August 2001

Dear W. Johnsty.

19901

As a resident of this constituency, I would like to encourage you to show your support for the position of people with haemophilia across the UK and especially Northern Ireland by signing up to the Carpet of Lilies Campaign.

With this Campaign we are remembering those friends and family who have already died from HIV and hepatitis transmitted from contaminated blood products used by the NHS, as well as those still coping with the day to day effects of these viruses.

On 3 July representatives of our committee met with Dr Joe Hendron, Chairman of the N.I. Assembly Health Committee. The Society received a very positive response and I would ask you now give your support the Campaign.

The Haemophilia Society has three campaign aims on which we seek your support:

Recombinant treatment for all to avoid the risks of blood borne infections in future
Currently recombinant – a safer genetically engineered treatment – is available only to
children under 16 in Northern Ireland. The system of postcode prescription leaves many that
would benefit from the treatment unable to access it.

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, Japan, France, Switzerland and Ireland the UK Government has refused to carry out an official inquiry into this extensive infection of haemophilia patients through their NHS treatment.

Financial recompense for those infected by Hepatitis C

In 1987 the Macfarlane Trust was created to administer payments to those infected with HIV but those with Hepatitis C who face the possibility of liver disease, cirrhosis of the liver and liver cancer have been excluded form these funds.

In March, a high court judgement delivered by Mr Justice Burton ruled that '... the public expects, (and is entitled to expect), clean blood.' This is the first time a national authority was brought to account for the human tragedy caused by contaminated blood used by the NHS – a tragedy that has affected so many of the haemophilia community. But this ruling does not benefit those infected before 1985-7 when blood products were treated to eliminate these viruses.

I urge you to support the aims of our 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.

Yours sincerely.	
G	RO-A