

Caring for people with bleeding disorders

NEW RELEASE

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THE
HAEMOPHILIA
SOCIETY

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HAEMOPHILIA SOCIETY CONDEMNS 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.

“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.

“People who have gone on to die from vCJD have given blood which has been made into blood products and given to our members. Those people have received letters informing them that they are at ‘at risk for public health purposes’. This can lead 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. Some of those affected are as young as 14 due to delays in making safer synthetic treatments available.

“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 should be offered the opportunity to take the test with the appropriate pre-test and post-test counselling.

“Secondly, the test should be used to protect the safety of the UK blood supply. Notwithstanding the discouraging effect that this may have on donation the Haemophilia Society believes that 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>