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DEPARTMENT OF HAEMATOLOGY

Haemophilia Clinic

Mrs Jane Thomas, Clinical Nurse Specialist in Haemophilia

Secretary: Mrs. Jan Ace ☎ (01792) Direct Line

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Our Ref: PWC/SI/JLA
Date Typed: 27th July, 2009
Hospital No:

DRAFT

[Patient name]

[Address]

Dear [insert name]

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, who are known to have been treated with UK plasma products between 1980 and 2001.

We have written to you previously in February 2009 regarding this issue. You may have also been in receipt of a letter from the Haemophilia Society and you may have become aware that the Department of Health has just published a Document called "vCJD Risk Assessment Calculation for Patients with Multiple Routes of Exposure".

The main reason for writing this letter is to inform you of the following:

- Up to the present date no Haemophilia or bleeding disorder patient has been diagnosed with, or died from, clinical vCJD.
- There has been new information about a patient with haemophilia who died of other causes but, on postmortem, had abnormal prion protein. This patient had no symptoms of variant CJD.
- The advice you received previously, on how to reduce the risk of spreading CJD to others, has not been altered. This advice can be summarised by the fact that you should not donate blood, organs or tissues and that you should inform the Health Care workers if you are to undergo medical or surgical procedures. You also need to advise your family about the increased risk.

- The information obtained up to date does not change the Public Health At Risk state of any patient with a bleeding disorder.

- 2 -

If you would like to discuss any of the above issues please do not hesitate to make an appointment with Mrs. Jane Thomas, Haemophilia Specialist Nurse and I will be happy to discuss any questions with you or with your family.

If you also do not wish to receive any further update on variant CJD I would be grateful if you could sign and date the enclosed reply sheet and send it in the stamped addressed envelope enclosed.

Yours sincerely,

GRO-C

Dr. S. Al-Ismael FRCP; FRCPath

REPLY SHEET IN RELATION TO VCJD

27.07.2009

The Haemophilia Centre
Haematology Department
Singleton Hospital
Sketty Lane
Swansea
SA2 8QA

Please note that by returning this sheet you are requesting that we **do not** send further information on vCJD.

If you do wish to receive further updates there is no need to reply.

Future circumstances may dictate that we contact you with information deemed necessary by the Department of Health.

Please do not send any further correspondence regarding vCJD from the Haemophilia Centre at Singleton Hospital.

Sign _____

Date _____