



HCV CAMPAIGN UPDATE

The Haemophilia Society

December 1998



WHAT IS THE CAMPAIGN ABOUT?

The HCV campaign has the following key aims:

- ◆ To persuade Government to provide assistance to meet the needs of people with haemophilia infected with HCV.
- ◆ To keep the issues of HCV infection through contaminated blood products high on the public and political agenda.
- ◆ To press for best treatment for people with haemophilia infected with HCV
- ◆ To raise public and political awareness of HCV.

RECENT ACTIONS

- ◆ November mailing to 200 supporting MPs.
- ◆ Society contacted all members of Health Select Committee to call for an inquiry.
- ◆ Questions asked in House of Commons.
- ◆ Individual briefing meetings held for key MPs.
- ◆ EDM25 put down by David Amess calling on Government to reverse the decision not to provide financial assistance for people with haemophilia infected with HCV.

The HCV Campaign is gathering new momentum in Scotland, Wales and Northern Ireland with the devolution process going forward. In effect, once each of these has their own Parliament or Assembly, those bodies will have the power to determine health policy and could choose to set up their own financial assistance scheme separate from what might be decided in Westminster. The message then for campaign supporters in Scotland, Wales and Northern Ireland is **START LOBBYING NOW** to seek pledges that the Scottish and Northern Ireland Parliament and Welsh Assembly will tackle this issue when they come into being.

Campaign Supporter becomes Deputy Leader of Scottish National Party

John Swinney, MP for Tayside North has become the Deputy Leader of the Scottish National Party. Mr Swinney has been a staunch supporter of the Society's campaign for financial assistance for people with haemophilia infected with HCV and has pledged his further support in the coming months. There are estimated to be around 300 people with haemophilia and hepatitis C in Scotland, hence numbers in-

involved are small compared to England. The Society has urged the SNP to make a pre-election pledge to address the HCV issue and is seeking a meeting with SNP leader Margaret Ewing MP to secure this. Other SNP supporters are Roseanna Cunningham (Perth), Alex Salmond (Banff & Buchan) and Andrew Welsh (Angus).

WALES

MPs from Wales supporting the campaign include



John Swinney MP

Alun Michael (Cardiff South), Dafyd Wigley (Caernarfon) and Julie Morgan (Cardiff North).

NORTHERN IRELAND

MPs from Northern Ireland supporting the campaign include Clifford Forsythe (South Antrim), Peter Robinson (Belfast East) and Martin Smyth (Belfast South).

Call for Public Enquiry

The Society wrote to David Hinchliffe, Chairman of the Health Select Committee requesting that an inquiry be held on how thousands of people were infected with hepatitis C through treatment with contaminated blood products in the 1970s and '80s by the NHS. The letter asked the committee to address the "large number of unanswered questions that remain" and to ensure that "all the facts about this infection via contaminated blood products are brought to light."

The Society's Chief Executive, Karin Pappenheim, commented "The Government's response to our request for financial assistance for those infected was issued by Frank Dobson on the last day of the last Parliamentary session and there was no opportunity given for debate or questions...." She went on "There is a dearth of information available on how the infection came to be spread so widely in the blood products used by the NHS.....We would like the Health Select Committee to investigate this matter fully....".

MPs ask questions in the House



MPs Mike Hancock (Portsmouth South) and Dennis Skinner (Bolsover), among several others of our supporting MPs, asked Parliamentary Questions in the House of Commons. In answers to questions health Minister John Hutton MP said that "... a comparable scheme [to that for HIV infected people with haemophilia] would cost in the region of £220million." He also stated that the Department of Health estimates 4,000 people with haemophilia were infected with hepatitis C and that the UK Transplant Support Service Authority's list of people awaiting liver transplants includes 6 or 7 who are believed to have haemophilia.

"That this House calls on the Government to reverse its July 1998 decision not to provide a financial assistance scheme for some 4,000 victims with haemophilia infected with hepatitis C virus via their NHS treatment in the 1970s and 1980s." EDM25



David Amess MP

Perth Group Grabs the Headlines!

The Perth Local Group managed to get the piece below into the Dundee Courier on 25th November, highlighting the weekend meeting of the Scottish groups and the Society's request to the Health Select Committee that a public enquiry be held into the safety of the blood service.

Blood service probe urged

MEMBERS OF the Haemophilia Society from throughout Scotland are meeting in Dundee this Saturday to discuss their call for a full public inquiry into the safety of the UK's blood service.

They would like the inquiry to determine how infections of HIV and HCV took place.

"This information is crucial for public health and we believe people with haemophilia and the general public deserve to be given answers," said the chair-

man of the society's Perth group.

GRO-A

The society is also campaigning to persuade the Government to provide assistance to meet the needs of people with haemophilia infected with hepatitis C through their treatment.

Mr. GRO-A said they were grateful to local MPs Roseanna Cunningham and John Swinney for their support.

"It is mainly thanks to them that most of the people with

haemophilia in Scotland now have safer treatment," said Mr. GRO-A.

"In England and Wales the situation is worse, with only children up to the age of 16 receiving the safer treatment and even then not every child receives it.

"It is very much a case of treatment by postcode."

The Perth group has just received a letter of support from Mr Swinney, giving backing to their latest efforts.

New EDM calls on Government to change its mind

A new Early Day Motion No. 25 calling on the Government to reverse its decision not to give financial assistance has been put down by David Amess MP.

Urge your MP to sign EDM No. 25 NOW!

Get involved! Support our campaign!

Speak to the press, contact your local MP.

Let us know your experiences, ie treatment.

Talk to others who might want to support the campaign.

Sign up below

"There was widespread public fear of HIV.....this is not the case

with hepatitis C."

John Hutton MP

Under Secretary of State for

Health

NAME	I HAVE/HAVE NOT WRITTEN TO MY OWN MP, WHO IS
ADDRESS	
	MY PARLIAMENTARY CONSTITUENCY IS
TEL	
FAX	I WOULD BE WILLING TO SPEAK TO THE PRESS/MEDIA (PLEASE TICK THE BOX) <input type="checkbox"/>
EMAIL	

For more information on the campaign contact KARIN PAPPENHEIM (Chief Executive) or SUE ROCKS (PA to Chief Executive) or for information on HCV services LUCY McGRATH (HCV Worker) at The Haemophilia Society, Chesterfield House, 385 Euston Road, London, NW1 3AU Tel: 0171 380 0600 Fax: 0171 387 8220 Email: info@haemophilia.org.uk Internet: www.haemophilia.org.uk