The Newcastle Upon Tyne Hospitals NHS

NHS Trust

Northern Regional Haemophilia Service
Newcastle Haemophilia Comprehensive Care Centre
Royal Victoria Infirmary
Queen Victoria Road
Newcastle upon Tyne
NE1 4LP

~~DirectTel:~~ GRO-C ~~(Secretaries)~~
GRO-C (Clinical Nurse Specialist)
(Nursing Staff)
Fax: 0191 2300651
E-mail: Linda.McBride@ GRO-C

Royal Victoria Infirmary
Queen Victoria Road
Newcastle upon Tyne
NE1 4LP

Tel: 0191 233 6161
Fax: 0191 201 0155
~~xxx xxxxxxxxxxxxx~~

Consultants:
John Hanley
Kate Talks

Haemophilia Nurse Specialist:
Julie Vowles

Physiotherapist:
Brenda Buzzard

Social Workers:
Dot Holder
Helen Weatherly

Haemophilia Secretary:
Linda McBride

Ref: JH/LM

20 September 2004

Dear Patient or Parent,

Variant Creutzfeldt-Jakob Disease (vCJD) and Plasma Products

We are sorry to have to write to you again on this issue but there has been another notification about variant CJD.

You will remember that when this happened a few years ago we discussed how you would like information about future notifications to be given to you.

At the time you expressed a preference for receiving the information face to face, rather than by post.

However, we thought it best to write to you about this as it is likely there will be some publicity on the matter in the media over the next few days. We do not want this to be a source of anxiety for you.

We look forward to discussing things in more detail when you come for your next clinic review. If you would like to bring this forward please do not hesitate to phone up to rearrange your appointment.

With best wishes,

Yours sincerely,

GRO-C

JOHN HANLEY
Consultant Haematologist
Haemophilia Centre Director

GRO-C

KATE TALKS
Consultant Haematologist
Haemophilia Centre Director

The Newcastle Upon Tyne Hospitals NHS

NHS Trust

Northern Regional Haemophilia Service
Newcastle Haemophilia Comprehensive Care Centre
Royal Victoria Infirmary
Queen Victoria Road
Newcastle upon Tyne
NE1 4LP

DirectTel: GRO-C (Secretaries)
GRO-C (Clinical Nurse Specialist)
(Nursing Staff)
Fax: 0191 2300651
E-mail: Linda.McBride@ GRO-C

Royal Victoria Infirmary
Queen Victoria Road
Newcastle upon Tyne
NE1 4LP

Tel: 0191 233 6161
Fax: 0191 201 0155
xxx xxxxxxxxxxxxx

Consultants:
John Hanley
Kate Talks

Haemophilia Nurse Specialist:
Julie Vowles

Physiotherapist:
Brenda Buzzard

Social Workers:
Dot Holder
Helen Weatherly

Haemophilia Secretary:
Linda McBride

Ref: JH/LM

20 September 2004

Dear Patient or Parent,

Variant Creutzfeld-Jakob Disease (vCJD) and Plasma Products

We are writing to you because there may be some publicity in the media this week about some patients with haemophilia and other bleeding disorders being at risk of carrying variant CJD from pooled plasma treatment given in the past.

You/your child have not received any of this treatment so we would like to emphasise that you are not considered in any way at risk of vCJD or passing it on to others.

We thought it best to write to you in case you are worried about any of the media coverage about this.

If you would like to discuss things further please do not hesitate to contact us, otherwise we look forward to seeing you at your next clinic appointment.

With best wishes,

Yours sincerely,

GRO-C

JOHN HANLEY
Consultant Haematologist
Haemophilia Centre Director

GRO-C

KATE TALKS
Consultant Haematologist
Haemophilia Centre Director

The Newcastle Upon Tyne Hospitals NHS

NHS Trust

Northern Regional Haemophilia Service
Newcastle Haemophilia Comprehensive Care Centre
Royal Victoria Infirmary
Queen Victoria Road
Newcastle upon Tyne
NE1 4LP

DirectTel: GRO-C (Secretaries)
GRO-C (Clinical Nurse Specialist)
(Nursing Staff)
Fax: 0191 2300651
E-mail: Linda.McBride@ GRO-C

Royal Victoria Infirmary
Queen Victoria Road
Newcastle upon Tyne
NE1 4LP

Tel: 0191 233 6161
Fax: [illegible]

Consultants:
John Hanley
Kate Talks

Haemophilia Nurse Specialist:
Julie Vowles

Physiotherapist:
Brenda Buzzard

Social Workers:
Dot Holder
Helen Weatherly

Haemophilia Secretary:
Linda McBride

Ref: JH/LM

20 September 2004

Dear Patient or Parent,

Variant Creutzfeld-Jakob Disease (vCJD) and Plasma Products

We have been instructed by the Department of Health to send you the enclosed information about variant CJD.

You may be aware that some anxiety has arisen because a number of blood donors who contributed plasma to batches of factor VIII and factor IX concentrates have subsequently developed variant CJD. Several years ago we were notified about some batches and we wrote to all patients and parents giving them the option of knowing this information.

We are writing again as there has been a further notification of additional potentially affected batches. If you would like to know if you have received any of these batches please let us know.

The Department of Health has decided that all patients exposed to these batches should be given the opportunity to have this information. In addition, they have decided further public health measures should be put in place. This is described in detail in the attached documents from the Department of Health.

We would like to take the opportunity to reiterate that these documents describe a theoretical risk that some individuals may be carrying vCJD. This **DOES NOT** mean that these individuals will develop vCJD. The emphasis is on taking extreme precautions to prevent even the faintest possibility of passing vCJD on to others at times of surgery etc.

We would also reiterate that no haemophiliacs or others with bleeding disorders have actually developed vCJD.

We are concerned that this information will cause you and your family considerable anxiety. We would like to offer you the opportunity to discuss this further either at your next appointment. If

you would like an earlier appointment please indicate this on the Patient Reply Sheet and return it to the Centre.

With best wishes,

Yours sincerely,

GRO-C

JOHN HANLEY
Consultant Haematologist
Haemophilia Centre Director

GRO-C

KATE TALKS
Consultant Haematologist
Haemophilia Centre Director

Health Protection Agency

Scottish Centre for Infection and Environmental Health

NHS National Services Scotland

National Public Health Service for Wales
Gwasanaeth Iechyd Cyhoeddus Cenedlaethol Cymru

Department of Health, Social Services and Public Safety
An Roinn Sláinte, Seirbhísí Sóisialta agus Sábháilteachta Poiblí

VARIANT CREUTZFELDT-JAKOB DISEASE and PLASMA PRODUCTS

INFORMATION FOR PATIENTS

1. What is variant Creutzfeldt-Jakob disease?

Creutzfeldt-Jakob Disease, or CJD, is one of a group of rare and fatal diseases in humans and animals that affect the structure of the brain.

There are four main types of CJD: of these, sporadic CJD (arising spontaneously) is the most common and accounts for 85% of cases. The other types are familial, iatrogenic (through medical treatment) and variant CJD (vCJD). In animals the best-known TSE is bovine spongiform encephalopathy (BSE or 'mad-cow disease'). Variant CJD is believed to be the human form of BSE.

Many people living in the UK have been exposed to BSE (Bovine Spongiform Encephalopathy or 'mad-cow disease') from eating infected beef and so are at a possible risk of developing vCJD.

2. What's this about?

Late last year the death of a person from vCJD who died some years after receiving a blood transfusion from a donor who themselves died of vCJD, was announced. This was the first case of transfusion-associated vCJD infection and increased concern about the possible infectivity of blood. A second probable case was reported in July 2004.

When a patient is diagnosed with vCJD, the UK Blood Services are informed and checks are made to find out whether the patient ever donated blood. Blood products include blood components, which are derived from a single donation of blood, or pools of up to six donations; and plasma products, which are prepared from the pooled plasma of several thousand blood donations in a process known as 'fractionation'.

To date, nine people are known to have donated blood before they became ill with vCJD, and their donations were used to make plasma products. Thus a number of patients may have been exposed to vCJD infection in the course of their past medical care.

This information sheet about vCJD has been developed with doctors' and patients' groups for patients who have been informed by their doctor that they are considered 'at-risk' We hope it will go some way to answering your first questions.

3. Why am I being contacted?

Patients who have received implicated plasma products may be at an additional risk of vCJD. This risk is 'additional' since it is on top of the general risk for many people in the UK from eating beef in the past.

It is impossible to put an exact figure on the chances of getting vCJD, either from BSE-infected beef and beef products, or the possible additional risk from receiving implicated plasma products. So far there have been no cases of vCJD amongst recipients of plasma products sourced from blood donors who later developed vCJD, and the risk of this happening is likely to be very low.

If you received implicated plasma products there is a small possibility that vCJD could have been passed on to you. If so it might be possible for you to pass vCJD on to others in certain circumstances, in which case you and the people providing your healthcare need to take some special precautions to avoid putting other people at potential risk. This is why it is important that you know, even if this causes you anxiety.

4. What measures are already being taken for vCJD?

A number of measures have minimised the risk of getting vCJD from eating BSE-infected meat and meat products. These include banning the feeding of animal protein to other animals, and removing certain parts of animals from the food we eat.

In the healthcare setting, the abnormal 'prion' protein, the infective agent that causes vCJD, is very hard to destroy. Using surgical instruments only once, or destroying those that have been used on patients diagnosed with vCJD, is one way to guard against passing on vCJD. In recent years much effort has also gone into ensuring that the decontamination of all surgical instruments is to the highest standards. The aim is to remove as much potentially infected material as possible.

5. And in relation to blood?

Because it is uncertain whether vCJD can be transmitted by blood the United Kingdom blood services have taken a number of precautionary measures:

- Withdrawal and recall of any blood components, plasma products or tissues obtained from any individual who later developed vCJD (December 1997),
- Importing plasma from the US to manufacture plasma products (1998),
- Removal of white blood cells (leucodepletion) from all blood components (Autumn 1999),
- Importing fresh frozen plasma from the US for patients born on or after 1st January 1996 (Autumn 2002),
- Not accepting donations from people who have received a blood transfusion since 1980 (April 2004),
- Promoting appropriate use of blood and tissues and alternatives throughout the NHS.

6. And in relation to patients?

In 2000 an expert advisory committee called the CJD Incidents Panel (CJDIP) was set up to advise on the handling of 'incidents' of possible transmission of CJD, including vCJD, in a healthcare setting. The CJDIP assesses the risk to other patients, and advises whether patients should be contacted and informed about their possible exposure.

The CJDIP has agreed that, in general, where patients may have been exposed to a 1% or greater possible risk of infection[1], they may have an additional unknown risk of developing vCJD, on top of the general risk from eating beef in the past, and should be contacted. These patients should be given advice about what they should do to avoid putting other people at risk. This advice includes not donating blood, tissue and organs, and informing healthcare professionals so that extra precautions can be taken if they require invasive medical or dental procedures, for example a surgical operation.

There are a lot of uncertainties in estimating the risk of infection with vCJD and a very cautious approach has been taken. The CJDIP has chosen this 1% threshold for informing patients of their exposure so that special precautions can be taken to limit the possible risk of transmitting vCJD between patients. This is considered the best balance between protecting the public from further spread of vCJD and causing excessive anxiety regarding a risk which is uncertain, but thought to be low.

7. So what's new?

Since the CJDIP was established it has been considering policy towards recipients of blood from donors who later developed vCJD.

When people are diagnosed with vCJD, any blood donations they have given are traced. The CJDIP has estimated the potential additional risk of vCJD from treatment with plasma products sourced from all donors known to have later developed vCJD. This risk depends on the type of plasma product and how each batch was manufactured, as well as the amount a patient may have received.

For certain plasma products (e.g. intramuscular immunoglobulin used for travel vaccinations against hepatitis A, or anti D for Rhesus negative pregnant women) the amount of estimated infectivity in the implicated products is so low that the possibility of reaching the 1% threshold can realistically be ignored. Patients who have received these products do not need to take any special precautions.

For other products (e.g. clotting factors and antithrombin, intravenous immunoglobulin, albumin 4.5%) the infectivity may be higher, depending on how the product was made. Once one of these plasma products has been identified the next step is to try to identify those patients who are likely to have had sufficient product to reach the 1% threshold and who need to take special precautions. These patients are considered to be 'at-risk' of vCJD for public health purposes.

[1] A 1% risk of infection means that there is a 1 in 100 possibility that vCJD can be transmitted.

8. Who is affected?

Patients who are considered 'at-risk' of vCJD for public health purposes will be informed by their doctor. The people who may be affected are in three main groups:

- some patients with bleeding disorders (including congenital and acquired haemophilia (haemophilia A and haemophilia B), Von Willebrand Disease, other congenital bleeding disorders) and congenital antithrombin III deficiency,
- some patients with primary immunodeficiency (PID), and
- some patients with other illnesses who might be considered 'at-risk'. These may include, patients with secondary immunodeficiencies; certain neurological conditions and autoimmune illnesses (such as idiopathic thrombocytopaenic purpura), plasma exchange recipients and patients with severe burns. Patients with certain other conditions requiring critical care (including acquired antithrombin deficiency or patients requiring rapid warfarin reversal) may also be affected.

9. How does this affect me?

If you have been informed that you are 'at-risk' for public health purposes, you are being asked to take the following actions in order to reduce the chance of passing on vCJD to other people:

- **Do not donate blood.**
- **Do not donate organs or tissues.**
- **Tell whoever is treating you before you undergo medical, surgical or dental treatment, so they can then arrange any special procedures for the instruments used in your care.**
- **It would be best if you tell your family about this in case you might need emergency surgery in the future.**

A note of this will be made in your hospital medical records and your GP notes. Your care should not be compromised in any way – it will be just the surgical instruments that will be treated differently. Nor will you need extra medical follow-ups because you are 'at-risk' for public health purposes. However, your doctor will always be willing to see you if you have any worries about your health.

10. So if I'm 'at-risk' for public health purposes - what happens now?

You need do nothing other than follow the advice given above (see Section 9).

Normal social contact and household activities do not spread the infection. Your family and friends are not at risk from you and you do not need to take any special precautions in your normal life.

Variant CJD is not infectious in the usual ways. There is no evidence that it can be passed on between people by sneezing or coughing (like colds and flu), sharing utensils, by skin contact, or through kissing or sexual intercourse.

There is also no evidence that vCJD can be sexually transmitted or transmitted from parent to child. However, as a precautionary measure, men who are 'at-risk' of vCJD for public health purposes should also not donate sperm.

11. Does this mean I'm going to suffer from vCJD?

Having reached the 1% threshold does not mean you will actually develop vCJD. This risk is unknown, but the chances of it happening are very low.

There is no evidence for transmission of vCJD by plasma products. Although the process of estimating risk is based on the best evidence available, there is much uncertainty about many aspects. As a result a cautious approach has been taken and may have over-estimated the potential additional risk of vCJD from receiving the various implicated plasma products. Despite these limitations it is still important to take extra public health precautions to provide the best protection for the population in general.

12. Can I be tested to see if I am infected?

No. Scientists are working very hard to develop a test, but as yet there is no test available that can be used to identify someone who may have been infected. Variant CJD can only be reliably diagnosed by brain biopsy or through examining the body after death.

13. What happens if I develop strange symptoms?

CJD causes dementia and a range of other symptoms, including difficulty with balance and extreme clumsiness. Unlike the other forms of CJD, vCJD often starts with psychiatric symptoms like depression and anxiety.

Go and see your doctor. It is unlikely that 'strange symptoms' will be the start of vCJD but your doctor will be able to arrange for you to see an expert if appropriate.

14. Will this mean I won't be able to get life insurance?

The Association of British Insurers have informed the CJDIP that their members will not refuse insurance just because someone is categorised as 'at-risk' for public health purposes.

15. General information about vCJD

What is the cause of vCJD?

Infections like influenza and pneumonia are caused either by viruses or bacteria. Some stomach infections are caused by microscopic parasites. Variant CJD, and the other TSEs, are different from these common infections. The cause is an abnormal infectious protein known as a 'prion'.

There is no test, treatment or cure for vCJD at present and the disease is always fatal. Scientists are researching the causes and possible tests and treatments for the disease.

How do you catch vCJD?

Variant CJD is believed to be caused in the first instance by exposure to the abnormal prion protein that causes BSE. Many of the UK population have been exposed through eating BSE-infected beef and beef products in the 1980s and early 1990s.

Variant CJD may also be transmitted between patients in the healthcare setting. So far there are no recorded instances of vCJD being spread through surgery, nor have there been any cases amongst recipients of plasma products sourced from individuals who later developed vCJD.

How many cases of vCJD are there?

So far, almost 150 cases of vCJD have occurred in the UK and a handful in other, mainly European, countries.

It is thought that the UK epidemic may have reached a peak. However no one knows how many people will contract this disease in the future.

16. Sources for Additional information

The process of informing patients about their possible additional risk status, and the special precautions they may need to take is being coordinated by the Health Protection Agency (HPA) in England, Wales and Northern Ireland, and in Scotland by the Scottish Centre for Infection and Environmental Health (SCIEH).

More information about vCJD with useful links is available from their websites
HPA: http://www.hpa.org.uk/infections/topics_az/cjd/menu.htm
SCIEH: http://www.show.scot.nhs.uk/scieh

Further information is also available from:

The Haemophilia Society http://www.haemophilia.org.uk
The Primary Immunodeficiency Association http://www.pia.org.uk
CJD Support Network http://www.cjdsupport.net
Human BSE Foundation http://www.hbsef.org
National CJD Surveillance Unit http://www.cjd.ed.ac.uk
Department of Health http://www.doh.gov.uk/cjd/index.htm
National Prion Clinic
http://www.st-marys.org.uk/specialist/prion/index_prion.htm
National Public Health Service for Wales
http://www.wales.nhs.uk/sites/home.cfm?OrgID=368
NHS Direct Online http://www.nhsdirect.nhs.uk

NHS Direct and its national colleagues are also operating a 'vCJD and Plasma Products' advice line for general enquiries (telephone: 0845 850 9850).

Health Protection Agency

Scottish Centre for Infection and Environmental Health

NHS National Services Scotland

National Public Health Service for Wales
Gwasanaeth Iechyd Cyhoeddus Cenedlaethol Cymru

Department of Health, Social Services and Public Safety
An Roinn Sláinte, Seirbhísí Sóisialta agus Sábháilteachta Poiblí

20th September 2004

IMPORTANT INFORMATION FOR PATIENTS WITH HAEMOPHILIA AND OTHER BLEEDING DISORDERS

Variant Creutzfeldt-Jakob Disease (vCJD) and Plasma Products

This information is being sent out to all patients and the parents of children with haemophilia and other bleeding disorders. It gives new information about certain plasma products available between 1980 and 2001, the possible risk of vCJD and the need for precautionary health care measures following certain medical procedures and surgical operations.

This information does NOT affect ALL patients.

- **PATIENTS AFFECTED** by this information are those with haemophilia or other bleeding disorders who received treatment between 1980 and 2001 with clotting factors manufactured by the UK Bio Products Laboratory (BPL) or the Protein Fractionation Centre (PFC) of the Scottish National Blood Transfusion Service (SNBTS) using plasma pools sourced from the UK. These include concentrates of factor VIII, factor IX, factor VII, factor XI, factor XIII and prothrombin complexes as well as antithrombin.

- **PATIENTS NOT AFFECTED** by this information are those who have only ever received recombinant products, DDAVP (desmopressin), clotting factors made with non-UK sourced plasma, or who have never been treated.

If you have ever received a blood transfusion or immunoglobulin this is treated differently and is not covered in this letter.

We realise this information creates uncertainty and may cause you concern.

It is important for everyone to read the rest of this letter and the enclosed 'Information for Patients' that has been prepared to help you understand this changing situation.

What has happened?

You may be aware of product recalls in 1997, 1999 and 2000 when donors who provided plasma used to make clotting factors or antithrombin were subsequently found to have vCJD. These previous notifications involved products made by the Bio Products Laboratory in England and the Scottish National Blood Transfusion Service. You may have been informed at the time.

The Department of Health is writing to you now to give you further information about these and about further batches of clotting factors or antithrombin that have been made using plasma from donors who later developed vCJD; what action is being taken; and to offer you the opportunity to discuss this with your local Haemophilia Centre. None of these batches are now in use.

Who is looking into this?

The CJD Incidents Panel (the Panel) is an expert committee set up by the UK Chief Medical Officers to advise on incidents of possible transmission of CJD through medical procedures. These include treatment with blood or plasma products. When people are diagnosed with vCJD, any blood donations they have given are traced. The Panel has reviewed in detail all batches of plasma products known to date to have been made using plasma from donors who later developed vCJD. These are referred to below as 'implicated' products and batches.

What is the risk from these implicated products?

The Panel has used scientific evidence and expert opinion, together with information from the plasma product manufacturers, to examine the possible risks to health from having received implicated plasma products. This risk is on top of the general risk from eating beef and beef products that may have been contaminated by the agent causing Bovine Spongiform Encephalopathy (BSE or 'mad-cow disease').

The potential additional risk to health depends on the type of plasma product and how each batch was manufactured.

For most batches of implicated products the potential additional risk is so low as to be considered negligible. For example some batches of factor VIII, where only the albumin (which is used to stabilise factor VIII in the vial) has been sourced from a donor with vCJD, are extremely low risk. However, batches of factor VIII where the clotting factor (and not the albumin) has been sourced from a donor with vCJD, and other implicated products, which include factor IX and antithrombin, carry a higher risk.

What does this mean?

The potential additional risk of actually developing vCJD from receiving any implicated plasma product, on top of the general risk from eating beef, is unknown, but the chances of it happening are likely to be very low.

Some patients who have received certain implicated products do, however, have a greater chance of passing the agent that causes vCJD to others through surgical operations and some other medical procedures. For public health purposes steps need to be taken to prevent spread this way.

Unfortunately, it is likely that further cases of vCJD will occur in people who previously donated blood. This means that more batches of UK-sourced plasma products may be implicated in the future.

Who is affected?

It is likely that special public health precautions will need to be taken for many patients with bleeding disorders because they will have received clotting factors that either are currently implicated (which include particular batches of factor VIII and factor IX) or that may be implicated at a later date. Therefore, **ALL patients with bleeding disorders[1] who have received clotting factors derived from UK-sourced plasma[2] between 1980 and 2001 are considered 'at-risk' of vCJD for public health purposes.**

This time period of 1980 to 2001 has been chosen as the most cautious: it runs from when BSE is thought to have entered the human food chain to the last possible expiry date of any product manufactured in the UK that was sourced from UK donors until 1998. Since 1998, plasma for manufacturing plasma products has been imported from the United States.

Am I 'at-risk' of vCJD for public health purposes?

[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.

If you have received any UK-sourced plasma derived clotting factors between 1980 and 2001, even if you have not received a currently implicated batch, you are 'at-risk' of vCJD for public health purposes.

If you are not sure whether you/your child have received UK-sourced plasma derived clotting factors between 1980 and 2001, and therefore whether you/your child are 'at-risk' of vCJD for public health purposes, please contact your Haemophilia Centre. You can do this using the reply form at the end of this letter.

What special precautions should I take?

If you are 'at-risk' of vCJD for public health purposes:

- you should not donate blood,
- you should not donate organs or tissues,
- you should tell whoever is treating you before you undergo medical, surgical or dental treatment, so that they arrange any special procedures for the instruments used in your care.
- It would be best if you tell your family about this in case you might need emergency surgery in the future.

If you are 'at-risk' of vCJD for public health purposes then a note of this will be made in your hospital medical records and will be recorded on the National Haemophilia Database. We will also tell your GP of your 'at-risk' status who will record this in your GP medical notes.

Does this affect my care?

If you are 'at-risk' of vCJD for public health purposes, your clinical care should not be compromised in any way. Healthcare professionals need to know you are 'at-risk' so that if any surgical instruments are used in your care they can be treated differently.

How does this affect my family?

If you are 'at-risk' of vCJD for public health purposes you do not need to take any special precautions in normal life. There is **NO** evidence that vCJD can be passed on between people by:

- living in the same house,
- sharing utensils,
- kissing,
- sexual contact,
- from mother to baby through childbirth or breastfeeding.

Can I find out if I have been treated with an implicated batch?

Patients' records are currently being checked to determine who was treated with UK-sourced clotting factors between 1980 and 2001, which of them have received implicated batches and the extent of their exposure. This will be recorded in patients' hospital medical notes.

If you would like to find out whether you/your child have received any of the implicated batches, or you wish to discuss this further with staff at your Haemophilia Centre, please indicate this on the reply sheet. We expect the process of identifying who has received those batches to take some time, as it may involve hand-searching records from many years ago, and liaising with other Centres. We are sorry for this unavoidable delay.

If you do not wish to find out whether you/your child have received one of the implicated batches, please be aware that this information needs to be recorded in the hospital notes. Despite the best intentions, it is possible that this information may become apparent to you/your child inadvertently, when, for example, looking at your/your child's medical records.

Whether or not you have received any of the implicated batches should **NOT** affect your care, as the same special precautions will be taken for **ALL** patients with bleeding disorders who received UK-sourced clotting factors between 1980 and 2001.

How can I decide whether to find out if I have received implicated products?

At present there is no known case of a patient with haemophilia developing vCJD through treatment with blood products. There is no diagnostic blood test for vCJD and there is no treatment or cure for this condition. In addition, the same special precautions will be taken for **ALL** patients who have received UK-sourced plasma derived clotting factors between 1980 and 2001, whether or not they have received an implicated batch.

In the light of the above, you may wish to consider carefully whether or not you wish to know if you have received any of the implicated batches.

How can I find out more?

Please find enclosed an information sheet about vCJD developed by the Health Protection Agency alongside the Scottish Centre for Infection and Environmental Health, clinicians' representatives and patients' groups, which it is hoped will go some way to answering your first questions.

It is appreciated that this information creates uncertainty that may worry and concern you. Do contact the Haemophilia Centre on: 0191 2824772 or 2829541 if you wish to talk about this.

Variant Creutzfeldt-Jakob Disease and Plasma Products
Patient Reply Sheet

Name of patient/child*:
Date of birth:
Telephone:
Address:

I understand that my/my child's exposure to an implicated batch will be recorded in my/my child's hospital and GP notes, and on the National Haemophilia Database.

1. I would like confirmation of whether I/my child* received UK sourced plasma derived clotting factors between 1980 and 2001.

IN PERSON / IN WRITING

2. I would like to know if I/my child* received an implicated batch.

YES/NO

3. I would like to have a specific consultation at the Haemophilia Centre to discuss the implications of this issue. If you answer yes to this an appointment will be arranged

YES/NO

Signature _____ Date _____

Print name _____