Charles Lister
20/11/2001 11:47

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Subject: SUNDAY MIRROR STORY: "21 EX-PATIENTS HAVE CJD BLOOD BUT DON'T KNOW"

Rachel

I understand from Alan Harvey that CMO has asked for briefing on this story which was also covered on yesterday's Today programme.

Charles

Background

The news reports confused two groups of people who received blood from donors who later developed vCJD:

- 22 recipients of transfused blood;
- an unknown number of recipients of pooled plasma products, including haemophiliacs.

The 12 year old boy from Manchester referred to in these reports is in the second group not the first.

Transfused blood recipients

These have been identified through a joint study between the National Blood Service and the CJD Surveillance Unit. This information has been in the public domain for some time and the numbers have been set out in PQ replies and the CJDSU's annual reports.

The NBS have asked the CJD Incident Panel for advice on whether these patients should be informed. The Panel's view, as stated in their consultation document, is that these patients should be included in the contactable group. However, before this can be done the proper support mechanisms need to be put in place. This issue is covered in Alan Harvey's minute to CMO of 5 October which makes recommendations on the way forward. We are waiting for a response to that minute in order to progress this work.

Pooled plasma products/haemophilia patients

In December 2000, the Bio Products Laboratory informed hospitals that a donor who had gone on to develop vCJD had donated plasma used in the manufacture of a number of batches of blood products, including Factor VIII, intravenous immunoglobulin and albumin. To the best of our knowledge, all haemophilia patients who received the implicated product have been traced by their clinicians and received information about the incident. Some patients have been informed; others offered a choice about whether they wanted to be given the information.

The 12 year old was one of the recipients of the implicated Factor VIII, 10 doses of which were given to him on 16 May 1997. On 22 January 2001, the boy's consultant and a haemophilia specialist nurse visted the boy's mother at her home to tell her what had happened. They provided support, advice and counselling. To date, the boy has not been informed of the situation.

On 26 February 1998 the Department instructed NHS Trusts that Recombinant Factor V111 should be given to children under 16 years old. This particular boy has been treated on Recombinant Factor V111 since May 1998.

Lines to take (provided for Hazel Blears for an Adjournment Debate today on haemophilia)

How many people with vCJD have been blood donors?

Eight people with vCJD have been identified as previous blood donors.

How many patients have received transfused blood from donors who contracted vCJD?

22 people have been identified as receiving transfused blood from donors who later developed vCJD

How many haemophiliacs have received vCJD implicated clotting factors?

We do not have this information. All haemophilia patients who received these products have been identified by their local Haemophilia Centres but we have not asked to see this information centrally.

Why did a 12 year old boy from Manchester receive vCJD implicated blood?

I understand that this boy was one of a number of haemophilia patients who received clotting factors made from a pool that included plasma from a donor who later developed variant CJD. This incident came to light in December last year and hospitals were immediately given the batch numbers of the products affected. The products concerned were made in 1996 and 1997 and used before 1998.

Following guidance from the UK Haemophilia Centre Doctors Organisation, clinicians wrote to patients with haemophilia, or the parents of patients, earlier this year to inform them of this incident.

Why did this boy receive plasma derived clotting factors when he should have been receiving recombinant? Was this because of the current shortage of recombinant?

There is some confusion here. The clotting factors implicated with variant CJD were used before 1998. This was before we stopped using UK plasma and before we instructed NHS Trusts to provide recombinant clotting factors for children under 16.

Some children have been put back onto plasma derived clotting factors because of the current shortage of recombinant. But the products they are receiving are made with imported plasma., mostly from the US where there is no evidence of BSE or variant CJD.

When are the other 21 recipients of vCJD implicated blood going to be told?

There is some confusion here. There are two groups of patients who received blood and blood products from donors who later developed vCJD:

- 22 recipients of transfused blood;

- an unknown, but larger, number of recipients of pooled plasma products, including haemophilia patients.

The Manchester boy belongs to this second group. All the haemophilia patients in this group have been traced and have received information from their clinicians.

When are the 22 transfused blood recipients going to be told?

The National Blood Service has sought advice on this from the CJD Incident Panel, which includes clinicians and ethical experts. This is a difficult ethical area - there is no evidence that vCJD can be transmitted through blood, no diagnostic test for vCJD and no treatment for the disease. It is therefore right that the Blood Service should be seeking the Panel's advice.

How many patients have contracted vCJD because of blood transfusion?

To date, there is no evidence world wide that CJD or vCJD has ever been transmitted through

blood or blood products, although the possibility of a risk cannot be ruled out.

Some haemophiliacs who received vCJD implicated products are being denied surgery/dentistry. What advice are you giving to clinicians?

We are looking to the CJD Incidents Panel to provide advice on these issues. The Panel is currently undertaking a consultation exercise on a proposed framework which sets out the basis for the advice that will be given in cases such as this. Furthermore, in order to assist the Panel with its work, the Department of Health has commissioned an update of the assessment of the risks associated with treatment with products derived from blood donations from individuals who later develop variant CJD. In the meantime, the Panel is providing advice on a precautionary basis and we would urge any clinician or dentist who is uncertain about the action they should be taking to contact the Panel for advice.