Black, Peter
Butler, Rosemary
Chapman, Christine
Davidson, Jane
Davies, Andrew
Davies, Ron
Edwards, Richard
Essex, Sue
Evans, Delyth
Feld, Val
German, Michael
Gibbons, Brian
Griffiths, John
Gwyther, Christine
Hart, Edwina
Hutt, Jane
Law, Peter
Lewis, Huw
Middlehurst, Tom
Morgan, Rhodri
Neagle, Lynne
Pugh, Alun
Randerson, Jenny
Sinclair, Karen
Thomas, Gwenda
Williams, Kirsty
Davies, Geraint
Davies, Janet
Davies, Jocelyn
Graham, William
Hancock, Brian
Jarman, Pauline
Jones, Elin
Jones, Helen Mary
Lloyd, David
Melding, David
Morgan, Jonathan
Ryder, Janet
Thomas, Owen John
Wigley, Dafydd
Williams, Phil

*Derbyniwyd y cynnig wedi'i ddiwygio.*
*Amended motion adopted.*

## Dadl Fer
## Short Debate

### Iawndal i Hemoffiligion a Heintiwyd gan Hepatitis C
### Compensation for Haemophiliacs Infected with Hepatitis C

**David Lloyd:** Datganaf fuddiant fel meddyg teulu. Yr wyf yn caniatáu i William Graham a Kirsty Williams wneud cyfraniad yn ystod y ddadl.

**David Lloyd:** I declare an interest as a general practitioner. I have allowed William Graham and Kirsty Williams to contribute to the debate.

Y mae'n bleser cael cyfle i drafod y pwnc pwysig hwn ar yr angen i ddigolledu hemoffilogion a heintiwyd gan hepatitis C o ganlyniad i'w triniaeth. Derbyniodd nifer ohonom wybodaeth oddi wrth Gymdeithas Hemoffilia De Cymru ynghylch y mater hwn a buom yn bresennol mewn cyflwyniad grymus gan y gymdeithas yn y Cynulliad ar 14 Chwefror. Yr oedd y cyflwyniad yn olrhain effeithiau enbydus hepatitis C ar y sawl a oedd eisoes yn dioddef o hemoffilia a chlefyd tebyg, sef Clefyd Von Willibrands.

It is a pleasure to have the opportunity to discuss this important subject on the need to compensate haemophiliacs who have been infected with hepatitis C as a result of their treatment. Many of us received information from the South Wales Haemophilia Society on this matter and were present at a powerful presentation given by the society in the Assembly on 14 February. The presentation described the terrible effects of hepatitis C on those who were already suffering from haemophilia and a similar disease, Von Willibrands Disease.

Yr oeddynt wedi dal y clefyd o ganlyniad i driniaeth ar gyfer eu hemoffilia, ac y mae 149 o hemoffiligion yng Nghymru sydd yn

They caught the disease as a result of treatment for their haemophilia, and there are 149 haemophiliacs in Wales who suffer in dioddef yn y modd hwn. this way.

Throughout the UK, more than 4,800 people with haemophilia are estimated to have been infected with the hepatitis C virus through the use of contaminated blood clotting concentrates given as part of their NHS treatment. Over 1,200 of those are also co-infected with HIV. Almost all haemophiliacs who received treatment before 1986, when viral inactivation procedures were introduced, have been affected. In other words, every patient over the age of 14 may have contracted hepatitis C and or HIV.

Imported blood products from the United States have caused the problems. US blood products tend to be sourced from prisons. Furthermore, people are paid for donating blood in the US, and therefore high-risk groups, such as drug addicts, tend to take part. No UK Government has been self-sufficient in terms of blood products. That goal was first promised in 1945, but we still have not achieved it. Hepatitis C is a significant condition and should not be dismissed as a minor infection. It can attack the liver, and is potentially life threatening. Up to 80 per cent of those infected can develop chronic liver disease, up to 25 per cent, according to certain studies, can develop cirrhosis of the liver, and up to 5 per cent have a risk of developing liver cancer.

1.05 p.m.

Sufferers have been telling us, and we heard some speak in the presentation, about the effects of hepatitis C on their lives as haemophiliacs. They have a reduced income through having to cut down on working hours, or giving up work altogether. They have increased costs due to special dietary requirements and medicine charges. They face discrimination and being ostracised at work. They fear for their future health and are afraid of dying and leaving dependants without financial support. We have all heard these stories and tales of the inadequate support services for managing hepatitis C and the lack of counselling support.

The same applies further afield. We do not have a national UK strategy to deal with hepatitis C or national UK guidelines on the management and treatment of those infected. In some areas of the UK, patients have to wait for months or years to see a hepatologist or a hepatitis C specialist and there are few counselling or support services. On treatment, interferon and ribavirin combination therapy was licensed last year. Certain studies have shown that it can clear the virus in about 30 per cent of cases. However, many health authorities have problems financing that treatment.

In 1987 the UK Government accepted the moral responsibility to recompense all haemophiliacs infected with HIV through blood products, and established the Macfarlane Trust in 1988 to fulfil this role. Haemophiliacs with hepatitis C were infected in the same way and at the same time as those infected with HIV and experience many of the same problems. Therefore, on moral grounds, they should be offered similar financial help. The Haemophilia Society would like the remit of the Macfarlane Trust to be widened to include haemophiliacs with hepatitis C. At present the trust can assist those with HIV and hepatitis C co-infection—but they cannot help those infected with hepatitis C alone.

Canada has held a large scale four-year investigation into the issue of haemophiliacs with hepatitis C and the Canadian Red Cross has set aside between $70 million and $100 million to provide compensation to those infected. In Ireland, compensation has been provided to those infected with hepatitis C and a detailed investigation into the safety of the Irish blood supply is being held. Similar investigations have been made in France, Japan and Switzerland.

These events relate to before 1986. For many years, the Haemophilia Society has called for a public inquiry in the UK into the safety of blood products and the infection of haemophiliacs with HIV and hepatitis C. To date, the Department of Health in Westminster has refused to hold a public inquiry. As that is a matter for the UK Government, we asked the Haemophilia Society, after its presentation, what we, as Members of the National Assembly for Wales, could do. We have 149 haemophiliacs infected with hepatitis C in Wales.

I would like a full Health and Social Services Committee investigation into the issues discussed and I have already written to Kirsty, as the Committee Chair, about this. These sufferers—some of whom are here today in the public gallery—are Welsh people. As the National Assembly we have a duty of care and a responsibility towards them. The needs of sufferers have to be taken into account and we must consider, as an Assembly, how we can meet them. The Scottish Executive recently announced the results of an inquiry into how this occurred in Scotland. A full Committee investigation would show that the National Assembly and the Government of Wales has not abandoned haemophiliacs in Wales infected with hepatitis C.

**Kirsty Williams:** The Liberal Democrat position on this matter was clearly stated in a statement of opinion tabled by my colleagues, Peter Black and Jenny Randerson, and myself in February last year. We are grateful to the other Members who subscribed to that statement of opinion. We believe that compensation should be granted to haemophiliacs who have been infected with Hepatitis C and the HIV virus.

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However, to date, the compensation scheme that exists for those infected with HIV has not been extended to those with hepatitis C. The Government's no-fault policy should be extended to cover those infected with hepatitis C. Nobody is saying that NHS workers set out to inflict this disease on haemophiliacs and nobody can doubt the sincerity of those who provide the services for hepatitis C. As a student in the United States, I remember the weekly trip some of my colleagues would make to the blood bank to finance that night out. It is easy to see how contaminated blood products were shipped into this country and used inadvertently by the NHS. This is not about apportioning blame, it is about rectifying a situation that has gone horribly wrong for—let us face it—a small number of people. This affects 149 people in Wales and the numbers decrease monthly because people are dying before they receive the help that they deserve.

I hope that the Government will consider ways of helping these sufferers through direct compensation. It should ensure that dual treatment therapy, which the National Institute for Clinical Excellence has recommended as effective, should be issued and financed in Wales. It should also ensure that people receive counselling and support services, which do not exist in the principality at present.

**William Graham:** On behalf on the Welsh Conservatives I support further investigation into this matter. I am hopeful that this matter will receive cross-party support in the Assembly and that the Minister for Health and Social Services and Chair of the Health and Social Services Committee will find the time and resources to make this debate relevant, so that those who suffer from this will have hope and certainty that action will be taken.

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Recompense

Looking through the information provided to me by the Library, I regret that I can only find one hope: it has been agreed that recombinant factor eight will be made available to children under 16 and to new patients. There is no other information available about compensation or compensation offers. That is poor and I am grateful to Dai Lloyd and to the members of the Haemophilia Society for making their presentation some weeks ago. I attended with my colleagues and everyone was moved by the plight of what is an unprovoked problem. I would not say 'an unavoidable problem' because one can understand how this came about. It is incumbent upon us as Assembly Members to find a way forward to offer these people relief. I echo the comments made by the previous speakers.

**The Minister for Health and Social Services (Jane Hutt):** I express my sympathy to haemophiliacs who have been infected with hepatitis C through their NHS treatment. Before talking about the issue of compensation for haemophiliacs, I reiterate the Assembly's commitment to learning from patients' experiences when planning and making provision for health services. We want patients to be well cared for in the NHS and to be involved in the planning of the services on which they and their families rely.

Successful patient and public involvement is not always easy to achieve. It requires time, commitment and a cultural change to overcome the barriers that often exist. However, there is a growing acceptance that patients are the experts on how they feel and on how it is to live or care for someone with a certain illness or condition. I am aware of the powerful presentation given to Assembly Members by the Haemophilia Society a few weeks ago.

In responding to the calls from Dai Lloyd and other Members for compensation for haemophiliacs infected with hepatitis C via NHS treatment, I will trace the history of this issue. When the Labour Government first came into office, before the establishment of the Assembly, Ministers from the Department of Health met with the Haemophilia Society and listened to its arguments for a special payments scheme for people with haemophilia and hepatitis C, similar to that in place for HIV sufferers. After long and careful consideration, they came to the conclusion that a special payments scheme should not be established. When I became Assembly Minister for Health and Social Services, I met with representatives of the South Wales Haemophiliac Group and Birchgrove Wales, for people who are affected by hepatitis C. I discussed these issues with them. We discussed similar issues during the presentation for Members a few weeks ago. It was a difficult decision, following the advice and the consideration given by the Department of Health, not to establish a scheme. However, I will explain why Ministers have come to this decision.

1.15 p.m.

Assembly and central Government policy remains that compensation or other financial help to patients is only paid when the NHS or individuals working in it are at fault. The underlying principles are clear-cut and independently established under common law. They apply to personal injury cases in general, not just those arising from health care. In general, there is no 'no fault compensation'. How can we be sure that the NHS was not at fault? The technology to make blood products free from hepatitis C, in sufficient quantities to treat all haemophiliacs in the UK, was not available prior to 1985. I regret that before this many haemophiliacs were inadvertently infected by a treatment designed to improve their quality of life. However, this is not a justification for special payments.

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Not true in case of Hep C.

Dai drew comparisons between the decision not to offer special payments to haemophiliacs with hepatitis C and the special payments established in the late 1980s for haemophiliacs with HIV. However, there are significant differences between the two situations. It was felt at the time that HIV was a unique condition in terms of its high mortality rate and the tremendous stigma attached to the disease in the early days. It reflected the widespread public fear at the time, as it was heavily associated with sexual transmission. Haemophiliacs infected with HIV face the prospect of developing AIDS and a consequent short life expectancy, which is not the case with hepatitis C.

There have been many calls for a public inquiry, which we discussed when I met representatives from the Haemophilia Society. I understand that people infected with hepatitis C want to know what happened and why it could not have been prevented. It is a global problem linked to the development of science and technology. It is not confined to the UK or linked to some local breakdown in blood product development. Therefore, a public inquiry would probably not provide a satisfactory answer. FOR WHO

To follow the route taken in Ireland would probably require primary legislation in Wales. We

Do Not confuse HIV unavoidable
HEPC or Non A Non B Hepatitis
WAS Avoidable.

would also have to consider the costs of following such a route. I understand that they have explored this in Scotland and have faced difficulties in terms of the time when there was potentially infected blood available for a longer period than in England and Wales. They have also concluded that they will not make special grants for compensation in Scotland.

We must move forward. Dai, Kirsty and William discussed how we should enable people with haemophilia and hepatitis C to lead their lives as fully and constructively as possible and how we can help to improve their health and wellbeing. Our aim is to improve health, tackle inequalities, modernise the NHS and provide appropriate social care. We want to ensure that people are not stigmatised because of their ill-health. We want high quality, modern, dependable health and social services and appropriate care. We want people with haemophilia to benefit from improvements in care similar to other patient groups. The new Arthur Bloom Haemophilia Centre based at the University Hospital of Wales is recognised as one of the 23 UK designated comprehensive care centres for haemophilia treatment. We must ensure that that centre is not the only provider of such services in Wales.

I now turn to the issue of drugs for hepatitis C. Until recently the only treatment available for hepatitis C was alpha interferon, which has a limited success rate, of about 20 per cent, in removing the virus and is not suitable for all patients. Several Members today, including Kirsty, have mentioned that the use of alpha interferon in combination with ribavirin appears to be more effective, clearing the virus in around 40 per cent of those treated. The National Institute for Clinical Excellence has approved that combination for use. I assure Members that we will fund that treatment in Wales.

Several other therapeutic agents are being developed, which also show great promise. Significant developments and improvements in the treatments available are likely during the next few years. The Assembly has commissioned three pieces of work from the Public Health Laboratory Service at a cost of £62,000. These will measure the prevalence of hepatitis C in a 50 per cent sample of patients who presented for HIV antibody testing in south Wales during 2000; measure the prevalence of hepatitis C in patients investigated for HIV throughout Wales from 1996 to 2000; and determine demographic details and exposure group information for patients investigated for hepatitis infection in south Wales during 2000. These studies will give an indication of the prevalence of the virus in Wales and I will inform Assembly Members of the results.

Therefore, a special payments scheme has not been established on the basis that compensation or financial help is only given when the NHS or individuals working in it have been at fault. Our efforts must concentrate on future care. We must ensure that people with haemophilia and hepatitis C are supported and do not face discrimination and exclusion in their daily lives and that their voices are as strong as other patient groups in Wales. That is one of the most important messages. I am grateful that Dai Lloyd raised this issue today. Members of the Health and Social Services Committee, myself as Minister for Health and Social Services and all Assembly Members must recognise that the needs of this patient group are important.

**Brian Hancock:** I am concerned about this compensation scheme. I have examined the health and safety issues, particularly in relation to work. Section 6 of the Health and Safety at Work Act 1974 refers to research and information regarding products for use at work. That was well established before 1985. People bringing these materials into the country are responsible for this research. The Consumer Protection Act 1987 was modified to ensure that articles for use were suitable and sufficient. Is it possible to consider this again? The NHS could have assumed they were good, but did it do any research to check that the products that they were giving were good? If that consumer protection element has not been considered before now, is it possible to do that, because it could be the basis for considering a compensation scheme?

**Jane Hutt:** The technology to ensure that blood products are free from hepatitis C, in sufficient quantities to treat all haemophiliacs in the UK, was not available before 1985. Those issues have been considered in relation to the compensation scheme. I hope that answers your question, Brian.

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I will conclude. It is important that members of the Health and Social Services Committee and myself as Minister consider these issues and ensures that NICE's recommendations are implemented and that the combined therapies are available and used. We must ensure that counselling services and treatment centres in Wales are considered in terms of our priorities. The care of people in Wales with haemophilia and hepatitis must be our main goal and intention. I am grateful that this has come before the Assembly today.

**The Deputy Presiding Officer:** That brings today's proceedings to a close.

*Daeth y cyfarfod i ben am 1:22 p.m.*
*The session ended at 1:22 p.m.*