GRO-B

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Glasgow

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February 2009

Dear Mr GRO-B

**Variant Creutzfeldt-Jakob Disease (vCJD) and patients with bleeding disorders who have been treated with UK plasma products**

We are writing to all our patients with bleeding disorders to tell them about a person with haemophilia who has been found to have evidence of the infection that causes variant Creutzfeldt-Jakob Disease (vCJD) in his spleen at post mortem. All Haemophilia Centres are contacting their patients throughout the UK to give them this information.

Tests carried out on a haemophilia patient who died last year have shown that he was infected with the abnormal prion protein that causes variant Creutzfeldt-Jakob Disease (vCJD). The patient did not die of vCJD, and never had any symptoms of this disease when he was alive. The patient was in his 70s when he died of a completely unrelated cause. The tests were carried out as part of a research study jointly co-ordinated by the UK Haemophilia Centre Doctors Organisation and the National CJD Surveillance Unit.

This patient had been treated in the 1990s with several batches of UK sourced clotting factors, including one batch of factor VIII that was manufactured using plasma from a donor who went on to develop vCJD.

A final view as to how this haemophilia patient became infected with the vCJD abnormal prion protein has yet to be reached and investigations are therefore continuing to establish this.

This is the first time that the vCJD abnormal prion protein has been found in a patient with haemophilia, or any patient treated with plasma products. This patient did not die of vCJD, and the only reason we know he was infected with the vCJD abnormal prion protein is because of the research tests carried out after he had died.

We are telling you about this case so that you have the latest information about vCJD and clotting factors made in the past from UK plasma.

**This new information does not change the way you will be treated.**

If you have a bleeding disorder or congenital antithrombin III deficiency[1] and you received clotting factors or antithrombin made from UK-sourced plasma[2] between 1980 and 2001, then you should have been told that you have an increased risk of vCJD, and you should follow public health advice (see box).

**Advice on how to reduce the risk of spreading CJD to other people**

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

- Don't donate blood. No-one who is at increased risk of CJD or who has received blood donated in the United Kingdom since 1980 should 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 about your at risk of vCJD so that they can make special arrangements for the instruments used to treat you
- 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 CJD if you need medical or surgical procedures in the future and are unable to tell them yourself.

If you are unsure about this, and would like more information, please contact the haemophilia centre and make an appointment to come and see one of the clinical team.

Other patients (those who have not been treated with UK plasma factor concentrates) who do not have an increased risk of vCJD, do not need to take any action. Again, please contact the haemophilia centre if you are unsure about your past treatment and your vCJD at risk status.

**The information from this case does not change the public health 'at risk' status of any patients with bleeding disorders.**

Two patient information leaflets are enclosed:

'Information for people who have an increased risk of CJD', and

'Who has an increased risk of CJD?'

These are also available on the Health Protection Agency website http://www/hpa.org.uk/CJD.

[1] Congenital and acquired haemophilia (Haemophilia A and Haemophilia B), Von Willebrand Disease, other congenital bleeding disorders and congenital antithrombin III deficiency.
[2] Factor VIII, factor IX, factor VII, factor XI, factor XIII and prothrombin complexes, as well as antithrombin.

We realise that you may find this new information worrying. Do contact the Haemophilia Centre if you wish to talk about this.

Yours sincerely

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GRO-C

Prof G D O Lowe

Prof I D Walker

Dr R C Tait

Haemophilia Centre Co-Directors