood from person to person. The risk is still seen as tiny and it was done mainly as a precaution.

## **What does it mean?**

Aside from not giving blood (maybe not a good idea with a bleeding disorder!), it shouldn't affect you that much. If you ever have surgery the current guidelines say that any instruments used on you can't be used again. So this means they might operate on you at the end of the day. These guidelines may change if it looks like the government were being over-cautious, but we don't know yet.

## **What about jobs?**

In some medical and dental jobs, there is a risk that infections can be passed on from person to person. However, if you don't have vCJD and are only 'at risk' in theory, we have been told there shouldn't be any barriers on what job you take out.

Please do contact us if you have worries or concerns and we will try to help.