

## Eglin Roger

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**From:** MIME :Stephen.Dealler@ GRO-C  
**Sent:** 09 June 2004 16:39  
**To:** Hewitt Patricia; Stephen.Dealler@ GRO-C  
**Cc:** Kitchen Alan; Eglin Roger; Mobed Marina; j.w.ironside@ GRO-C ; R.Knight@ GRO-C  
pminor@ GRO-C ; jcooper@ GRO-C ; michael.painter@ GRO-C  
**Subject:** RE: blood from people that have received vCJD blood

Thanks, Patricia

I am sorry for being so pushy in this but the individual blood recipient who contacted me is to some degree furious that the potential work from NIBSC and Microsens had not been forwarded to him. I think that his main annoyance is that he has been told that he might have been infected with vCJD...and then he was simply left. He originally contacted me through some obscure route in the internet and had found out about the blood testing following the presentation of the work by Stuart Wilson at the Prion Conference in Paris recently that was reported on the internet. When explained to him that the tests did not claim to be the answer he was quite clear that he wanted to be tested. This seems to be quite reasonable (although it may not seem so to doctors), particularly if many others in the same situation want to be tested also. I have just got back to his GP and told him to deal directly with Microsens for the time being and NIBSC when possible. The question is whether, simply, the information about testing should be given to these patients, testing permitted through the GPs if they want it, and pile of advice organised following these results...or whether we should deny the certainty of test and refuse its availability (which is not actually possible). So, please don't just take a 'we know best' attitude for the patient. Many of them want to make their own decisions...and, as we may have infected them, I think we should give them a chance to do that. Steve Dealler —Original Message—

**From:** patricia.hewitt@ GRO-C [mailto:patricia.hewitt@ GRO-C]  
**Sent:** 09 June 2004 14:51  
**To:** Stephen.Dealler@ GRO-C  
**Cc:** alan.kitchen@ GRO-C ; roger.eglin@ GRO-C ;  
marina.mobed@ GRO-C ; j.w.ironside@ GRO-C ; R.Knight@ GRO-C ;  
pminor@ GRO-C ; jcooper@ GRO-C ; michael.painter@ GRO-C  
**Subject:** RE: blood from people that have received vCJD blood

Dear Stephen You telephoned me this week to discuss the e mail (below). I know that you have also approached Liz Love on this topic, and copied your messages to Roger Eglin. There are a number of inter-related and very important issues raised in your various messages. Liz will be replying to you, giving a composite answer from the NBS perspective, which will draw together the views of all of us. This is probably simpler than each of us replying separately!

Regards

Pat Hewitt

—Original Message—

**From:** MIME :Stephen.Dealler@ GRO-C **Sent:** 04 June 2004 14:54  
**To:** Hewitt Patricia  
**Cc:** Kitchen Alan; Eglin Roger; Mobed Marina; j.w.ironside@ GRO-C  
R.Knight@ GRO-C ; pminor@ GRO-C ; jcooper@ GRO-C  
michael.painter@ GRO-C  
**Subject:** blood from people that have received vCJD blood

Dear Dr Hewitt, The possibility of testing blood for PrPsc is appearing, in that several groups are now claiming that they can do this (Aventis-InPro, Microsens). The potential of testing large numbers of blood samples may make the assessments of these methods possible...and this seems quite exciting. One problem with this is that it is difficult to find controls that are

positive for PrPsc in blood. One answer to this might be to contact vCJD cases as the source of PrPsc in blood...but the clinicians realise that the taking of blood from these patients is to some degree difficult to ethically justify.

One of the answers to this might be to ask people that have received by transfusion the blood from people who have then developed vCJD cases (who gave blood earlier) to give some blood and use this as the potential positive control. The results from the work in Edinburgh in which blood from asymptomatic sheep

with scrapie is infused into other sheep has shown a transmission rate of over 50%. This suggests that we will be able to use the humans that had received blood from asymptomatic vCJD cases as a source of potential positive controls. I have discussed this with the HPA people, who feel it is a good idea and

have been encouraging in this (Mike Painter (GRO-C)). The HPA have been involved in contacting the patients directly since February 2004 and feel that many of the people that received the blood transfusion would be happy to give blood and some of them would like to know the results of the tests (but some of them would not). As a result it would be possible to ethically carry this out. Could I ask you to come back to me concerning this in that I will try to

write the ethics for it as soon as possible,

Yours sincerely,

Dr Stephen Dealler  
Consultant Medical Microbiologist

GRO-C

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