

# THE HAEMOPHILIA SOCIETY

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BEFORE 22 JULY 1998**

## **HAEMOPHILIA SOCIETY DAY OF ACTION FOR HEPATITIS C VICTIMS**

20 July 1998

People with haemophilia have today held a day of parliamentary action to urge the Government to respond to the plight of those infected with the potentially deadly hepatitis C virus through contaminated blood products used in their NHS treatment.

Starting with a presentation to the Prime Minister of a petition signed by thousands and 90 white lilies in memory of those who have died as a result of hepatitis C, the day culminated in a mass lobby by people with haemophilia to the Commons.

The delegation to Number 10 was accompanied by MP's of all parties, including Roger Godsiff (Lab Birmingham, Sparkbrook), Dr Peter Brand (Lib Dem, Isle of Wight), and Geoffrey Johnson-Smith (Conservative, Wealden) together with Lord Alf Morris, who are among the hundreds of parliamentarians of all parties who are supporting the campaign.

During Prime Minister's Question Time that afternoon, MPs asked when Government will respond to the suffering of people with haemophilia infected with hepatitis C.

Haemophilia Society Chief Executive, Karin Pappenheim said: "It's a scandal that seriously ill patients suffering the combined impact of a lifelong disabling condition and the hepatitis C virus are still waiting for justice from the Government. We are calling on Prime Minister Tony Blair to end the injustice now and accept that the Government has a moral responsibility to provide financial recompense to people with haemophilia infected with hepatitis C through their NHS treatment in the same way as has been done for those infected with HIV in exactly the same circumstances."

The Haemophilia Society and Manor House Group (the Society's special interest group for people with haemophilia and hepatitis C) met with the Secretary of State for Health, Frank Dobson last September.

Karin Pappenheim said: "At that meeting Mr Dobson promised a speedy response. Ten months later people with haemophilia are still waiting while more suffer and die. The delay is unacceptable."

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"We have a great deal of parliamentary support, much of it from among the Labour party, and with the NHS celebrating its 50<sup>th</sup> anniversary, this issue could be a real political embarrassment to the Government

"A new poll of opinion leaders shows majority support for our case. We want to shame this Government into taking action now."

Carrying the lilies and petition were six representatives of the UK's haemophilia population [GRO-A] [GRO-A] whose son has hepatitis C; [GRO-A] who has the virus himself [GRO-A], whose father died as a result of hepatitis C; [GRO-A], who has the virus, [GRO-A] who has the virus, and Vice Chairman of the Haemophilia Society [GRO-A] who lead the delegation.

Haemophilia Society Vice Chairman [GRO-A] said: "Virtually everyone with haemophilia or related bleeding disorders who was treated before 1986 was infected with hepatitis C. We have all lost good friends to this illness, and our day of action was to show just how severely this terrible virus has impacted on the haemophilia community.

"We hope that it will bring it home to the Government that people with haemophilia are suffering and dying now as a result of NHS treatment given 20 years ago and that we need urgent action."

Karin Pappenheim, Chief Executive of the Haemophilia Society said: "This Government has powerfully stated its commitment to the vulnerable in our society. How can they then ignore the plight of this highly vulnerable small patient group who in addition to suffering a chronic lifelong condition, which is both painful and disabling, have been hit with life threatening viral infection through their NHS treatment.

"The last Government under John Major in 1989 recognised the special circumstances of people with haemophilia infected with HIV through their NHS treatment and provided financial support through hardship grants via the Macfarlane Trust. We want this Government to extend that principle to cover people with haemophilia infected with hepatitis C through their NHS treatment. Our particular priority is to obtain financial help for those people who are currently receiving nothing."

"Blood is one of the best mediums for transmitting disease, and people with haemophilia are exposed to thousands of donors by their treatment. That is why the haemophilia community has been hit so hard by blood borne viruses such as HIV and hepatitis C.

"There are now new concerns about the safety of blood and blood products from new variant CJD. Although the risk of this disease is theoretical, the Courts have shown they are willing to recognise the psychological impact that the fear of new variant CJD can have on people who have been exposed to infected tissue even if they show no signs of being infected. It is baffling that the courts can respond in this way to people who may have a theoretical risk of infection, yet the Government refuses to help people with haemophilia who were infected with hepatitis C by their NHS treatment and who are actually suffering from the disease.

Ends

**Notes to Newsdesk**

Haemophilia is a genetically inherited bleeding disorder where one of the clotting factor proteins in the blood is either absent or present at a very low level. In severe haemophilia this can cause spontaneous internal bleeding, most commonly into the joints. If uncontrolled, these bleeds can cause crippling joint damage.

Haemophilia is treated by replacing the missing clotting factors, allowing the blood to clot normally. The replacement clotting factors have traditionally been produced by pooling the plasma from many thousands of donations and separating out the appropriate clotting factor proteins. Before 1986 the clotting factor proteins produced in this way were not treated to inactivate viral contaminants. This meant that should blood donors be infected with HIV or hepatitis C, their plasma could infect the entire batch of clotting factor proteins used for the treatment of haemophilia.

This resulted in the infection of more than 1,200 people with haemophilia with HIV and some 4,800 with hepatitis C. Following a campaign for financial recompense the last Government under John Major in 1989 accepted its moral responsibility to provide help and established a hardship fund - the Macfarlane Trust - to help those infected with HIV and also made across the board ex-gratia payments. The total paid out to date is well over £80million.

Those people with haemophilia infected with hepatitis C through their NHS treatment have so far received nothing. More than 90 have already died as a result of their infection.

The Haemophilia Society is campaigning for the Government to extend the principle of moral responsibility that was applied to HIV to cover hepatitis C as well. Representatives of the Haemophilia Society and the Manor House Group - a special interest group of people with haemophilia and hepatitis C within the Society - met with the Secretary of State for Health, Frank Dobson, in September 1997 to put the case for financial help. To date, the Government has not indicated whether it will provide help.

**The Society is held a series of events on July 22 1998 to highlight the plight of people with haemophilia infected with hepatitis C. These are:**

**9.30am** - press conference in the Jubilee Room at the House of Commons.

Speakers included: **GRO-A** - Vice Chairman of the Haemophilia Society, Karin Pappenheim - Chief Executive of the Haemophilia Society, Lord Alf Morris, who was the first Minister for Disabled People and chaired the World Commission on disabled people's rights, Roger Godsiff MP, Dr Peter Brand MP, Dr Alexander - consultant hepatologist, Addenbrookes Hospital, Cambridge, **GRO-A** - person with haemophilia infected with hepatitis C.

Also present were MPs of all parties who support the campaign, including: Gerry Bermingham, Bob Blizzard, Dennis Canavan, Patrick Cormack, Cynog Dafis, Jeffrey Donaldson, Norman Godman, Paul Goggins, Dr Brian Iddon, Melanie Johnson, Terry Lewis, Robert MacLennan, Michael Mates, Eddie O'Hara, Andrew Stunell.

**10.45am** - presentation of petition and 90 lilies representing those who have died to 10 Downing Street. The delegation included six people affected by haemophilia and hepatitis C and a group of supportive MPs.

**2pm onwards** - lobby of Parliament. Around 120 people with haemophilia and hepatitis C took part. Prime Minister's Question Time - the Government were asked when it will respond.

**For further information please contact: Mark Weaving Tel: **GRO-C** or Karin Pappenheim Tel: **GRO-C****