

Edwina Hart MBE OStJ AM

Y Gweinidog dros Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

Our ref: EH/00457/11

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28 March 2011

Dear Peter,

On 8 March, I announced that a package of measures would be introduced in Wales to support those affected by hepatitis C and/or HIV via NHS supplied blood. I have attached a copy of my statement.

My officials will now work with those in the Department of Health and the Skipton Fund to implement these measures in Wales. If you are aware of any individual that may benefit from the new arrangements, they may wish to contact the Skipton Fund who will provide further details of the claims process. The Skipton Fund's contact details are: Online: <http://www.skiptonfund.org/>, By email: apply@skiptonfund.org, By phone: 020 7808 1160.

In your email of 27 January you said that you intend to contact potential claimants who may wish to make a claim in respect of an individual who was infected with hepatitis C but who died prior to 29 August 2003. In order for us to encourage as many prospective claimants as possible, I would be grateful if you could discuss this matter with Dr Chris Jones, Medical Director, NHS Wales (Chris.Jones@GRO-C; GRO-C) to ensure that the Welsh Assembly Government can assist and help facilitate this process.

GRO-C

STATEMENT BY THE WELSH ASSEMBLY GOVERNMENT

Title: Response to the Contaminated Blood Review

Date: 8 March 2011

By: Edwina Hart, Minister for Health and Social Services

I would like to make a statement on the support provided to those infected with hepatitis C and/or HIV via contaminated blood.

On 14 October, the UK Government announced that it would review the support available to those who had been infected with hepatitis C and/or HIV by NHS supplied blood transfusions or blood products.

The Secretary of State for Health announced the review's findings on the afternoon of 10 January. I received a copy of that report for the first time that day, just 3 hours before publication. I wrote to the Secretary of State for Health on 9 February expressing my concerns about this. My counterpart in Scotland, Nicola Sturgeon MSP has written to the Secretary of State for Health to express similar concerns. The Minister for Health, Social Services and Public Safety in Northern Ireland also sent a letter on 11 February.

Having now had the opportunity to consider the review's findings and to consult with affected groups, I have decided, with certain exceptions, to implement the review's recommendations in Wales. I consider it would have been inequitable not to implement a comparable package of measures which match those in England and Scotland, to support those affected in Wales.

It is difficult to estimate the exact cost of the package, but I believe the new arrangements could provide about £6 million worth of additional support over the course of the next Assembly term.

The package of measures to be implemented is as follows:

- A new, annual payment of £12,800 will be introduced for each living person infected with hepatitis C from contaminated blood and who have developed serious liver disease. This is the same amount as that received by those who were infected with HIV. Individuals who have been infected with HIV, and who also have severe liver disease as a result of their hepatitis C infection, will receive two flat-rate annual payments of £12,800 in respect of each infection. All flat-rate recurrent payments will be backdated to 10 January 2011.
- There will be a further lump sum payment of £25,000 for those with serious liver disease, increasing the amount of the Stage 2 Skipton Fund payments from £25,000 to £50,000. This will apply retrospectively, so that if a person has already received an initial stage 2 payment of £25,000, they will now get another £25,000 lump sum, bringing the total to £50,000.
- Patients who have developed hepatitis-C related B cell non-hodgkins lymphoma will become eligible for a Skipton Fund Stage 2 payment, as well as the additional lump sum of £25k for Skipton Fund Stage 2 payments.
- All annual payments that are made, both to those so infected with HIV and to those infected with hepatitis C who have serious liver disease, will be uprated annually in line with the consumer prices index to keep pace with living costs.
- At present, no payment can be made to those infected with hepatitis C who passed away before the Skipton Fund was established. In England, the Secretary of State for Health announced that, until the end of March 2011, there will be a window of opportunity in which a posthumous claim of up to £70,000 can be registered on behalf of those infected with hepatitis C who died before 29 August 2003. I have decided to implement these arrangements for bereaved families, but not to introduce a registration deadline for prospective claimants from Wales. These new payments, will go to the individual's estate, and should help more families get the support they deserve.
- Over and above these changes, I intend to ensure that guidance, and where relevant, regulations, are amended to reflect which ex-gratia payments are exempt from means testing for social care.
- Officials will work with the Skipton Fund and various patient groups to publicise these new payments to those who may benefit.

In his statement on 10 January, the Secretary of State for Health announced that a discretionary fund would be established in England to provide access to additional discretionary payments, targeted at those in greatest need, for those infected with hepatitis C from contaminated blood, and their dependents, including the dependents of those who have since died. This is similar to current arrangements established for those with HIV. These payments would be available for those at all stages of their illness, based on individual circumstances.

Whilst I agree that access to a discretionary fund should apply in Wales, I believe the management of a discretionary fund is an important issue. Ensuring equity of access to such funds is notoriously difficult. I have therefore sought clarification from the Secretary of State for Health about how this fund will be fairly accessed, and for details on the criteria for claiming from the fund.

I also have serious concerns that the financial assistance available to people infected by chronic hepatitis C, but who do not reach the criteria for Stage 2 Skipton Fund payment, is an underestimate of the impact the disease can have on those with chronic hepatitis C. I consider the lack of additional support for these individuals to be a significant omission in the review's recommendations and I have expressed these concerns to the Secretary of State for Health.

There are 2 aspects of the review which are being handled differently in Wales:

- The changes to prescription "season tickets" will obviously not apply in Wales as charges here have been abolished.
- The proposal for additional access to counselling services for those affected by contaminated blood will be considered as part of a review of current service provision for those with haemophilia in Wales.

NHS services for patients with haemophilia are currently provided from three centres in Wales, a comprehensive care haemophilia centre in Cardiff and two smaller haemophilia centres in Swansea and Bangor.

I recognise that in some parts of Wales, the current level of service provision and support for people affected by haemophilia may fall below expectations. I am aware that Local Health Boards, through their collective work on the Welsh Health Specialised Services Committee are undertaking a number of measures to address these issues.

I have asked Dr Chris Jones, Medical Director, NHS Wales, to establish a Ministerial Task and Finish Group, to consider service provision for this group and to make recommendations. The Task and Finish Group will also address issues surrounding access to therapy services.

I recently agreed £1.377m funding for Year 2 of the implementation of the Blood Borne Viral Hepatitis Action Plan. As part of the funding allocated for Year 1 of the Action Plan, 2 Health Boards - Abertawe Bro Morgannwg University LHB, Cardiff & the Vale LHB - are now intending to purchase Fibroscanners which offer a painless and non-invasive test for diagnosis of liver disease. I would like to see the results from Fibroscan tests used as an alternative to the current evidence required for prospective Skipton Fund Stage 2 claims. I have written to the Secretary for State for Health to ask him to ensure the eligibility criteria for Skipton Fund Stage 2 payments is amended to emphasise that Fibroscan results may be used as an alternative to liver biopsies and blood tests.

I recognise that my response to the recommendations is unlikely to satisfy all the concerns and wishes of those individuals that have been affected by contaminated blood. I am however committed to maintaining a dialogue with representatives of affected groups, to continuing to improve service provision, and to ensuring that we all work together to address the significant public health issues posed by blood borne viruses in Wales.