

2 November 2009

Dear HFNZ member,

**Public health implications for people who have received plasma derived clotting factors in the United Kingdom between 1980 and 2001.**

We wrote to you in February this year to inform you of new information regarding Variant Creutzfeldt-Jacob Disease (vCJD). This information was concerned with the discovery of the vCJD infectious agent or prion at post-mortem in a person with haemophilia in the UK. As you will be aware, this person did not have vCJD disease and died of other causes.

The means by which this patient acquired the prion has not been determined with certainty. However, an expert panel concluded that exposure to plasma-derived clotting factor was the most likely cause.

The Ministry of Health has asked us to write to you again. This time we are writing to inform you of the public health implications for people who have received plasma products in the UK during the period 1980 and 2001. There is a possibility that some of these people may have been treated with product from batches that included plasma from donors who subsequently developed vCJD.

This raises the theoretical risk that people treated from these batches might carry the vCJD prion. The Ministry has therefore asked us to identify those of you that received plasma product in the UK during the at risk period. This is so that precautions can be put in place to minimise the risk of the vCJD prion being passed on to other people.

We understand that notification of this sort can create anxiety. However, it is important for us to contact you as public health authorities have a duty to act to prevent the spread of disease. In the case of vCJD, special decontamination measures need to be taken to sterilize surgical instruments used on people that may be carrying the infectious agent, the vCJD prion.

If you are identified as someone who has received plasma product in the UK between 1980 and 2001, your haemophilia treaters will, with your permission, contact the UK haemophilia authorities to find out which products you received.

Based on the information received back from the UK authorities your haemophilia treaters will determine whether these special precautions apply to you. Your 'at risk' status would be recorded in your hospital and general practice medical notes. Being identified as someone at risk for vCJD will not affect your treatment in any way.

As this letter may cause you some distress, we wish to provide you with the facts of the situation.

**Information on vCJD**

vCJD is a very rare disease in humans. It affects the structure of the brain and leads to death. vCJD is

one of a group of diseases called transmissible spongiform encephalopathies (TSEs) that affect animals as well as humans. BSE (bovine spongiform encephalopathy), sometimes referred to as 'mad cow disease' is a type of TSE that affects cattle. These diseases are caused by an abnormal form of a prion protein which accumulates in the brain.

Variant CJD is the human form of BSE. Many people in the United Kingdom were exposed to BSE because they ate beef and beef products from cattle that were infected with BSE. There have been under 170 cases of variant CJD in the United Kingdom since 1995 and a few cases in other countries. One person died of variant CJD in the United Kingdom in 2008.

Four people in the United Kingdom have been infected with vCJD following blood transfusions. Earlier this year, one haemophilia patient has been found to have evidence of infection with the variant CJD abnormal prion protein, only in his spleen, when tested at post mortem. This patient did not have any symptoms of variant CJD, and died of an unrelated cause. No other types of CJD are known to have spread through blood.

### **Risk of vCJD from UK plasma products 1980-2001**

Some UK plasma products made between 1980 and 1998 (and used for treatment up to 2001) were made with plasma from donors who later developed vCJD. None of these products were imported into New Zealand. There is, however, a possibility that some people who are now living in New Zealand and who previously lived in the UK may have received clotting factor concentrates at risk for passing on vCJD.

We do not know how many of the people who received potentially contaminated UK products will now have the vCJD prion themselves. At the present time, there is no test that can find out whether someone does or does not carry it, except at post-mortem examination.

To put this in perspective, the person that we wrote to you about in February remains the only person with a bleeding disorder ever to have been found to carry vCJD-related prion. It is important to remember that no-one with haemophilia or other bleeding disorder has been found to have vCJD disease. In addition, the World Federation of Hemophilia continues to view plasma-derived products as an important treatment option for the global bleeding disorders community.

### **If you were treated in the UK between 1980 and 2001**

If you are one of the people who were treated in the UK between 1980 and 2001, please inform your haemophilia treatment centre. They will then be able to find out whether or not you have been exposed to potentially infected batches of plasma derived blood products in the UK. In order to do so, they will need to know when you were in the UK and it would be very helpful to know which haemophilia centre or centres you attended for treatment.

For people who are found to have been exposed to batches of clotting factor that could have contained vCJD prion, the Ministry of Health have asked that we take precautions to make the risk of them passing this on to other people as small as possible.

### **How can I reduce the risk of spreading vCJD to other people?**

If you have been identified as being at increased risk of developing vCJD, you can reduce the risk of spreading vCJD to other people by following this advice:

- Don't donate blood.
- Don't donate organs or tissues, including bone marrow, sperm, eggs or breast milk

- If you are going to have any medical or surgical procedures, you should tell whoever is treating you beforehand so that they can make special arrangements for the instruments used to treat you to be decontaminated or disposed of.

You are advised to tell your family about your increased risk. Your family can tell the people who are treating you about your risk of vCJD if you need medical or surgical procedures in the future and are unable to tell them yourself.

### **How could blood, tissue or organ donations spread vCJD?**

If a blood donor or organ donor is infected with vCJD but has no signs of the disease, their blood, tissues and organs may still spread vCJD to other people. This is because the abnormal prion proteins are present in different parts of the body in vCJD before symptoms develop.

There is no test available at present that can detect blood that is infected with vCJD, and no method that can completely remove abnormal prion protein from blood.

### **Risk of vCJD in people treated exclusively in New Zealand**

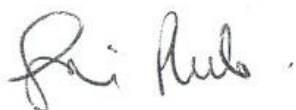
It is very unlikely that people with bleeding disorders treated exclusively in New Zealand would acquire the vCJD prion. In New Zealand, unlike in the UK, there have been no cases of the cattle infection, bovine spongiform encephalopathy that is caused by the vCJD prion. No cases of vCJD have been reported in people living in New Zealand. No fractionated blood products for the treatment of haemophilia derived from plasma collected from the UK have ever been used in New Zealand and New Zealand fractionated blood products are derived exclusively from New Zealand donors and have never been manufactured in the UK.

### **Risk of vCJD in countries other than the UK or New Zealand between 1980 and 2001**

Some potentially contaminated UK plasma products were exported to other countries. The Ministry considers that the risk of people with haemophilia and other bleeding disorders being able to pass on vCJD as a result of exposure to UK plasma products outside of the UK is very low. They have not asked us to identify people who may have been exposed to UK plasma products between 1980 and 2001 in countries outside of the UK. If, however, you think that you may be one of these people and wish to discuss this further, please contact your haemophilia treatment centre.

If you think you may have received plasma products in the UK during the affected time period (1980-2001) please contact your haematologist. If you have any questions regarding any of the issues raised by this letter, please contact your haematologist or haemophilia nurse to discuss this further.

Sincerely,



**Dr Julia Phillips**  
Chair of Haemophilia Treaters Group



**David Habershon**  
HFNZ Vice President