From: DENNIS CANAVAN MSP

The Scottish Parliament

RECEIVED IN MCH
15 JUN 2001
PASSED TO CCU

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Our ref:- DC/AT

13 June 2001

Susan Deacon MSP
Minister for Health
Scottish Executive
St Andrew's House
Edinburgh EH1 3DG

Dear Susan

Mr GRO-C

I enclose a copy of a letter and relevant correspondence which I have received from the above constituent.

I share my constituent's concern about the matter outlined in the correspondence and I would be grateful, therefore, if you would consider its contents with a view to taking appropriate action. I would also be grateful for any background information or advice which might enable me to reply to Mr GRO-C.

I look forward to hearing from you.

Thank you for your attention.

Yours sincerely

GRO-C

Dennis Canavan MSP

Enc

C.U. received
15 JUN 2001

GRO-C

11/6/01

Dear Mr. Canavan,

I am once again writing to you and hope you will be kind enough to raise the questions raised by The Haemophilia Society in "The Carpet of Lilies Campaign".

Enclosed are some of the pages from the Society which are self explanatory together with a copy of a letter I have received The Royal Infirmary of Edinburgh where I am treated in the event of a bleed.

This letter will give you some idea of the problems experienced by Haemophiliacs regarding best treatment and indeed is a clear indication of the dangers of using plasma derived products in treating bleeds.

I Susan Deacon is of the opinion that there

is no proof that no causal effects can be attributed to early use of plasma based products in causing hepatitis "C", I wonder why there is a desire by the medical profession to treat people with recombinant factor VIII to the exclusion of plasma based products.

I would be extremely grateful if you would raise this matter again in the Scottish Parliament and note that I have also written to Donald Gorrie along similar lines.

Yours sincerely,

GRO-C

The Lothian University Hospitals NHS Trust

HAEMOPHILIA AND THROMBOSIS CENTRE
ROYAL INFIRMARY OF EDINBURGH
1 Lauriston Place, Edinburgh, EH13 9YW
Tel: 0131 536 2161

5 June 2001

To all individuals with Haemophilia A

Dear Patient

Availability of Recombinant Factor VIII

We are writing to you to bring you up to date with the current position regarding the ongoing worldwide shortage of recombinant Factor VIII products and how this will effect those with haemophilia in Scotland. As you will be aware from our previous letter of 12 May and other correspondence from the Haemophilia Society, the current problems have arisen following suspension of deliveries of the specific recombinant Factor VIII products, Helixate and Kogenate. In Scotland, we have effectively had no deliveries of these two products since January this year, and although there may be small deliveries in May and June, it is unlikely that full monthly supplies will be received until early Autumn. Fortunately, we are still receiving deliveries of two other recombinant Factor VIII preparations and have even secured some extra supplies of these.

Unfortunately, despite implementing conservation measures as advised by UKHCDO Advisory Committee on 29 March, our monthly usage of recombinant Factor VIII significantly exceeds our monthly deliveries of recombinant product. In addition, our stock levels have fallen to 3-5 week supply.

On Friday 11 May, the Scottish Haemophilia Directors met with colleagues from National Services Division and Scottish Healthcare Supplies (who service the contract for recombinant Factor VIII), and a representative of the Scottish Executive to reassess the situation. At that meeting, we agreed the following:

- in Scotland, and indeed throughout the United Kingdom, the priority should be to maintain those patients who have never received plasma derived Factor VIII, on recombinant Factor VIII products.
- given the supply problems, current usage and stock levels outlined above, it will be necessary to transfer some patients with Haemophilia A from recombinant Factor VIII back to plasma derived Factor VIII (Liberate).
- older patients with haemophilia will be transferred back to plasma derived product before younger adults and children.
- SNBTS have agreed to produce additional quantities of Liberate so that an adequate supply of Factor VIII will be available for treatment in Scotland throughout this year.
- there should be adequate supplies of Factor VIII (recombinant or Liberate) to fulfill summer holiday requirements.

The UKHCDO Advisory Committee met on Tuesday 15 May. The shortage of recombinant Factor VIII is more severe in England and Northern Ireland where some children have already been transferred back

Revised Advice from the UKHCDO Advisory Committee on Managing the Shortfall in Recombinant Factor VIII.

The UKHCDO Advisory Committee met on 15/5/01 to discuss the current shortage of Kogenate and Helixate and revised the guidelines for dealing with this shortage as follows. It is clear that there is no shortage of plasma-derived factor VIII (pdVIII), and the use of these products does not have to be restricted at this time. Measures for optimal use, to conserve stocks of recombinant factor VIII, are as follows:-

1. Haemophilia Centre Staff should review infusion practices (i.e. rVIII units/dose) being used by individual patients with a goal of potential reduction in dosage if possible.

2. Those patients for whom there is insufficient recombinant factor VIII for reatment should be switched to plasma-derived VIII (use UKHCDO Guideline for selection of product). Priority for recombinant factor VIII (rVIII) should be given to children who have always been treated with these products and to PUPS.

3. Patients over the age of 16 years currently treated with rVIII should be changed to pdVIII until an improvement in supply permits them to change back to rVIII. Consideration should be given to changing children currently treated with recombinant, but previously treated with pdVIII, back to pdVIII until supplies improve.

4. Treatment centre staff should consider increasing the interval between doses on an individual basis and using individual dose of 25 units/kg for children on long-term prophylaxis with rVIII. Such modifications to prophylaxis must be accompanied by advice on sporting and life style activities.

5. Non-urgent surgery with rVIII should be postponed with immediate effect.

6. Starting patients on immune tolerance with rVIII should be postponed. Immune tolerance may start using high-purity pdVIII. Immune tolerance currently in progress should continue without dose-alteration, but using pd VIII rather than rVIII.

7. Patients currently using pdVIII should not be switched to rVIII until the shortage is over and patients previously treated with rVIII have changed back to those products.

8. Product usage in all patients should be decreased by considering the greater use of continuous infusion for surgery and serious haemorrhage.

9. Patients using plasma-derived factor VIII may be treated as before the shortage, using these products.

15/5/01

to treatment with plasma derived Factor VIII. Following the meeting, the committee have issued a revised advisory statement (copy enclosed) taking account of both the deteriorating recombinant Factor VIII stocks and the adequate supplies of plasma derived Factor VIII. In England, where most adults have yet to receive recombinant Factor VIII products, it was perceived that consideration should be given to individuals over the age of 16 years being treated with plasma derived Factor VIII in order to release sufficient recombinant product for treatment of children under this age, especially those who have never had plasma derived products.

However, in Scotland it is likely that all haemophilia patients born on or after 1st January 1970 can be maintained at present on recombinant Factor VIII treatment, if older patients are treated with plasma derived Factor VIII until recombinant Factor VIII supplies return to normal. Therefore, with this one exception, we intend to implement the revised advice from UKHCDO Advisory Committee (15.05.01). We are writing individually to those patients who will need to transfer now to plasma derived Factor VIII.

We will keep the situation under very close review and will endeavour to keep you as fully informed as possible. In the meantime, it is clearly important that we all use recombinant Factor VIII (including home treatment) as carefully as possible. If you have any specific questions or issues you wish to discuss, please contact your Haemophilia Centre staff.

Yours sincerely

GRO-C

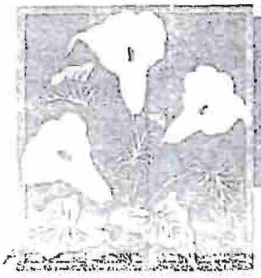
GRO-C

GRO-C

Professor C A Ludlam
Professor of Haematology
& Coagulation Medicine

pp Dr L Horn
Consultant Haematologist

pp Dr A Thomas
Consultant Paediatric
Haematologist



The Campaign for Justice for people infected by contaminated blood products

The Haemophilia Society needs your support!

- **We aim to cover the UK with a Carpet of Lilies to show support for our campaign.**
- **You can help by targeting candidates of all parties in the General Election and MPs who will make up the new Parliament after 7th June**

Our campaign aims

The Haemophilia Society has intensified its campaign activity with the help of Weber Shandwick Public Affairs. Our campaign aims to achieve:

- Recombinant for all, children and adults alike, throughout the UK to avoid the risks of future blood borne infections
- A public inquiry into the tragedy of contaminated blood products that infected people with haemophilia with HIV and hepatitis viruses.
- Financial recompense through a hardship fund for people with haemophilia infected with hepatitis C in addition to the financial assistance scheme established by Government in 1987 for those infected with HIV (the Macfarlane Trust).

Key Messages for Campaigners

➢ **Why is the Carpet of Lilies Campaign happening?**

The Carpet of Lilies campaign is rolling out from May to show mass support for the many thousands of people in the UK who have been infected with HIV and Hepatitis A, B and C due to contaminated blood products used in their NHS treatment. It aims to raise awareness of those people having to live with these viruses and gain support for the Haemophilia Society's campaign aims.

➢ **What are The Haemophilia Society's campaign aims?**

- Recombinant for all, children and adults alike, throughout the UK to avoid the risks of future blood borne infections
- A public inquiry into the tragedy of contaminated blood products which infected people with haemophilia with HIV and hepatitis viruses.
- Financial recompense through a hardship fund for people with haemophilia infected with hepatitis C in addition to the financial assistance scheme established by Government in 1987 for those infected with HIV (the Macfarlane Trust).

1. Recombinant treatment for all

There is now a safer, genetically engineered 'recombinant' clotting factor that carries a much lower risk of transmitting blood borne viruses. This has been recommended as the treatment of choice by the UK Haemophilia Doctor's Organisation (UKHDO) since 1996.

The recombinant treatment is more expensive but offers least risk as it is not manufactured from large pools of human blood. However, although recombinant is available to adults in Scotland and Wales, and also children under 16 in England and Northern Ireland, it is generally unavailable to adults there. This treatment by postcode is unfair and distressing to the haemophilia community.

2. The public inquiry

The infection of the haemophilia community with HIV and HCV has been described as one of the greatest tragedies in the history of the NHS – and yet no official inquiry or report has ever been carried out.

The Department of Health refuses to hold an inquiry yet internationally Canada has conducted a wide investigation, Ireland has held full official inquiries and has provided compensation to those people infected and in France, Japan and Switzerland government ministers and officials have all faced court cases over the infection of their haemophilia communities.

3. Financial help through a hardship fund

In 1987 the government accepted a moral responsibility to recompense those infected with HIV through contaminated blood. It established the Macfarlane Trust to fulfil this role, but those infected with Hepatitis C were specifically excluded from benefiting from the money allocated by this fund – despite having contracted Hepatitis C in exactly the same way and at exactly the same time. The Irish, Canadian and Italian governments have all provided financial help for those infected with Hepatitis C as well as HIV – the UK government refuses to.

- **A public inquiry into the whole issue of the safety of blood products and the infection of the haemophilia community with HIV and Hepatitis C through contaminated blood**

Despite inquiries in Canada, Ireland, Japan, France and Switzerland the UK government has refused to carry out an official inquiry into this extensive infection of haemophilia patients through their NHS treatment – often described as one of the greatest tragedies in the history of the NHS.

- Financial recompense for those infected by HCV

In 1987 the Conservative government accepted a moral responsibility for the tragic infection of the haemophilia community through their NHS treatment and created a special fund – the Macfarlane Trust – to administer payments to those who were infected by HIV through contaminated blood. The Government also made further *ex gratia* lump sum payments to people with haemophilia infected with HIV in 1990 and 1991. But those with HCV who face the possibility of liver disease, cirrhosis of the liver and liver cancer have been excluded from these funds.

In March, a high court judgement delivered by Mr Justice Burton on a case brought by 114 people contaminated with hepatitis via infected blood ruled that '...the public expects, (and is entitled to expect), clean blood.' The ruling is the first time that any national authority in the UK has been brought to account for the human tragedy caused by contaminated blood used by the NHS – a tragedy which has affected so many of the haemophilia community.

But this ruling so far is only a symbolic moral victory for people with haemophilia. Financially it does not benefit them because the action was brought under the Consumer Protection Act which came into force in 1988 - too late for people with haemophilia who were infected with HIV and HCV *before 1985-7* when blood products were treated to eliminate these viruses.

I urge you to sign up as a supporter of The Haemophilia Society's campaign and help those constituents in this area – people with haemophilia, their family and their friends – achieve these much needed aims.

I look forward to your response in the near future.

[I/we look forward to meeting you on -date -]

Yours sincerely,

[Your name]

NOTE: You will need to adapt the first and last paragraphs of this letter if you are inviting the PC/MP to meet you and participate in a press/media photo opportunity. You may choose to add your own personal circumstances in the letter.

Fast Facts

- Around 5,000 people with haemophilia in the UK were infected with the Hepatitis C virus through the use of contaminated blood clotting concentrates given as part of their NHS treatment, of those 1,200 were infected with HIV. Over 95% of people with haemophilia treated in the 1970s and 1980s by the NHS with clotting factor concentrates contracted HIV or hepatitis viruses or both.

- Every patient over the age of 16 years may have contracted HCV/HIV or both.

- Figures from the United Kingdom Haemophilia Centre Doctor's organisation show that up to 1998 over 121 people with haemophilia had died from liver cancer and/or liver disease. Over 800 people with haemophilia have died from HIV

- For people with haemophilia infected by HCV, medical experts estimate that:
  - At least 80% will develop chronic liver disease
  - Up to 25% of those may develop cirrhosis of the liver
  - 1-5% may develop liver cancer

- Treatment with interferon and ribavirin offers the only chance of a cure for the HCV virus but success rates for people with haemophilia may be as low as 30%. Many people with haemophilia may be unable to benefit from those treatments because of previous treatment failures or because of other medical complications. Some are unable to complete the treatment, which is onerous, lasting for 6-12 months, because of unpleasant side-effects.

- From 1985 onwards in England, and 1987 onwards in Scotland, blood products manufactured by the NHS were treated to eliminate HIV and HCV viruses, thereby preventing further infections. Blood products today are safer than they have ever been due to screening and inactivation processes. Nevertheless, some (non-enveloped) viruses such as hepatitis A and parvovirus B19 are known to escape these modern processes. There is also a "theoretical risk" that blood products may transmit variant CJD; there is still no screening test for vCJD. Recently there have been three reports of plasma from blood donors later found to have vCJD being used to manufacture haemophilia treatment products in the UK.

- A Haemophilia Society impact study submitted to the Department of Health showed that people with haemophilia infected by Hepatitis C had
  Difficulty obtaining life insurance
  Discrimination and ostracism at work, school and in society in general
  Inadequate support services for managing HCV
  Poor management and care after diagnosis

There is no national strategy to deal with Hepatitis C so care and counselling services are extremely patchy.