

Caring for people with bleeding disorders

NEW RELEASE

Contact: Dan Farthing
Petersham House
57a Hatton Garden
London EC1N 8JG
Tel: GRO-C
Fax: GRO-C
Email: dan@GRO-C
Website: www.haemophilia.org.uk



THE
HAEMOPHILIA
SOCIETY

Embargo: Immediate
Contact: Dan Farthing GRO-C

HAEMOPHILIA SOCIETY CONDEMS GOVERNMENT ADVISORS CALL TO DENY AT RISK PATIENTS RIGHT TO vCJD TEST

On the 20th of October it was widely reported that the Safety of Blood Tissues and Organs Advisory Committee is opposed to the use of tests for vCJD, currently in development, when they are available.

The Haemophilia Society is fundamentally opposed to their position and believes that failure to deploy the tests would repeat the mistakes which lead to 1,757 people with haemophilia dying of Hepatitis C and HIV.

Chris James, Chief Executive of the Haemophilia Society says:

"People with haemophilia are all too familiar with the issues surround the use of new and often imperfect tests for contamination in blood. Blood products contaminated with Hepatitis C infected over 4,800 people with haemophilia in the 1970s and 1980s. Over 1,200 people were also infected with HIV. Now 1,757 people have died. How many more deaths must there be before the Government finally learns this difficult lesson?

"In our submission to the Independent Public Inquiry being conducted by The Rt. Hon The Lord Archer of Sandwell QC into Contaminated Blood and Blood Products we made it clear one of the main contributors to the high death toll was the failure to use new tests as they were developed. The vCJD prior cannot be destroyed using heat treatment, meaning that donor testing is the only line of defence in this case.

"Sadly, some people who donated blood went on to develop vCJD. The blood that they donated was given to others during blood transfusions, and to some of our members in the form of their haemophilia treatment. Unfortunately, four recipients of these infected blood donations have since developed vCJD and

died. Because vCJD has a very long incubation time, this may be the tip of the iceberg.

Because it is now known that haemophilia can be transmitted though NHS treatment, our members have received letters informing them that they are at 'at risk for public health purposes'. Some have also received a second, even more worrying, letter, which tells them that they have been treated with blood products manufactured from the blood of someone who has since gone on to develop vCJD. This has caused much anxiety, and also leads to difficulties accessing healthcare ranging from having to wait to be treated last in clinics so that the instruments can be used on all the other patients first right up to having to buy medical instruments themselves.

The Haemophilia Society believes that if a test becomes available it should be immediately used in two ways.

Firstly, that those who have been informed that they are at risk must be offered the opportunity to take the test with the appropriate pre-test and post-test counselling.

Secondly, the test must be used to protect the safety of the UK blood supply. The Haemophilia Society believes that the safety of the blood and blood products relies on effective donor screening in the first instance. In the same way as anybody else whose takes the test, blood donors should be offered appropriate counselling.

The lessons of previous contaminated blood disasters must be learnt. Every possible precaution should be taken to keep blood and blood products safe and give those at risk the chance to know as much as possible about their risk of developing vCJD."

ENDS

Notes: -

- The website of the Lord Archer Inquiry into Contaminated Blood and Blood Products can be found at www.archercbbp.com
- The Haemophilia Society's first submission to the Archer Inquiry, which sets out the details of the contaminated blood disaster, can be found at <http://www.haemophilia.org.uk/UserFiles/Campaign%20briefings/Haemophilia%20Society%20Submission%20to%20the%20Archer%20Inquiry.pdf>
- The Haemophilia Society's second submission to the Archer Inquiry, which sets out what recommendations the Society would like to see, can be found at <http://www.haemophilia.org.uk/UserFiles/Campaign%20briefings/Second%20Submission%20to%20the%20Archer%20Inquiry.pdf>
-